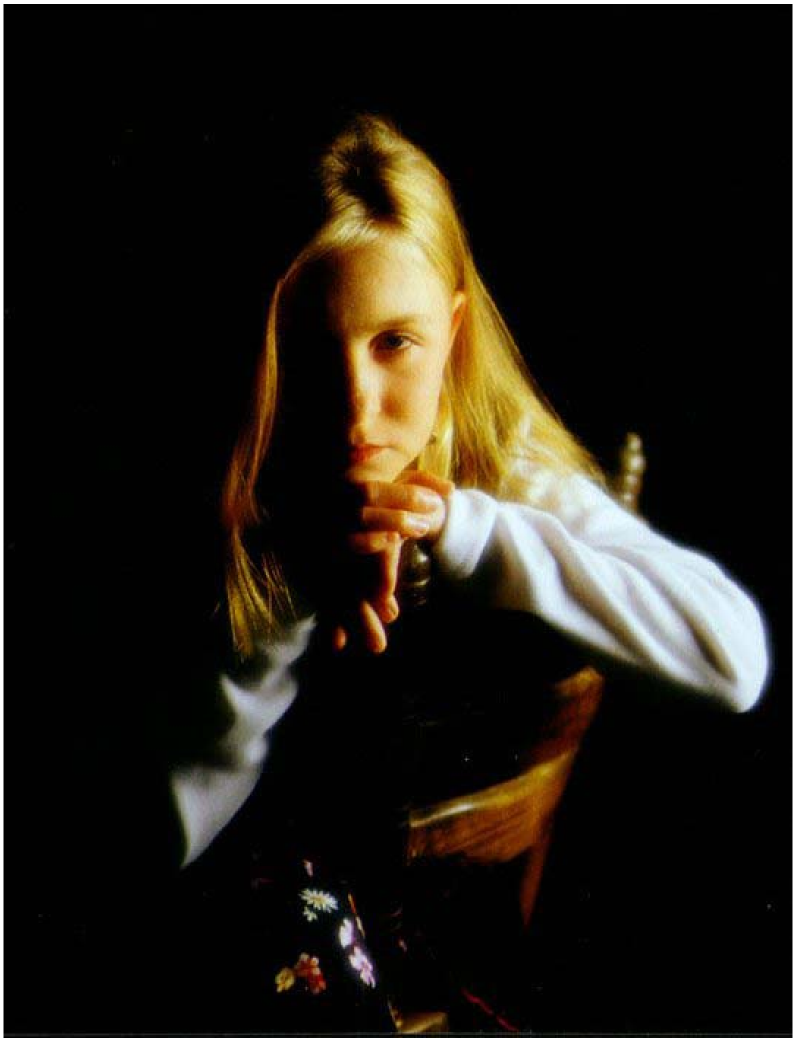
We just want our daughter TO LIVE!

the KELLY TURNER story



Jan Turner as told to Grant Shanks

We Just Want Our Daughter to Live!

Kelly Turner has the fatal condition Fanconi's anaemia. Her only hope of surviving is to have a bone marrow transplant. However, Jan and Richard Turner soon discover that the FA transplants with the highest success rate are only carried out in Paris, and that the New Zealand Government has limited funds for overseas operations. So the Turner family takes to the streets and the airwaves, with a band of helpers, and attempts to raise the $360,000 needed to get Kelly her operation.

Little do they realize that the roller coaster ride to Kelly's happiness and health has only just begun.

Jan Turner, Kelly's mother, tells their story to professional writer **Grant Shanks,** author of *A Long Goodnight.*

We Just Want Our Daughter to Live!

JAN TURNER
with
GRANT SHANKS

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From the Authors

Jan Turner

I WANT TO thank all those people who so generously gave their time and their money to help save Kelly's life. In particular, for the wonderful work of Professor Gluckman and the doctors and nurses both here and in France – thank you! To our family and friends, thank you for your unflagging support; to our local chapter of the Lions, thank you for your incredible fundraising efforts on Kelly's behalf.

To Grant, thank you for sharing in the struggle to tell our story. The compassion you feel towards the trials of others is an extremely valuable gift, and I am grateful that fate drew us together.

Because this story is told from my perspective, with the focus firmly fixed on Kelly, I don't always acknowledge the tremendous part that my husband Richard played throughout those hectic years. Richard was always there for me and for us, a tower of strength working away behind the scenes to keep everything together. Bless you, Richard.

You, the reader, will notice that Daniel doesn't have a voice in the earlier part of the book. To Daniel, through his early years, so much of what was happened to Kelly was 'normal'; it was only when he was approaching his teens that he began to realize otherwise. He was a wonderful big brother for Kelly to have through her many trials and tribulations, and today the pair of them are still the best of friends – fighting, laughing, playing, and getting into mischief like any other kids anywhere. I wouldn't have it any other way.

I dedicate this book to every parent who has been through what we went through, and trust that it will provide a ray of hope to those who have a child suffering from a life-threatening disease. There *is* light at the end of the tunnel.

Jan Turner
Taupo, January 1996

Grant Shanks

About the co-author: Grant Shanks is a full-time professional writer living and working in Christchurch. He is the co-author of A Long Goodnight, *the tragic story of friends Warren Ruscoe and Greg Nesbit.*

Shortly after the publication of *A Long Goodnight* in 1994 I received a phone call from Jan Turner. She had read *Goodnight,* and told me that she had written a manuscript on the ordeal that here family had gone through in their fight to save the life of their daughter, Kelly. Several publishers had rejected the story. She was calling to ask if I would be prepared to read the manuscript and offer her some advice. I agreed to do this, but made no further commitment: after the trauma of Warren's tragic death in a motorbike accident six weeks before the publication of his story, I had decided not to become involved in another emotional project for some time. However, I was deeply moved by Kelly's story, and suddenly found myself calling Jan to say that I would help her tell the story of the struggle for Kelly's life. It is a tale of courage and of hope, and truly deserves to be told.

My special thanks go to my wife Carol for her love, support and endless patience, and to Lynne for her input as a mother, writer and friend.

Grant Shanks
Christchurch January 1996

Prologue

IT WAS SUCH a long way to the stage. I felt all eyes boring into us. Once we got up there, Richard grabbed Kelly and took two steps back. I was left standing alone at the microphone, knowing I had to speak to these people. I had never felt so alone in my life; I was panicking, my heart racing. The whole room felt like it was all spinning. What had started as one of my bad days was getting worse. I was angry at myself – angry at how it was all going. Normally I could handle speeches, but now I just stood there, frozen, looking at all the faces. We were so grateful for the fundraising efforts, but we were lost in it all. How many of those sitting out there considered us bludgers? Why were we having so many problems making people really understand?

God! It was all getting to be too much. I could feel my eyes getting wet. I had to find the words I needed, but they wouldn't come.

It seemed like such a long time before I somehow managed to muster up a trembling voice. 'We're just an average family, and . . .' I stopped. What came next? My mind went blank again. Then my mouth moved of its own accord. 'It's very verve-wracking, you know,' I blurted out (and the moment I said it I thought that it was a stupid thing to say). Then I heard myself add, 'We *just want out daughter to live!'*

It sounded so pitiful, and so true. All we wanted was for Kelly to live. 'Thank you for your help,' I managed, then just turned back to Richard and Kelly. I felt so weak. It was as if I'd been drained of the last of my strength, my eyes were full of tears. I wanted to say more – I had intended to – but emotion was overwhelming me. I knew I was right at the end of my tether. Money, damned money. We needed $360,000 to save Kelly's life, and some people thought we were just going on a grand holiday.

The only sound was that of our footsteps as we left the stage and the hall. It had never been this bad.

When we got home, I just went into the bedroom and cried.

CHAPTER 1

Something is wrong with Bubs

IT IS ESTIMATED that 50,000-100,000 genes make up the 46 chromosomes that each of us has in our bodies. Included are between five and eight non-working genes, one or more of which are potentially lethal. Fortunately, because genes are paired, if one does not function correctly the other compensates. This effectively means that a person with the defective gene is not harmed by whatever condition the rogue gene represents, but becomes a carrier. When a man and a woman with the same non-working genes produce a child, there is a one-in-four chance that the child will be born with both non-working genes. When this happens, a disease state results.

'To give birth to a baby with deformities was a great shock to us. Then, to learn later that your child has a genetic, life-threatening condition that you unknowingly passed on, is totally devastating. We lived this nightmare.'

Jan: In January 1983, we had been living for only a few weeks on a government farm at Ohope, a sleepy little seaside resort near Whakatane. We were a normal, happy family. Richard and I had two-year-old Daniel, a healthy, robust son, and I was six months pregnant. Everything was near-perfect for us. My pregnancy was going well, and Ohope was beautiful.

We all loved living by the sea. Our home was situated on a hill overlooking the estuary, an idyllic setting, perfect. The house was an old state house, but had been newly wallpapered and painted. It wasn't a mansion, but it was pleasant, all we needed, and the views were superb.

Life couldn't have been better for us. My childhood dream of a wonderful husband and a happy, beautiful family was a reality, something I didn't take for granted for one moment. Sometimes I would find myself standing at the lounge window or out on the deck looking down over the paddocks, watching the horses frolicking, with the estuary and the sea beyond, and I would hug myself with sheer joy. I was so lucky. I had no idea that fate was about to shatter my dreams and almost destroy us.

Shortly after arriving in Ohope, I went to see Russell Meads, the local doctor, in order to continue with my antenatal checks. I liked Russell immediately. His manner was very welcoming; I had never felt so comfortable with a doctor before. I explained to him that I felt much bigger than I had been at the same stage with Daniel. Russell recommended that I have an ultrasound scan to see how far along I was. I happily agreed, I was worried that I had the dates wrong. Daniel had been born a month early, but because he had been a good weight at birth, no one knew if he had been premature or not. I didn't want to be in that position again: it had been quite scary going into labour much earlier than expected.

Something else had been nagging me about this pregnancy. It was a little niggle, playing away in the back of my mind at times. This pregnancy felt a lot different from that with Daniel. I suffered a fluid build-up in my feet and ankles, and I tired easily. Still, I wasn't worried - yet.

Because Whakatane Hospital didn't have an ultrasound unit, an appointment was made at Rotorua, an hour's drive away. I was quite excited because I knew we could now work out a date for the birth. That excitement was followed by a little disappointment when Richard wasn't allowed to be present at the scan, as this was against hospital policy. So he waited outside.

I thought at the time that it was odd when the technician left the room without saying a word to me, only to return a few minutes later to finish the scan. It was then that I felt the niggle inside me become something else. What had he seen - what wasn't he telling me?

❖ **What the operator had detected was that Jan's baby had no amniotic fluid flowing through its system. Ultrasound works on fluids, and it appeared that the baby had a throat condition which was preventing the amniotic fluid from reaching the stomach. It was to be twelve days before Jan and Richard would be told of their unborn child's condition, and the implications it carried for them all.**

After the scan, we were told that the results would be available through our doctor in a week's time. Richard was still annoyed that he hadn't been allowed in to see the scan. We both wondered why fathers were encouraged to be at the birth, but not at scanning - it seemed a strange policy to us. Later, on the way home, I told him how the technician had suddenly left the room without a word to me. We both thought it odd, but there didn't seem to be anything to worry about. I succeeded in pushing my doubts to the back of my mind. If something had been wrong, surely they would have told me there and then, or set up more tests. After all, they were the experts.

I resigned myself to a week of waiting, but I found that time hung heavily on my hands. We hadn't been in Ohope long enough to make friends, and for the very first time I felt lonely in the house with just Daniel for company. Richard was busy, and rarely around during the day. As head shepherd, his daylight hours were spent out on the farm.

I went through a frustrating count-down several times a day. After a week, I rang Dr Meads's surgery and asked the receptionist if the results were back. She checked with Russell, and told me that they hadn't come yet and to call the following day. But it wasn't to be: I rang on three consecutive days, and each time the reply was the same. By day four, I was getting agitated. Alarm bells inside had started to ring, and the nagging feeling had teeth. This time I couldn't dismiss the feeling that something could be wrong, and it began to gnaw away at me.

On the fifth day, the receptionist said she was sure that the results had arrived. She asked me to wait until she got the doctor to speak to me about them. When she returned, she said that Dr Meads couldn't talk to me at the moment and that he would call me back. I felt deflated, still not openly worried, but more apprehensive. I knew Russell was a busy man. I thought that if anything serious had shown in the results, he would have been in touch immediately. I spent the rest of the afternoon wondering when he would ring and tell me everything was fine. But he didn't call.

At about five o'clock I heard a car coming up our driveway. I was shocked to see it was Russell, and right at that moment I knew something was wrong. 'Doctors don't visit people on farms unless it's really important. Something is wrong. There must have been something wrong on the scan,' I was saying in my mind as I watched him get out of his car. Suddenly, I was in a panic. I prayed to God to give me the strength to calm down.

I eventually consoled myself with the thought that he might just be one of those doctors who likes to deliver results in person. He was such a friendly man. I convinced myself I could see him doing it that way. I was calm when I greeted him at the door and introduced him to Richard.

When we went to sit down, I noticed how nervous and awkward Russell was. He didn't seem to know where to start, so I grabbed the bull by the horns and asked him if he had the scan results back. 'Yes,' he said. I then asked him when the baby was due. He hesitated, then said the words every mother-to-be dreads: 'Something is wrong with Bubs.'

I was stunned. Speechless. My heart started pounding and my stomach was in knots. Russell carried on speaking, but his words seemed to be coming from a long way off. I felt like I wasn't there any more. It was as if I was listening to someone else's conversation. Somehow I managed to tune back in to what he was saying. He explained about the amniotic fluid and the possible throat blockage. He couldn't tell us what else might be wrong. The scan couldn't detect abnormalities such as brain damage or a cleft palate. He said that they suspected that the baby's oesophagus hadn't formed properly, and this had caused the blockage preventing amniotic fluid reaching the stomach. The stomach hadn't shown up on the scan. Now I knew why the technician had left the room - he must have gone to discuss the problem with other staff.

Russell did confirm a delivery date of approximately 22 April. It was then he revealed to us that he hadn't sent me for the scan just to verify the due date. When he had examined me, he had trouble feeling the baby and knew that it had far too much fluid around it. This was a signal to him that perhaps something was wrong.

The nightmare had begun for us. I was praying that I would wake up and it would all be over. Hell, I'd only wanted a scan to confirm my delivery date. I never even suspected that there would be something seriously wrong with the baby. From somewhere, I found the strength to ask, 'Where do we go from here?' I was grateful that Russell had already worked that one out. He told us that I needed to see a specialist, and recommended a Dr Richard Fisher at National Women's Hospital in Auckland, a doctor he had worked with and considered to be the best in his field. If we were agreeable, he would arrange an appointment as soon as possible. I remember nodding, and saying 'Yes, yes, yes,' to myself. There was nothing more Russell could tell us. Further, extensive tests needed to be performed in Auckland for the full extent of the problem to be known. I remember that, although I was rocked to the core with shock, I managed to put on a brave face. I thanked him for delivering the news to us in person.

When Richard took the doctor out to his car, I grabbed Daniel. Thank goodness I've got you,' I thought. I was already facing the possibility that we might lose the baby I was carrying. Daniel was looking up at me, his little round face full of concern. I wished at that moment I could have had the innocence of a child in what was going to come.

I went into a strange mental warp then. Everything became unreal, I was looking at things through a haze. I put Daniel down to play and went to get dinner organised. There I was, standing at the sink preparing our meal as normal. At least, my hands were doing that - my head was spinning. Thoughts just kept crowding in, overlapping each other. Something devastating had just been dropped on me. Why couldn't I be back in time, living yesterday again? I wanted the ignorance of not knowing. I started peeling the potatoes, and I felt anger raging inside. I slashed at them, sending great chunks of potato and skin flying. 'Why, why, why?' I was mumbling, not wanting to disturb Daniel, I think. I really wanted to scream. Eventually I stopped waving the knife about, and moments later I just felt sad, and the numbness came. What a bloody mess everything had become.

Richard was back. He put his arm around my shoulders and asked if I was all right. I lied through my teeth and told him I was fine, trying to appear brave. Then I looked at him and broke down, crying uncontrollably. He pulled me close and held me while Daniel came to watch us, so confused, with the concern of an innocent child, all big eyes and not knowing whether to laugh or cry. 'Why is this happening?' I sobbed at Richard, 'Why is this happening to us?' I cried and cried until I was exhausted. Richard just held me and made comforting noises. He didn't know what to say.

Richard: When Dr Meads told us something was wrong with the baby, my initial concern was for Jan: was she going to be all right? The shock didn't set in until after the doctor left. I felt so scared not knowing what was going to happen. I was worried about Jan and the baby. I felt so damned inadequate, so very, very helpless. I didn't know what to do except try and comfort Jan. I hated ever seeing her upset. I knew though that no matter how bad I was feeling, she would be feeling so much worse. The baby was part of her, growing inside her. She could feel it moving inside, and the bond between them was already so strong. As with Daniel, I knew that the bond between me and the baby wouldn't form until it was born - if it ever was! That thought just made me hang onto Jan all the harder.

Jan: When my mind was a little clearer, I thought about breaking the news to our families. Not because they would want to know, rather because we needed all the support we could get. We were both in shock and poor Daniel was so confused.

I would ring my mother first. I dreaded telling her, but I needed to. Mum had had a lot to bear over the years. First, my brother Reg suffered brain damage through oxygen deprivation prior to birth, and was handicapped. He had needed a lot of extra care and attention as he grew up. It had been tough going at times, and then, on top of that, Dad suffered a massive stroke and was unable to talk. Or work again for the rest of his life. The strain had taken its toll on I Mum, and she wasn't in the best of health. But I needed to tell her.

I took a deep breath and dialled her number. Mum knew something was wrong right from the start, and I could hear the panic start to build in her voice. I didn't know how to break the news. In the end, I just blurted it out. 'Mum, it's baby. There's something seriously wrong . . .' I couldn't go on. I just dissolved into tears. Poor Mum! She tried so hard to comfort me, but it's so difficult when you can't reach out and hug the hurt away. After a while, I calmed down enough to give her the details and promised to let her know as we found out more. Then it was Richard's turn to phone his parents. He was much less emotional than I had been. I wished at that moment that I could have been as contained as he was. It has always been like that. He comes across as the big, silent Kiwi bloke. He thinks a lot but says little in public. Only when we were alone would he tell me his innermost thoughts. Now with his parents, he simply gave them the facts as we knew them. When we hung up, we just looked at each other.

'What do we do now?' I asked, on the verge of tears again. He gave me a hug.

'We can only wait; he said, and we just stood there holding each other and Daniel. We were a sad, confused little family at that moment.

My mind went back to my childhood. Standing there in Richard's arms, I could see myself playing with my dolls, my 'children', in the orchard behind our house. I spent so much time there. It was my special place - my world when I needed to escape. There, I had dreamed: I meet a wonderful man, we marry in a beautiful, extravagant ceremony; we make children together, beautiful, happy children, and love envelops us all. This wasn't a fantasy to me then, it was simply my future - and it had come true. But why were we now standing huddled together, crying?

Eventually, we ate and put Daniel to bed, showering him with lots of kisses and hugs, which only added to his confusion. Later, Richard and I sat and tried to think it all through. It was only Friday night, we had to wait until Monday before we could arrange anything with the specialist. We had the whole weekend to think and talk, and we did. I managed to control my emotions in front of Daniel, but when he was in bed I broke down crying. I couldn't believe, didn't want to believe, that anything was wrong with my baby. To think it was anything but perfect was inconceivable. I kept thinking, 'Maybe they're wrong, maybe they've made a mistake, and it isn't serious after all.'

That was the way the weekend passed for me: thoughts racing round and round in my head. I hardly slept, and was emotionally exhausted long before Monday came. My mood swings were terrible, hovering between disbelief and absolute, paralysing fear. Every time the baby moved inside me, I went into denial. I kept thinking, 'As long as baby is alive, I'm determined it's going to be fine.' The thought of losing my child at this stage of my pregnancy made me so angry. I'd lost my first at 12 weeks, and although that was painful both physically and emotionally, I got over it fairly quickly. I wasn't prepared to lose this one. We'd been together for six months and our bond was so strong.

❖

On the Monday, Dr Meads made an appointment for Jan and Richard to see Dr Fisher the following week. Richard arranged for time off from the farm. Russell Meads had informed Jan that there was every likelihood that she would be admitted to National Women's Hospital in Auckland for observation. The day before the appointment, Jan and Richard travelled to the home of Jan's sister, Therese, in Manurewa. It was ironic that Therese, a nurse, had recently worked in the Neonatal Care Unit at National Women's. Therese gave Jan and Richard a lot of hope that everything would turn out well; Jan went to the appointment with Dr Fisher feeling much less apprehensive.

Dr Fisher explained in detail to Jan and Richard about their baby's suspected oesophagus problem. The food pipe (gullet) and the windpipe (trachea) are one tube until between 23 and 28 days after conception, when the tube divides into two. In one in 3000 pregnancies, this division doesn't take place correctly, and two conditions known as oesophageal atresia and tracheo-oesophageal fistula may occur. Atresia means 'no way through': a gap is left between the upper and lower oesophagus. With this condition, nothing can pass through to the stomach from the mouth, not even saliva. A fistula is an abnormal connection, in this case between the oesophagus and the trachea, which can let food or acidic stomach juices into the lungs, or air into the stomach. At this point, Dr Fisher was unable to determine which condition the baby was suffering from.

Dr Fisher gave Jan a physical examination which confirmed that she was suffering from polyhydramnios (an excess of amniotic fluid). The immediate danger was that this could send her into premature labour; the doctor noted that her

cervix was already dangerously dilated. There was a good chance that Jan would not carry to full-term.

Dr Fisher explained that Jan needed to carry the baby as long as possible to give it the best chance of survival. She had seven weeks of her pregnancy left, and so he admitted her to the hospital immediately. There would be many tests carried out to confirm the baby's condition and to detect any other abnormalities.

Jan: I asked Dr Fisher how they treated the problem with the oesophagus once the baby was born. He explained that this depended on the actual deformity. If the oesophagus was not too short, they could simply attach it to the stomach. If the gap was longer, there were several other alternatives available. After the birth, until surgery could be carried out, he told us that the baby would be fed via a stomach tube (gastrostomy), and he reassured us that this had a good success rate. He also said that I would need a course of steroid injections to mature the baby's lungs, to give it a better chance of survival if born prematurely.

I began my long period of hospitalisation feeling much more reassured. I was apprehensive about some of the tests, but relieved that with the steroid injections, baby would have a far better chance of survival. That was all that was important: I wasn't going to lose my child. I was on cloud nine when the test results came back, as there were no other abnormalities, such as Down's syndrome. That had been a real concern to me. Now it was one thing we didn't have to worry about. Following X-rays, I learned something I hadn't expected to: baby was a girl.

At the end of the first week, Richard and Daniel returned to Ohope. I had six weeks to wait before I was full-term. Seeing my family go brought on a lot of depression. I hated the separation, and despite the fact Richard had family in Auckland and they were great, I missed Richard and Daniel so much. I gave myself over to a regimen of poking and prodding and never-ending questions, as interns came to study my case. I had no objections, as I was prepared to do anything to help medical science, and anyway I didn't have a lot else to do during the day but feel sorry for myself. I remember my session in the lecture theatre; it had a positive side for me personally. I went into this big room, surrounded by seats. It was full of people. I was shown to a table in the centre of the room and asked to lie down. Then I was covered with a blanket, with only my huge stomach exposed. The lecturer talked about my condition and invited the interns to come and examine me, which they did one-by-one. Later I was thanked, and sent back to the ward. It was quite an experience. The benefit to me was that, from that point on, virtually every intern I passed in the corridors would say 'Hello' to me, as if they knew me. I guess they did. It was a pleasant distraction.

Richard: When Jan was admitted to the hospital, I didn't know what the hell I was going to do. We had only just moved to Ohope and here she was stuck up in Auckland, for weeks perhaps. What was going to happen with Daniel? The boss was great, he told me to take as much time as I needed, but I had to go back to work sometime. I felt guilty because we'd only been on the place such a short time.

Apart from the farm manager, the only person I knew was Dr Meads, and he was tremendous. I contacted him when I first arrived home, and he invited Daniel and me to dinner. I met his wife Bronwyn for the first time that evening, and she was such a kind person, like her husband. She offered to mind Daniel during the days I was working. That was a major worry off my mind. It meant getting up extra early in the mornings to get Daniel's breakfast and drop him off, but it was a blessing.

I found the nights the hardest to take. After I put Daniel to bed, the house was so quiet. I missed having Jan to talk to and curl up with. I hated the thought of her stuck in that hospital so far away. I rang as often as I could. It was so good to hear her voice and find out what was going on. Every weekend, Daniel and I would get in the car and head for Auckland to spend as much time as possible together as a family.

Jan: In hospital I wasn't alone with my depression or my problems. I shared a room with three other women who were in hospital with various conditions ranging from high blood pressure to potential premature labour. One woman came from New Caledonia, and spoke little English. She had lost two babies from previous pregnancies. A professor at the hospital offered a technique that was possibly the only chance to save her baby. It involved a complete blood transfusion for the baby at birth. Here I was, depressed and lonely, with Richard and Daniel only a few hundred kilometres down the road and in to see me every weekend, while this poor woman's husband and son were a whole world away. She would cry when she read their letters. She proudly showed me their photographs, and it struck me as being really cruel that she was going through this all alone. Communicating was difficult because of the language barrier, but we developed a real empathy because of what we were both going through with our unborn babies.

This was my first experience ever with a person who couldn't speak English well. It made me wish I had been more diligent with my French language studies at college. I wasn't to realise what was to come years later, when I was to regret that fact even more.

❖ When Jan had been in hospital for three weeks, she noticed one day that her baby was hardly moving. Her instincts told her that something was wrong. The nursing staff immediately connected a foetal heart monitor, and found that the baby's heart rate had dropped. The head of the team informed Jan that she would be induced first thing in the morning. She was 36 weeks pregnant.

It was a Monday. Richard had just been up for the weekend. I phoned him and told him they were going to induce me at nine in the morning. It was a panic. He had to get time off work, bundle Daniel up and come north straight away. That night the nurses offered me a sleeping tablet because I was so uptight. I turned them down initially, but an hour later I relented and, under its influence, slept soundly until morning.

When I awoke, I was unnaturally calm. It wasn't the aftermath of the sleeping pill; this sensation came from inside me. I knew that everything was going to be okay. Richard hadn't arrived by the time they took me down to the delivery suite. That worried me for a few minutes, but they had no sooner settled me in the room than he came in.

I remember that when they broke my forewaters there was an enormous amount of amniotic fluid. The staff laughed as they had to get more containers. That made things a lot easier for me. I noticed that my stomach was so much smaller: all that was left was a tiny bump showing the baby. I went into labour within minutes.

- **The baby went into foetal distress, and oxygen was administered to Jan. As a former nurse herself, Jan was aware that time was everything and a caesarean would need to be performed. Just as her medical knowledge helped her understand what was happening now, it would help save Kelly's life much later.**

People came from everywhere. Two nurses were shaving my pubic hair and it felt dreadful. Then we were away down the corridor, the team pushing my trolley at a run. I can remember one of them pounding along beside me, his mask half-undone, flapping in the air behind him. Suddenly someone realised that I hadn't signed a consent form, so they stopped. Richard was offering to sign, but it had to be me. I signed and we were away again. In the theatre there was no time for introductions and explanations. They put me out straight away, and I wasn't about to argue.

CHAPTER 2

Our baby

KELLY HAD COME into the world. Jan and Richard knew about the deformity to her oesophagus, but fate was to play yet another cruel trick on them.

Jan: I awoke groggy. I was in agony and wailed with the pain until they gave me an injection and I fell asleep again. When I came around properly sometime later, Richard was sitting beside me.

'How is she?' I demanded, desperate for words of reassurance. 'She's fine,' he answered, but his voice was flat. It was obvious that something was wrong. They've taken her to the children's hospital to check her throat problem,' he said quietly. 'What's wrong?' I asked. 'What else? Tell me!' The warning bells were clamouring in my head. Richard took my hand and squeezed. look, she's O.K.; he said, trying to sound calm, 'She's fine . . . there's just one small thing . . .' I knew it, something else was wrong. Despite the drugs, I started to panic. 'What?' I yelled, 'What?' My grip on his big hand must have hurt, but Richard didn't flinch. Tell me!' 'She's got two thumbs on one hand, that's all; he replied. Two thumbs!' I must have been almost shrieking in horror. I denied it: 'No she hasn't. She hasn't!' Richard tried to calm me. All I could think was that baby had a problem with her throat and stomach. There couldn't be anything else wrong. There couldn't! All the time, Richard was telling me that it wasn't a problem and that they would fix it when she was old enough. Despite his reassurances, the thought of our baby having two thumbs on one hand just freaked me out. One thing that every new parent delights in is counting their newborn's fingers and toes. I hadn't had the opportunity ... I had been mentally prepared for the other problem - apart from that, I just wanted to know that she was perfect. Now this had come, so totally out of the blue that it hit me for six.

Later, as they wheeled me to the Neonatal Unit, I was struggling to stay awake. They pointed to a tiny baby lying in a special incubator bed. This was my first glimpse of my daughter. She was so very thin, but longer than I had expected. There was a tiny head with a thin covering of dark hair. I thought she looked beautiful, with the tiniest, little cherub face. 'How much did she weigh?' I asked. '1540 grammes,' was the reply. I couldn't keep my eyes open, I wanted to keep looking at Kelly but I couldn't. '1540 grammes,' I remember thinking, 'not bad under the circumstances.' Then I just slipped away into sleep again.

Richard: Jan was asleep moments after we saw Kelly. The Neo-natal Unit was an intimidating place. It seemed very cramped, very intense, with electronic monitors everywhere and constant beeping sounds. The walls seemed to close in on me. The nurses and doctors were buzzing around continually. I thought howl different it had been in the quiet country hospital in Taumarunui when Daniel was born. It had been so laid-back by comparison. In this place I felt so awkward. But the nurses were great, and they really went out of their way to include me in what was going on j with Jan and Kelly.

Jan: When I awoke, Richard was there as always. He told me that! Kelly had had to be resuscitated at birth, but that she was extremely I alert and they didn't think she had suffered any brain damage. When I heard that, I felt an overwhelming sense of relief. I had dreaded that, after poor Reg. I felt so grateful to the staff. I relaxed then, I knew that Kelly was in the safest of hands. They were taking her to another hospital to have the problem with her oesophagus assessed. I was told that they would have to paralyse her temporarily from the neck down to insert a tube inside to do| their tests. The thought made me cringe, but there was no alternative. They gave me a Polaroid photograph so I could at lea look at her when they shifted me back into the ward. I wasn't put in with the others, this time I had a room to myself. I looked at the photo for a long time, and then I just fell asleep again.

It was much later when I resurfaced. I was in dreadful pain and still connected to a drip and a drain. I was lying there, wondering what was happening to Kelly, when the paediatrician arrived. He said that Kelly had a short oesophagus that hadn't grown to meet her stomach, a condition known as pure oesophageal atresia. They hadn't found any fistulae connecting the oesophagus and trachea, and had inserted a gastrostomy tube in her stomach so that she could be fed. He told me that she was doing fine and was quite alert, despite the fact that she was connected to a ventilator so she would breathe until the anaesthetic wore off. It all seemed so much for such a little baby to have to face. I asked when she would be able to have the corrective surgery and was told six months, but that she would have to be a lot bigger than she was at this stage. At those words, my heart sank for my little girl. I wanted so much for her to have a normal life. Would she have to stay in hospital all that time? I couldn't take her home if she was still being fed through a tube. These questions, and more, whirred around in my head; I didn't ask them, I couldn't find the words -I don't think I wanted to know just then. Instead, I thanked the paediatrician for coming to see me. I don't think he had the faintest due as to just how lousy I was feeling.

I lay there for some time, my head swimming with depressing thoughts. I felt cheated that, as yet, I hadn't even got to hold my daughter. I knew that mood swings were part of the birthing process, but I couldn't control them. Then, suddenly, I just snapped out of it. The swing simply went back the other way and I started counting my blessings, for I knew I had more than a few. For now, I was grateful that Kelly was alive and that nothing else major was wrong with her. I didn't like the fact that she wasn't perfect, but I could live with that. Things could have been so much worse.

❖ **Jan and Richard then began asking themselves, 'Why was our baby born with deformities?' Jan felt guilty that she had smoked through her pregnancy; something she had done with Daniel, who was fine. She wondered if she was being punished for something she had or hadn't done in her life. Richard was thinking of all the agricultural sprays he had used over the years, wondering if the chemicals had affected Jan in the early days of her pregnancy. There were no answers to be found. Jan admits that, in the past, she had always seen medical people as having all the answers: this was the first time she realised that they didn't. This was to be the first of many such instances.**

The day after Kelly was born, my milk came in. I had heaps of it, and didn't know what I was going to do. I wanted so much to feed Kelly myself, but how? That was when the staff introduced me to an electric breast pump. It took me a while to get used to it, but I persevered. I was absolutely determined that Kelly should have my milk. I felt that it was all I could do for her. The routine we established was that I would draw milk off and the staff would take it down to Neonatal and feed it to Kelly through her tube. God, how I missed seeing my baby. I was still very sore from the caesarean and couldn't get down to her. Richard would visit the unit, and come back and tell me how she was doing, but I felt a very real sense of loss. I still hadn't held Kelly in my arms.

❖ **It was to be several days before Jan was allowed to go to the Neonatal Unit, by wheelchair, to see her daughter. It was a magic moment for her.**

Kelly was in an incubator. The room was crowded with the units; somehow that made it easier. She wasn't a special case, just another little baby being treated like so many others. Then I could see her lying there, and I cried. She was just so beautiful. I sat looking at her, oblivious to everyone and everything else. The nurses on duty in the unit encouraged me to stroke her through the opening in the incubator's cover. It was such a wonderful feeling to be touching her for the first time. She was so tiny, so delicate. No matter what, she was the most loved baby in the world, I was totally sure of that. 'So beautiful!' I must have whispered to myself a hundred times as I sat there beside my daughter that first time.

After the initial visit, I spent all the time I could with Kelly. I watched how they fed her through the tube in her abdomen. I was horrified at first that this tiny little baby, my baby, had to go through this. Poor little mite. She also had an opening on the side of her neck, called an oesophagotomy. This, in effect, was a drain through which anything in her mouth (such as saliva) could flow out so she wouldn't choke. On the second or third day, they let me hold her for the very first time. Since the birth, those few minutes were the most precious of all. She was so light. I felt very emotional. I was holding 'my baby' at last. Now I really felt like a mother, despite the fact I couldn't breastfeed her.

Then one day I was amazed when the nurses said I could put Kelly to my breast for a feed. I was puzzled. 'Why?' I wanted to know. The milk can't get to her stomach.' 'We call it sham feeding,' replied one of the nurses. 'Because she is being fed through a tube, we need to encourage her reflex sucking.' Once explained, it made a lot of sense to me. It also gave me hope that the tube feeding would be a temporary thing. They wrapped Kelly in a nappy, and carefully handed her to me. She latched onto my nipple very quickly and my milk responded. It felt wonderful: the motherhood cycle was complete for me at that moment. I had my child at my breast - but what a mess! As fast as Kelly took the milk in, it flowed out of the opening in her neck. Looking at how well she was suckling, I found myself wishing, yet again, that she was normal. It seemed such a waste, knowing the milk wasn't going where it should. It was a very strange and unnerving experience.

❖ **Kelly was restricted to 2ml of milk per feed for most of her first week. Staff wanted to wait until she had had her first bowel motion before increasing her feed. They were worried that there could be a problem with her bowel: sometimes with oesophageal atresia, the bowel is not formed properly.**

On the seventh day, there was great excitement in the unit. A nurse had checked Kelly's rectal temperature and found evidence of an impending motion. Jan recalls the nurse running around the unit waving the thermometer for all to see. It reinforced to her just how deeply the staff felt about their charges.

From this point on, Kelly's milk intake was increased and her intravenous fluids were stopped.

Kelly began to thrive from that moment on, and it was wonderful to see. I got to hold her more and more, and she was very alert. Richard and Daniel left for Ohope at the end of the second week, knowing that everything was under control.

Richard: It had been difficult dividing my time between Daniel and Jan and Kelly at the hospital. I didn't want to go home, but the doctor said Jan would soon be home. Jan and Kelly were doing fine now, and I had to get back to the farm. I had felt guilty enough about my not being there. So Daniel and I headed back to Ohope, knowing Jan and Kelly wouldn't be far behind us. It was the following weekend that they told me Jan could come home with us, and Kelly would be down in days. It suddenly seemed that life was about to become 'normal' for us. I was looking forward to that more than anything else.

Jan: When they told me I could go home and that Kelly would be flown down to Whakatane Hospital within the week, I suddenly felt very mixed up. I'd certainly been in hospital long enough. But what about Kelly? Reluctantly I went, leaving behind mountains of frozen breast milk, knowing that, really, I could do nothing more for my wee daughter at this time.

I was very mixed up when we arrived home. To have had a baby, yet come home without her, left me with a terrible feeling of loss. Back in Ohope, Dr Meads arranged a breast pump for me, and I took my milk off and froze it for Kelly's arrival. Each day I. rang Auckland to see how she was doing. 'Really well!' was the constant reply.

When she flew down, it was an exciting day for us all. We were waiting in the children's ward at the hospital when they brought her in and popped her into a bassinet. We all crowded around. She looked more beautiful than ever. Her little body had filled out so much. There was one moment of concern when the resident paediatrician came in. He was very agitated, and ordered that Kelly be put in a side room in an incubator. The doctor's attitude and that action made me immediately feel comfortable with him. He obviously knew exactly what special care was required, and that was a real relief for me. Once Kelly was settled, he gave her a thorough examination and pronounced her to be in very good condition and to have come through her flight well. He agreed that 'mother's milk' would be the best nourishment for Kelly, sol made arrangements to bring in expressed milk daily for her feeds. The best news was when he said that Kelly could come home as soon as her weight reached 2270g. At this stage, she was four weeks old and weighed 1818g. We left the hospital in high spirits. Kelly was home - almost.

CHAPTER 3

Kelly comes home

WITH KELLY JUST a few kilometres away in Whakatane, and with the knowledge that she would be home just as soon as she was strong enough, Jan began to worry about how to gain the confidence she needed to feed her infant daughter through her tube. She and the Whakatane Hospital paediatrician discussed what was involved in the operation to correct Kelly's oesophageal atresia. There were two alternatives.

The first was to use a portion of the bowel to connect the oesophagus and the stomach, a procedure that sometimes failed because the bowel section didn't 'take'. The other involved raising the stomach up into the chest cavity. The method to be used was to be determined by the paediatric surgeon at Auckland's then children's hospital, Princess Mary Children's Hospital. Jan and Kelly were scheduled to see the surgeon there when Kelly was three months old, and would also see a plastic surgeon at Middlemore Hospital for an examination of Kelly's thumbs and to schedule a corrective operation.

Happy that an end was in sight and that life was beginning to become much more manageable, Jan settled into a routine. As well as looking after Daniel and running the household, she expressed milk four times a day and spent as much time as she could at the hospital caring for Kelly, preparing herself for the day Kelly would come home.

Jan: When Kelly was six weeks old and weighed 2270g, the paediatrician told me she could go home. Although I had known the time would come, I was suddenly so excited and so apprehensive. I had been doing her feeds and bathing her, but that was all in the protective environment of the hospital. Suddenly I was going to have all the responsibility. It was scary.

That last weekend, I stayed in hospital with Kelly, getting used to looking after her on a 24-hour basis. Then, it was Monday! There was great excitement in the ward, and also a lot of sadness. Some of the nurses had got very attached to Kelly. She was a delightful baby, everyone's favourite.

I was very nervous when it was time to go. Kelly looked so tiny, just like a little doll. Now though, I had confidence in handling her, and she didn't seem so delicate any more. I was full of mixed emotions. There had been a time, not so very long ago, when I had thought this moment would never come. Now we were taking our little girl home at last. How wonderful it felt. We drove off with the sounds of everyone's farewells ringing in our ears.

Richard: With Kelly in hospital in Whakatane, Jan had become much more at ease and relaxed. She told me how strange it had seemed having had a baby but not having one, and of the great emptiness she felt at first. But she was determined to learn everything she could to take care of Kelly at home. I felt a tremendous relief. I knew only too well just how capable Jan is, and it gave me a feeling of confidence for the future. Life had settled down so much from those early days.

The day we took Kelly home, I was pretty nervous. To me she was still so small and delicate-looking. I felt very awkward whenever I held her. Jan's confidence at handling her soon rubbed off on me, however, and I began to feel much more confident.

Jan: Along with Kelly, we took home enough medical supplies to stock a small hospital. Richard took the first week off work and we quickly established a routine. I expressed milk and fed Kelly four times a day. I tried sham feeding at my breast at first, but it was too messy. The milk simply poured out of the hole in her neck and soaked everything. I tried a bottle, but that was less than successful. I think Kelly had figured out that the bottle couldn't actually feed her and that her stomach was filled by the syringe.

❖ **At this stage Jan was told that she was eligible for government assistance. A local woman was hired to do four hours of housework a week, and a Karitane nurse came one morning each week to look after Kelly while Jan took Daniel to playcentre, very mindful of the need to give Daniel as much care and attention as possible. Plunket nurses visited weekly, and the paediatrician saw Kelly regularly. Jan admits that, at this stage, she had wonderful support from the local health authorities. Kelly, although below average height and weight for her age, was thriving. However, Jan herself was severely lacking in sleep. Kelly demanded constant attention throughout the night. Despite this, there were no dramas, until one night when Kelly was three months old, just a few days before she was due to return to Auckland to see the specialists.**

Richard: Jan was exhausted through her broken sleep. I heard Kelly crying for a feed, and I offered to give Jan a break with the feeding. I had never done it before, but I had seen her do it. I had almost finished filling the tube with milk when Kelly waved her arm, and caught the tube and pulled it out. I got a hell of a fright as milk started shooting everywhere from the hole in her stomach. I yelled, and Jan rushed in. We took off for the hospital and sorted things out. I felt lousy, as if it had all been my fault. It was a long time before I plucked up enough courage to feed Kelly again.

Jan: We had been told the tube would not come out easily, as it was secured inside Kelly's stomach. We sure proved that theory wrong! At the hospital there was a lot of confusion. Kelly's case was a new one to them, and they didn't have any gastrostomy tubes in stock - that came as a bombshell. Eventually, though, they put in a urinary catheter tube as a temporary measure until we could get to Auckland. The staff reassured us that this tube would hold, because it had a little balloon in it filled with sterile water to keep it in place. Eventually we got home again, relieved (to say the least) that everything had worked out in the end. Poor Daniel was very confused by the pandemonium, and we were exhausted. Because of this, we decided to go to Auckland on the Sunday afternoon and stay with my sister Therese. Our appointment with the paediatric surgeon was for first thing Monday.

On the way to Auckland, Kelly was upset. She was definitely out of sorts and was suffering from diarrhoea. As she was normally so placid, I began to get worried. At

Therese's, when I went to give Kelly a feed she started screaming. Therese immediately suggested we take her to the Emergency Department at Princess Mary Hospital.

At the hospital, Kelly was examined fairly quickly. She had stopped screaming and it was very difficult to make the doctor understand how upset she had been only minutes before. There was no fever, and they couldn't find anything wrong. The doctor suggested that we take her home and see how she was when we saw the surgeon the following day. Reluctantly, we did as he said. Big mistake!

Back at Therese's, Kelly continued to have diarrhoea, and at the next feed she began screaming again. We bundled her up and went straight back to the hospital. The same doctor was still on duty and once again examined Kelly. He still couldn't find anything wrong, and by this time he was insinuating that 1 was an 'overanxious mother'. I saw red about then and told him, 'I know my baby and I know something is wrong with her. I'm not taking her home until we find out what it is.'

I had no idea that this would be the first of many times when I put my foot down with medical professionals. Even though Kelly was so young, my instincts regarding her well-being were very acute. The doctor didn't like it, and I knew Richard was getting very agitated at the way the man was treating me, so I gave him one of 'those looks'. The last thing I wanted was Richard going off at him. I have always been shy of confrontation, but this time I wasn't going to be budged. If both of us went off at the doctor, the situation could have gotten out of control. We needed Kelly taken care of. That was *all* that mattered.

Richard: I found it very difficult controlling my temper at the arrogance of this guy. He was treating Jan as if she were a neurotic. I knew just how capable she was as a mother, and that she sine didn't exaggerate. I really did want to 'sort him out'. Jan told me to calm down. She always worried about me rocking the boat; Jan didn't like scenes.

She has much more diplomacy than I could ever manage. Some-times this has caused a lot of friction between us, and we have argued about it. This time, though, she got 'stuck in' - polite, but really tough with it. The doctor gave in very reluctantly.

Jan: The doctor really glared at me. He obviously wasn't used to someone standing up for themselves and their child. He went over to where Kelly lay, and started examining the feeding tube. He began pulling it, and suddenly it started lengthening. He pulled it right out, and it was followed by a great big clot of old, black blood. We all got a shock, including him. Why was there so much tube inside poor little Kelly? The doctor concluded that the tube must have been sucked into Kelly's intestines, and she had been getting fed directly into her bowel. No wonder the poor little thing had been in pain. The doctor found the correct gastrostomy tube and inserted it. He never once apologised for the way he'd spoken to me and treated me. Over-anxious mother? No, just a mother who knew her child and wasn't ever going to take no for an answer. Looking back, this was definitely a major turning-point in my life. From that moment on, I put total trust in my instincts when it came to my children's health.

❖ The appointment with the paediatric surgeon brought mixed blessings. The specialist informed Jan and Richard that he was about to leave for the United States to learn the latest techniques on the gastric interposition operation he was going to perform on Kelly. They also learned that Kelly would have to be 12 months old

before the operation could be performed, as it was a major procedure and she had to be strong enough to handle it. This news came as a real shock to Jan, who had the six-month figure firmly in mind. The surgeon asked to see Kelly again in three month's time, when he had returned from the United States.

After this meeting the Turners went on to Middlemore Hospital to see the plastic surgeon. They found him a very friendly and approachable individual. After taking X-rays of Kelly's thumbs, he concluded that a single good thumb could be built, and that the problem with Kelly's 'floppy' right thumb could be corrected. There was, however, yet another shock in store for the parents: the surgeon told them that the operation would be best done at about four years of age, so that Kelly could go to school having the best possible mobility in her thumbs. He suggested that an appointment be made for three months' time, to coincide with the paediatric surgeon's appointment. Resigned to nine months of further tube feeding, Jan, Richard and Kelly picked Daniel up from Therese's home and returned to Ohope, rather deflated by their Auckland visit.

In the months ahead, Kelly lost her tube twice more; each time the hospital didn't have replacement tubes in stock. In the end, Jan and Richard obtained a supply from Auckland and kept them on hand. As Kelly grew, she graduated to a larger-sized tube and a diet of puréed vegetables mixed with milk. The only problems with her feeding occurred when she cried; then, the contraction of her stomach muscles sent everything shooting back up the tube. Jan learned to clamp the tube until Kelly quietened down.

For the rest of the year, Kelly had no major medical problems except for colds and thrush caused by the gastrostomy tube. Life, though, was settled. Kelly was introduced to a walker, and she and Daniel became what Jan described as 'the fearsome duo', getting into all sorts of usual kiddie mischief.

Jan: All I wanted was for our family to have a 'normal' life, and, despite the naughtiness, I was pleased that there was a normality about things. Unless people saw the dressing on Kelly's neck, or her being fed, they wouldn't have known there was anything wrong with her. Daniel saw no reason to treat his little sister differently to the way any other youngster would. In fact, when he saw another mother breastfeeding her baby, Daniel wanted to know why baby didn't have a tube like Kelly. He thought that was the way all babies were fed.

I must admit, though, that when I saw other mothers feeding their babies normally, I envied them. I just wished it could be like that with my little girl. It hurt deeply, particularly the lack of breastfeeding. Many times at night I would cry about that in Richard's arms. Kelly and I were both being deprived of the basic mother-and-child act. It hurt then; even today the memory still hurts.

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Kelly continued to thrive. Jan ceased expressing breast milk after ten months when Kelly was well-established on solids. That brought on its own set of problems. Kelly's calorie intake had to be limited, to prevent her becoming too fat. She first walked at 14 months, one month before her gastric interposition operation which was scheduled for 26 June 1984.

CHAPTER 4

The first step

THE DAY THE Turner family had waited so long for had arrived: Kelly was admitted to Auckland's Princess Mary Hospital. Jan decided that she would stay in Kelly's room in order to lessen her daughter's trauma.

Jan: I remember thinking, when I gave Kelly her last feed the night before the operation, that this would be the last time I had to feed her through the tube. I felt elation at the prospect, but was also very apprehensive. My little girl was going to undergo major surgery. I just didn't want to think about what she was going to have to go through. But of course I did - I was awake the whole night. I felt terrible in the morning. When Richard arrived I gave him a big hug. 'It'll be all right!' he said, 'Kelly will come through it fine.' He sounded so positive he almost convinced me.

When it was time, I couldn't take Kelly down to the theatre. I was too distressed. I couldn't bear the thought of handing her to strangers and walking away and leaving her. Instead, Richard took her. She looked so tiny in his arms. He handed her to the waiting nurses, the theatre doors swung closed, and the waiting began. Richard and I went back up to the room. There, we paced, and hugged, and sat, and waited and waited. It seemed like an eternity.

❖ **Kelly was in theatre for almost five hours before being removed to the Critical Care Unit at Auckland Public Hospital. When she found out where her daughter had been taken, Jan was terrified. Because of the time the operation took, Kelly's body had been under great strain, and she had required a blood transfusion. It was some time before Jan and Richard were allowed to see her. When they finally did, the shock was devastating.**

As soon as I saw Kelly my heart sank into my boots. Our dear little girl was lying there, looking so tiny, so frail. There were intravenous tubes and monitoring lines all over her body. She was also attached to a respirator and a chest drain. There was even a drip in her head. I couldn't touch her body anywhere where there wasn't a piece of equipment. The extreme seriousness of her condition hit me like a sledge-hammer. I hadn't expected this. I struggled to make sense of it all. Major surgery yes, but this was incredible!

The nurses couldn't answer any of my questions, other than to say that Kelly was stable. God! How naïve I'd been. I desperately needed to talk to the surgeon to find out what was happening to my daughter. In a panic, I left the unit and went looking for him. I caught him as he was getting into the elevator, and threw myself in just as the doors began to close.

'How did the operation go?' I asked, my heart pounding as I struggled to try and stay calm. The surgeon looked tired and not at all pleased to see me.

'As well as can be expected,' he replied. 'It was major surgery and a lot for her body to cope with. So when her blood pressure dropped, it was best to bring her to the unit here.'

'Is she going to be all right?' That was the question I needed answering more than any other. He looked down at me.

'The first 24 hours are the worst. We have to get her through that time and then see how she is,' he replied bluntly. We were out of the elevator and he was striding away along a corridor. I was running to keep up. He didn't even stop to talk to me.

'What can go wrong?' I desperately needed to know what might be ahead for Kelly. I wasn't prepared for what he said next.

'Well, she is the first one we've done this particular operation on in New Zealand, so we just have to wait and see.'

I stopped dead in my tracks, and he carried on. I was totally stunned! My daughter had been nothing but a bloody guinea-pig I couldn't believe it. Had I failed Kelly? I should have checked this out before letting this arrogant man go ahead. I should have done more, asked more questions, not blindly trusted him or the damned system.

I suddenly felt the fear I'd experienced when we'd nearly lost Kelly at birth. It is a feeling so gut-wrenching that it is indescribable I thought of Kelly and Richard back upstairs in the unit, and somehow pulled myself together. Kelly had survived before, she was going to again. She had to, the poor wee thing had come so far. I clamped down on my panic and my anger, and went upstairs. Hold Richard what I'd learned, but I smoothed the edges a bit. He was as shocked as I was. He would have been totally furious if I'd told him how uncaring the surgeon's manner had been. Richard cares for his family with a total commitment. He admits he's not as subtle as me. If he had faced the surgeon at that time, I hate to think who might have needed the surgery.

Looking back, I understand only too well the strain of what goes on in an operating theatre. I'd seen it when I was just a teenaged nurse, and so much more since. But the big question I ask is this: where does humanity stop and the mechanical aspects of it all take over? I've read somewhere the expression the 'God syndrome' that affects some doctors, particularly surgeons. At what point do they switch off and cease to be human beings, parents, husbands, wives, lovers, whatever? When does the medical role actually take over from all else? I've met many who remain human beings, people, throughout, no matter what the stresses. Professor Gluckman, for one, was a shining example. What is the cost of stopping just for a moment to answer the questions of an anxious parent? Is that too damned much to ask? How ludicrous it must have seemed. A towering, big man walking, striding, almost running away, being shadowed by tiny me, struggling to keep up.

My anger finally gave way to a kind of sadness. I suddenly had the urge to get Kelly baptised in case she didn't make it. We called for the hospital chaplain, and he immediately came up and performed the ceremony while Kelly and her machines fought to keep her alive. I'm not a terribly religious person, but I prayed for my little girl like I've never prayed before in my life.

❖ **Kelly made it through the first 24 hours, but other complications emerged. As the days passed, she became strong enough to get off the respirator, but every time the machine was disconnected, Kelly's windpipe collapsed. A floppy windpipe, it was revealed, had been another birth defect. The anxious parents were told that the cartilages would harden in time.**

During the time that Kelly was on the respirator, she couldn't talk. All she could do was sob. She was being fed intravenously, and she lost all her excess

weight. The respirator was removed for longer periods each day, but it was only in the fourth week of recovery that she could breathe on her own.

At last! Kelly's breathing was very rattly, but she was off the machine. However, that wasn't the end of it. The plan was that once we got her eating right, we could take her home. I was so relieved. It was then we discovered another problem. Kelly didn't want to eat or drink through her mouth. They had stopped the intravenous feeding, and what was left of her condition just dropped off. Suddenly, I was watching my daughter starve right before my eyes. The staff told me that if she didn't start taking food orally very shortly, they would have to put her back on an IV. I knew that would be a backwards step, and I tried harder and harder to get her to eat normally. I tried medicine glasses, a bottle, with lots of encouraging, tasty foods and drinks, but Kelly just didn't want them. She'd been fed through tubes so long she didn't understand that she needed to eat and drink through her mouth. It was so frustrating. She was too young to even realise that we were fighting to save her life. After each failed feeding session, I would find a quiet place and cry, my heart was breaking. Richard had gone back to Ohope with Daniel - I felt so alone.

❖ **Eventually, Kelly began to take small amounts of food and drink orally, and she was moved back to a private room. When she had gone in for the operation, Kelly had weighed 7.7kg. Now, four weeks later, she was down to 5kg. Jan was fretting, but it was at this point that she started taking notice of the patients around them. Kelly's room was beside the entrance to the Oncology Unit. When Jan saw the children undergoing chemotherapy, her heart went out to them and their parents.**

It suddenly made me realise that things could have been so much worse for us. Here were so many kids with conditions that couldn't be surgically corrected. It was heart-breaking to watch them pushing their drip stands with them as they moved around the department. It caused me to reassess everything, and start counting our blessings. Kelly still wasn't eating well, but that was hopefully just a phase that would soon pass. On the days when I felt sorry for myself, I would just think of those poor children - that made me snap out of my self-pity. Kelly had survived and things could have been much worse.

❖ **After five weeks, the surgeon said that Kelly could go home. Rather than have Richard drive up from Ohope to collect them, the hospital social worker arranged for them to fly. The homecoming wasn't to be as they had all hoped and dreamed it would be.**

Richard: I still have such a vivid picture of Jan and Kelly's arrival home. The image that comes back again and again is of Jan standing in the kitchen holding Kelly. Jan was so thin and haggard, and Kelly was so tiny, just like one of those starving children we all see on television. Her whole body seemed lifeless. She was just flopped in Jan's arms, her eyes dead. Jan was crying tears of frustration. She couldn't get Kelly to eat. I was scared shitless and felt so totally helpless. Usually Jan knew exactly what to do. I had never seen her so defeated before.

CHAPTER 5

My baby is dying and I don’t know what to do

THE DAY AFTER Jan and Kelly arrived back from Auckland, Jan, who was becoming desperate at Kelly's refusal to eat, went to see her sister Therese, who had separated from her husband and was now living in Whakatane.

Therese: I was so excited that Jan was bringing Kelly to see me. They had been away for five long weeks. I wasn't prepared for what I was about to see. As I opened the door to greet them, Jan fell to her knees with little Kelly cradled in her arms. I couldn't believe how Kelly looked. Gone was the chubby little girl I remembered - in her place was this thin, pale little figure. She was like a little, wizened-up old woman. Gone was the beautiful hair, now it was thin and wispy, her eyes were dead-looking and out of focus, sunken deep in her head. She couldn't even manage a smile for me. And Jan, she was so thin and haggard. She just knelt there in the doorway, beaten. She looked up at me and said, 'My baby's dying and I don't know what to do.' I just stood there looking at them, unable to believe my eyes or my ears. I wanted to join them on the floor and just cry for them.

Somehow I kept my emotions inside, I couldn't let Jan see how upset I was. She desperately needed strength - not weakness at this moment.

'Bullshit!' I said. 'Come on, get up mate. She'll be fine!' I got Jan to her feet. As I held Kelly, I could see how weak and unresponsive she was, and how very light. She was dying . . . of starvation. When Jan told me how little food she was managing to get into Kelly I was shocked that the hospital had discharged her, telling her not to worry, Kelly would learn to eat more in time.

Jan was beaten. I got her a hot drink, then tried to get something into Kelly. She just shook her head from side to side. Eventually I got her to take a couple of sips of fluid. Right at that moment I felt that the poor little thing hadn't actually learned to swallow, never having used her throat muscles in all her short life.

'Right,' I said, 'it's off to the chemist.' There I bought anything and everything that had a high calorie value with the minimum of bulk, including lots of children's vitamin preparations. Instead of plain milk, we were going to try it fortified with Complan, vitamins and iron. Neither of us had any money, so I wrote a cheque and hoped for the best. We weren't going to let anything stop us getting Kelly well again.

❖ **Between them, Jan and Therese worked out their own dietary plan for Kelly. Therese managed to get some food into the little girl, and when Jan left to go home, she was feeling much better. However, yet another shock was waiting for her in Ohope.**

Jan: I was feeling much happier as I drove home. Therese had been so practical and down-to-earth, and she had managed to get Kelly to take a feed. I thought that this was the start of something good. I was surprised to see an unfamiliar car in our driveway. I left the kids strapped in the car as I carried in the bags of 'special' food for Kelly. I went quite cheerfully into the kitchen to greet Richard's grandparents, who had come to stay and help.

There was a stranger waiting in my kitchen, a very stern-looking woman in a nursing uniform, and no sign of the grandparents. I gave the woman a smile and had hardly put the groceries down when she started in on me.

'I'm the district nurse and I've been waiting over an hour for you to get home. What do you think you're doing taking a sick child like that into town?' I was totally taken aback.

'I'm sorry I wasn't here when you came. I had no idea you were coming.' I started to explain about Kelly, that she wasn't sick as such, but the woman didn't even seem to register my apology -or anything else I was saying for that matter. She just went on and on, harping about me taking a sick child to town when she should have been in bed. I tried again and again to get through to her, but she was in full broadcast mode, the 'receive' switch was turned off. It was like trying to talk to a damned radio.

Suddenly, I had had enough. All the events of the last days came crowding in on me, and I got mad. Who the hell did this woman think she was?

'What are you talking about?' I yelled at her, any pretence at good manners gone right out the window; 'Kelly doesn't need to be in bed. She's not sick, she just needs building up. I've been at my sister's home working out a dietary plan for her.'

'She just had an operation yesterday,' the woman threw at me.

'Yesterday!' I was really steaming now - she was totally wrong, she didn't have a clue about what was happening. 'Kelly had her operation five weeks ago!' I pointed at the door. 'I want you out of my house now. I will not be treated as an irresponsible mother. You obviously know nothing about the situation.' I turned my back on her, and left her standing there as I went out to the car to get Daniel and Kelly. I was absolutely furious, I couldn't believe the way this woman had treated me.

In the meantime, the district nurse was calling out to me. I just yelled back at her. 'Get out of my house, now!' I unbuckled the kids, carrying Kelly back inside while Daniel walked in with us. The nurse was standing waiting for me.

'I was led to believe that your child had only just had an operation yesterday,' she said. I was still fuming, and I let rip again.

'I looked after my daughter at home till she was 15 months old, feeding her through a gastrostomy tube and caring for the oesophagotomy on her neck. I will not be treated as if I don't know how to look after her properly. I certainly don't need people like you coming out here when you don't know anything about her medical history. I want you to leave now.'

Finally, I knew I had got through to her. Her face dropped. She realised that she had made a big mistake, and was suddenly looking extremely guilty. I just didn't care. This was perhaps the final straw for me after the run-around and the attitude of some of the medical people we'd been exposed to in the last few months. I'd come home almost cheerful and this woman had verbally kicked me in the stomach. She now changed her tone and started talking about applying the silver nitrate solution to Kelly's neck.

'Leave the bottle and don't come back!' I snapped at her. She looked at me as if trying to find some words that would change my mind, then just turned and left.

All the time the nurse and I had been battling, Richard's grandparents had stayed in the lounge. Still indignant and shocked at what had happened, I went in to talk to them. 'Can you believe how she treated me?' I asked them, and was totally stunned by their reply: they agreed that Kelly should have been at home in bed. That was it, the final kick in the stomach. I had no energy left for another battle. I was convinced that I had done the right thing, taking Kelly to Therese's. Even now, I believe it saved Kelly's life and my sanity. 'If you feel that way you may as well leave too,' I told them. It felt as if the whole world were against me. Without a word, they walked off and packed. Before they left I thanked them for helping look after Daniel while Kelly and I were in Auckland. As their car went down the drive, I wished Richard were with me. I felt so alone and still so angry.

First, there had been the doctor in Emergency in Auckland all those months ago, who had virtually accused me of being an over-anxious mother. Now this district nurse had accused me of being a negligent mother. I phoned Therese: I needed to talk to someone.

Therese: When Jan had left my place she looked a little better. Kelly was sitting in her car seat, still looking terrible. The poor little thing didn't even manage her usual enthusiastic wave. I went inside feeling absolutely sick to the stomach, wondering why all of this had happened to Jan. She was so tiny, so delicate: I wondered how much more she could take. Now that they were gone, I just let go and sobbed and sobbed for my little sister and her baby. It was so unfair.

They had been gone under an hour when the phone went. It was Jan. She was so angry that she could hardly get her words out. My first thought was that something had happened to Kelly. My heart climbed into my mouth. Then Jan calmed enough to tell me the story. I just thanked God that she had had enough energy left to stick up for herself.

The moment Jan got off the phone, I called Russell Meads, Jan's GP, and told him the way she had been treated by the nurse. He was very concerned, he knew full well what a wonderful, caring mother Jan was. Later, Richard phoned me and said he was really worried about Jan. He asked me to come and stay at the farm for a few days and help her. I agreed.

❖ **Therese took over Kelly's feeding from the moment she arrived at the farm in Ohope. She developed her own method of feeding Kelly, and asked Jan to go for a walk at feed times. Therese didn't want Jan to see just how hard she had to fight to get Kelly to take her food.**

I could not do what I had to with Jan watching. I literally force-fed Kelly, all the time feeling cruel and mean. I would pour the liquid into Kelly's mouth, then hold her mouth shut and tilt her head back. I wouldn't let her lower her head until she swallowed. My heart ached, her big eyes accused me of being cruel, instead of being her nice aunty. But there was no other way. In a few days she didn't fight as much, and was finally swallowing most of her little feeds.

❖ **It was only when Therese and Jan tried increasing Kelly's food intake that yet another problem came to light. Following her feeds, Kelly started wheezing and became short of breath. At first Therese thought food might have been getting into Kelly's lungs, but soon discounted that as the wheezing eased off after a time. Because of the breathing difficulty, they limited the amount they gave her.**

After one particularly bad scare, Jan and Richard rushed Kelly to hospital. X-rays showed that the operation to raise Kelly's stomach into her chest cavity meant that a full stomach pushed on Kelly's windpipe and reduced her lung capacity to such a

degree that it severely hampered her breathing. The irony was that, now Kelly was feeding orally, her meals had to be small and frequent to prevent her over-eating.

Jan: From time to time, Kelly's breathing problem would reappear. It was difficult to stop her now that she was happily eating away. We could tell by the sound when she was getting full, and sometimes she got really annoyed when we took her food away. The only way to relieve the pressure when she did have too much was for me to put my finger into the back of her throat to make her vomit. This relieved the pressure in the most practical and immediate way possible. Later, it became almost a 'normal' thing for Kelly. After her meal, she would go and play. Ten minutes later she would come running up to me and say, Towel, Mummy, towel.' That was the signal for those in the know to get a paper towel. We'd give her the towel, Kelly would vomit into it, give it back to me, and run away to play again. She knew herself that when her breathing started to get difficult there was only one cure for her - Towel, Mummy, towel.'

❖

Despite the fact that Kelly was eating fairly well, her regular weighing sessions showed that there was no sign of her gaining weight. Once again, Jan was concerned.

I felt something wasn't right. She should have been gaining weight by this time. When we went to Auckland for Kelly's next check-up, I mentioned my concerns to the surgeon. He wasn't very receptive to the suggestion that his operation hadn't been totally successful. However, he reluctantly ordered a barium meal to see what was happening. The results showed that the pylorus valve (which empties the contents of the stomach into the intestines) was not opening quickly enough. Apparently the valve had been pulled tight because of the stomach stretching up through Kelly's diaphragm. So now they had to perform an operation to enlarge the valve. Poor Kelly: would it never stop?

❖

Kelly was admitted to Princess Mary Hospital immediately to have the operation. Unfortunately, the day before the operation, she contracted a gastrointestinal infection and diarrhoea. The operation had to be postponed for a week to allow the infection to clear. Once again, Kelly had to be fed through a tube, this time a nasal-gastric one. On the day of the operation, Jan was apprehensive. She remembered Kelly's long spell in Critical Care Unit the previous time she had been operated on. This time, however, Kelly came straight back to the ward. She had to use an oxygen tent for a short time, but she recovered quickly and the Turner family returned to Ohope, relieved and happy. There was just the surgery for Kelly's thumbs sometime in the future. Then they could be a 'normal' family.

CHAPTER 6

The first five years

❖ FOLLOWING THE OPERATIONS to correct Kelly's feeding problems, life for the Turners settled into a semblance of normality. Kelly was just like any other little girl; but the word *little* was definitely significant. Ever aware of the fact that people could judge her as an 'uncaring mother', taking her daughter about with her 'with such a bad cold', Jan took pains to explain that Kelly had a breathing condition. She also became adept at explaining about Kelly's small size to people who frequently commented about it, often within Kelly's hearing. This is something that was, and is, a constant annoyance to her.

Kelly was enjoying life with Daniel and her friends. When she was four, two operations were carried out to correct her thumb problems. By the time Kelly started school, she had virtually complete mobility in both thumbs. Life for the brave little girl was looking good.

For Richard and Jan, however, things weren't going so well. Ohope had become the source of too many bad memories for Richard and he lost interest in his job, preferring to take up a guiding position in his father's tourist business, based in Taupo. Jan didn't want to leave the beautiful little seaside town. Her medical support network at Whakatane was so very important to her. The paediatrician, Dr Russell Meads, the Plunket nurse and a 'very obliging' pharmacist all knew Kelly's history intimately, and combined to form a reassuring safety net. In spite of the fact that, on the surface, Kelly was doing well, Jan had an over-riding sense of dread that she couldn't shake. Despite these misgivings, the Turner family shifted to Taupo and had to adapt to becoming 'townies'.

Taupo didn't have a resident paediatrician, but one based in Rotorua visited on a monthly basis. Kelly saw him when he came to town. Because there were no major medical problems evident, the paediatrician's tasks were mainly confined to weighing and measuring Kelly. Although always well below average in both areas, Kelly's paediatrician was satisfied that she was growing at her own rate. Jan, however, was constantly bothered by Kelly's small size, and she questioned it again and again. Almost always her concerns were explained away, generally with reference to her own small stature.

Super-sensitive to the attitudes of medical people because of her previous experiences, Jan resented the paediatrician's attitude that he found Kelly a 'manipulative' child. To her, what made this all the more galling was the fact that he based this assumption on a mere 15 minutes a month spent with Kelly. Despite these minor aggravations, outwardly the Turners were an ordinary family. But there were other problems. In his new job as a tourist guide, Richard was often away for three days at a time, leaving Jan alone with the children and her fears - fears that tormented her.

Jan: I would go to bed once the kids were down. I couldn't stand being 'alone' in the house, without Richard there. I felt the loss of my support network terribly. The whole situation with Kelly was always with me. She had regular problems with coughing at night, and Richard (when he was home) and I were constantly seeing to her. Often we were quite exhausted, yet it became a way of life. When Richard was away, I would crawl into bed with the sound of Kelly's breathing in my ears. I would lie in bed alone and hug myself, trying to shut out that horrible, rasping noise. These hugs were so different to those I used to give myself in Ohope when I stood looking out at the magnificent view, so thankful that my dreams had come true. Those hugs had been brought on by joy -the ones in my bed in Taupo were hugs of sheer loneliness.

Richard and I talked frequently of having more children. Ever since Kelly's birth, I had felt cheated. I hadn't been able to fulfil my maternal instincts with Kelly, even though I loved her dearly. I had spent most of my time with her in those early years more as a nurse than a mother. Richard was keen on the idea of having another child. He kept reassuring me that the chances of us having another with the same deformities as Kelly were pretty slim. I just wasn't convinced. I had this terrible 'gut feeling' that kept bugging me. Often we would talk about why Kelly was born with problems. It really bothered me not knowing why it had happened. I had this recurring fear that they would find something else wrong with my little girl. Yet I had no concrete foundations for my fears. Call it 'mother's intuition' - whatever - the sensation never really went away, it hovered in the background like a mist cloud. My insecurities lead to many tearful nights with me just lying on Richard's chest, crying. Eventually Richard went for a vasectomy - I just wasn't prepared to have another child.

It was during this period that Richard and I almost blew ourselves and our marriage apart. With him gone so often and for such long periods of time, my anchor was gone. The feeling that there was something terribly wrong with Kelly never left me. I was constantly on edge, struggling to stay sane, scared for Kelly and myself, scared for our marriage, our family. Then, at one point, I knew that I had to do something to save myself and us. I would get strong again and I would find out what was wrong with Kelly.

Looking back, something, someone, God or whatever, was guiding me along a path to an inevitable end. When I made the decision to enter counselling, it was the best thing I could have done. Very gradually, over months, my demons came out of the cupboard to be confronted and were banished. I began to feel so much stronger in myself. I asked Richard to go to counselling for the sake of us and our family. Thank God he agreed. Quite honestly I believe it would have been all over for us if he hadn't done so.

The counselling was tough, but it worked for us. Richard gave up the guiding job and we became a family again. But still, I knew that something was wrong with Kelly: that thought had never left me. Now, however, I was strong enough to go and find the answers.

Richard: Jan was haunted by not knowing why Kelly had been born with her problems. That, and many other things, put a great strain on our relationship. Working with counsellors helped sort us out, but that one thing never went away. It was strange that all the time we worked in counselling, we never touched on the problems associated with Kelly's medical history - which, looking back, was ultimately the cause of many of our problems in the first place. We worked on our childhoods and the day-to-day attitudinal problems we had developed in general. We never brought it up ourselves which was probably a mistake, but it was as if we had simply become so tolerant of Kelly's medical problems that it wasn't even part of our stress.

Despite the fact that the counsellors and ourselves missed that, things worked out and, by 1989 we had our marriage back on track. Still, Jan never lost her preoccupation with Kelly's health. I encouraged her to speak with the paediatrician and I didn't like the way he ignored her concerns. I was so tempted to 'sort him out', but as usual Jan wanted to do it diplomatically.

Jan: By the time Kelly started school, she was a pretty little thing with long blonde hair and blue eyes. She really was cute and we all adored her. We had made a real effort to treat her normally and it had paid off. She was very well adjusted emotionally. It was also very important for Daniel that they be treated equally. It would have been so easy to wrap Kelly in cotton-wool. We didn't do that, couldn't if we'd tried. Nothing held her back: she was such an active kid, into everything, always covered in bruises. Little did we know the significance of those bruises.

❖

Jan's intuition was to be proved painfully true shortly after Kelly's sixth birthday. The paediatrician was now only seeing her once a year. This time, Jan's new-found strength made her demand that the doctor do a more complete examination of her daughter. Once again, she was treated as an over-anxious mother, but she wasn't about to take no for an answer. The visiting paediatrician reluctantly gave in, and ordered chest X-rays and blood tests for Kelly.

Within a few days, Jan received a call from her doctor to say that the platelet count in Kelly's blood was quite low, at 75 (normal was twice that). The doctor assured her that it probably wasn't serious. She was to take Kelly to see the paediatrician again in a fortnight.

I didn't understand what I was being told, so I immediately went to the library. I found out that platelets play an important role in the clotting process, gathering in an injured area and giving off a substance necessary for the clotting of blood. Kelly's low count explained why she bruised so easily.

When we entered the paediatrician's office two weeks later, I wondered if I would receive an apology for his reluctance to run the tests previously. Of course I didn't get one - I didn't really expect it. It isn't the way these people do things. He hid behind a lot of medical jargon, and told me that Kelly had idiopathic thrombocytopenia, meaning a decrease in platelets by an unknown cause. He reassured me that it was quite common in children, and usually came right of its own accord. I asked him how long her platelet count had been low, as I couldn't remember when she'd last had a blood test. He didn't know, but guessed the last test would have been when Kelly had had her thumbs done at Middlemore Hospital the year before. He also said that it was unlikely they had done a platelet count; they would have just noted that the platelets were present.

❖

The paediatrician decided that Kelly should have monthly blood tests and that they would wait for her platelets to increase spontaneously.

Over the next five months, Kelly's blood counts showed platelet levels of around 70. Everything else was in the normal range. It was then that both Kelly and Daniel contracted chickenpox. Daniel recovered quickly, but not Kelly. A blood test showed that her platelet count was down to 40.

Jan was concerned at the low count, but was told it was because of the infection. Kelly recovered, but when Jan took her for another blood test, she was shocked when the platelet count came back at 24. Immediately, she insisted that the paediatrician refer Kelly to a specialist.

For six months I had believed what I had been told about Kelly's platelet problem. No more! Now, even the other blood counts had dropped as well. So much for 'spontaneous improvement'. The paediatrician doubted that it was leukaemia, which had been my first fear. Needless to say, I wasn't about to take his or anyone else's word until it had been double-checked. I was losing faith in the medical profession at an incredible rate.

We were referred to Dr Scott MacFarlane, a paediatric specialist at Waikato Hospital, who worked closely with a haemotologist named Stephen May. Kelly would have to have a bone marrow aspiration, to find out what was happening in the 'factory' where the blood cells are produced. I wasn't familiar with the role that bone marrow played in the body, so once again it was back to the library to learn about it. The more I knew, the better I could make my decisions as a mother. I needed to know exactly what was happening to Kelly.

Therese: With her usual determination, Jan hit the books. She read all the medical ones I had and raided the library again. Little did she know that she was going to become an expert in laboratory results, red and white blood cell counts, platelets, bone marrow function, donor cells, DNA matches, and so much more. My mind boggles when she shows me the charts she kept with all of Kelly's results and drug regimens. She knows things that a parent should never have to know. I think, in a way, doing this helped her 'keep a handle' on what was happening to Kelly. By understanding what was going on, she maintained some degree of control, and hope. I also think she was at a stage where her trust in health professionals was failing, and that the best way to ensure that Kelly was safe and received the best possible care was to keep a sharp and knowledgeable eye on everything.

❖

While Jan threw herself into learning all she could about the functions of bone marrow and blood, Richard was lost, not able to comprehend the seriousness of Kelly's condition.

Richard: It wasn't until we started asking questions about Kelly's treatment that it hit me. All I could think of was, 'Okay, let's treat it and get on with life.' Only now I realise just how naive I was. Then, I just didn't understand.

Jan took it really hard; she was devastated, crying a lot, desperate for answers. Once again, our differences came to the fore. She was so emotional; I was being the 'strong man', trying to keep it all together. I knew that it wasn't going to do any of us any good if we were both messed up.

❖ **The role of bone marrow is to produce blood cells. They are 'born', grow and divide in the marrow. Red cells carry oxygen to the body tissues, white cells are responsible for fighting infection, and the platelets aid blood clotting. In a healthy person, the platelet count is in the range of 150-400. Any illness targeting the bone marrow inevitably affects the blood.**

Jan: When Kelly and I entered the Oncology Unit for our appointment, I couldn't help but remember our time in Auckland after her surgery, all those poor kids. I also remember how I used to count our blessings. I'd never dreamed that one day I'd be bringing Kelly here; now, here we were. I was terrified at what we would find out. In the waiting room, there were a lot of children with bald heads and pale complexions. Kelly looked at them curiously and I imagined her like that. The thought sent my heart into my boots. I kept thinking, 'We're in the wrong place.' But we weren't.

Drs MacFarlane and May were very pleasant. I guess they had to be$ to work in this area. They told me that they wouldn't know much until the bone marrow aspiration had been done. They would take a sample from Kelly's hip with a needle. They explained that the bone marrow was in fact a liquid and this was the usual means of obtaining a sample. Poor Kelly: I told her that she would just be having a short sleep. They put the gas mask over her face and, as soon as her eyes closed, I ran out of the room. 'What will they find?' The question just kept rolling over and over in my head.

In the waiting room I was alone. I put my head in my hands, and sobbed and sobbed. I felt an arm around my shoulders, and looked up to see a young lady. She introduced herself as the social worker. She asked if there was anything she could do. I just let it all go, crying, rambling - it poured out of me. There was nothing she could say other than to wait for the results: They might not be as bad as you think.' I grasped at that thought: not as bad as we think.

❖ **A week later, when Jan and Richard returned to Waikato Hospital to meet with the doctors, the news was even worse than Jan had feared.**

'It's not leukaemia,' both doctors told us in unison. It was like music to my ears and I heaved a big sigh of relief. Thank goodness,' I said out loud. I wasn't prepared for what came next.

'We'd be happier if it were leukaemia,' they continued, 'as we have a lot of success treating it these days. We're dealing with something much rarer and possibly more serious.'

More serious? The words bounced around inside my brain like ping-pong balls. More serious than leukaemia? I sat there staring at the doctors. I couldn't believe what I was hearing. Like most parents, I guess, I thought leukaemia was as serious as it gets. For a moment I thought we were in a television show and had just been delivered the old, ‘I’ll tell you the good news, then the bad,' line.

The doctors carried on to say that the bone marrow was definitely failing; they had a hunch what was causing it, but didn't want to tell us until they had done some special blood tests. I was numb by now. It was as if that cold mist of apprehension or fear that had been hovering over me all those years had just settled on me. I was definitely on 'autopilot' when we took Kelly for more blood tests. Then, we had to wait for one of the most hellish weeks of our lives for the specialists to confirm their theory.

Kelly in the incubator at Whakatane Hospital, aged one month.

Jan feeding Kelly, aged four months, through the tube into Kelly's Stomach.

Kelly at Princess Mary Hospital, just before the pyloroplasty Operation, November 1984.

In the oxygen tent after the pyloroplasty operation, November 1984.

Before the operation to remove Kelly’s extra thumb,
June 1987

After the operation to remove Kelly’s extra thumb,
June 1987

Kelly aged five years.

CHAPTER 7

My intuition becomes reality

KELLY WAS DIAGNOSED as having Fanconi's anaemia (FA), a rare genetic condition in which the chromosomes are extremely fragile, leading to a high risk of cancer. The specialists told Jan that Kelly's medical history - particularly her deformed thumbs and small stature - had alerted them to the possibility of this condition.

Jan: Even while the doctors were telling me about this very serious problem, I felt a strange exhilaration, a great weight had been lifted off me. We finally knew why Kelly had been born with her deformities. The next thing was to get on and beat this thing. I immediately asked, 'How can you treat it?'

'That's the problem,' they replied. 'There has been some treatment with androgen drugs but they are very hard on the liver. With Fanconi's patients having fragile chromosomes, liver failure is the biggest risk. The other option is having a bone marrow transplant, which is becoming more successful all the time.'

That at least was a comfort. I knew from my reading that bone marrow transplants were quite common. It was then that I asked how Kelly had got Fanconi's anaemia. That's when they explained about the genes and how a disease may be carried through them.

There was so much to absorb. I had to come to terms with the fact that Richard and I were the cause of Kelly being born with deformities. It felt horrible to know that we carried the condition with us. The doctors wanted to blood-test all four of us. Kelly's platelet count had climbed to 59. I asked the specialists when that would become a problem. They replied that 20 or below was where maximum risk occurred, and stressed that, if Kelly ever needed a blood transfusion, she should not be given whole blood. Any blood product had to be filtered in preparation for bone marrow transplantation at a future date. In other words, if she needed platelets, she must receive platelets only; the same if she required red cells. This was to prevent any white cells from being given and causing a reaction. I didn't understand it all properly then, but I stored the information away. Later I would read up on it.

When Kelly and I left the hospital, my head was swimming. After six long years, we had finally found out why Kelly had been born with her deformities, even why she was so small. All of what I had just learned raised more questions, though. The major one was why they hadn't been able to detect Fanconi's anaemia at birth. Were there any other cases in New Zealand? Just how long had Kelly's bone marrow been failing? There were just so many more questions than answers at this stage. I went home to tell Richard, and then the children.

Kelly and Daniel seemed to handle the news pretty well. Of course, only Richard and I understood the full implications of what we'd learned that day. Later, when the children were in bed, we talked and I cried, this time at the thought of losing Kelly. I was asking, Why? Why? Why? Why Kelly? Why hadn't it been picked up? Why everything? It was so hard to tell what was happening with Richard. He just kept telling me everything was going to be all right. He said it once too often and I turned on him. 'You don't know that this time. This is really serious!' All I could think of was Kelly dying.

As the next week passed, my emotions were all over the place. I spoke with my mother and Therese many times. Therese was now living in Rotorua, I didn't have her just down the road any more. She hadn't heard of Fanconi's anaemia so she got what reference books she could, only to find out there was depressingly little information available. Generally, what she found indicated a very poor prognosis.

Therese: My medical books only had a quarter-page in them on Fanconi's anaemia. I was looking while Jan and I talked on the telephone. What I read I didn't like the look of… it was all bad, very bad, with virtually a nil survival rate. I didn't want to tell Jan that, so I edited as I read, but she wanted to know it all. I had no choice, so I read her everything. I ended up by telling her that my book was old and to wait for the doctors to give her the latest information. I was lying through my teeth: the reference book I was using was the very latest. I felt ill when I got off the telephone.

❖ **At Kelly's next appointment with her usual paediatrician, he admitted he knew nothing about Fanconi's anaemia. It was now that Jan, who was feeling very fragile, took the opportunity to unload a lot of her feelings and anxieties about the medical profession to him.**

Jan: I told him how angry I was that it had taken six years for Kelly to be diagnosed and that had happened only because I had insisted. I told him how, for all those years, my concerns had been brushed aside, and I finished by letting him know in no uncertain terms that medical people had to learn to listen to parents more. He wasn't pleased by my frankness, but I must say that for once I saw a humble look on his face. I think he was very relieved when our appointment came to an end. I did feel a sense of satisfaction as we walked away from his office. I'd finally got to say what I had wanted to say for so long. If it only made a difference in the way he treated another mother, it would have been well worth it.

I reaffirmed my vow to myself at that moment: I would never again hesitate to speak out on anything to do with Kelly's well-being. I knew that when it came to my daughter, I was the expert. I knew her better than anyone else in the world; my instincts had never been wrong and I must continue to listen to them. I would work alongside the medical people and trust them when they earned it, but I would have my concerns listened to. If another surgeon ever walked away from me again, I would tackle him and sit on him until he heard me. All of these realisations combined to give me a new strength that I never knew I even possessed. Looking back, that was definitely another major turning-point in my life, and one for the better.

❖ **For the next appointment with the specialists, the whole family went to Hamilton. Jan was relaxed with the two doctors; she felt she could trust them. She and Richard were looking forward to getting some answers, and they did.**

A bone marrow transplant was the only permanent cure for the bone marrow failure. Apart from Kelly there was only one case of Fanconi's anaemia in New Zealand. An Auckland teenager named Anna Keegan was shortly due to have a bone

marrow transplant in Paris, the acknowledged centre for the procedure as it related to FA.

Jan and Richard immediately realised that they would have no choice but to go to France if a transplant was the chosen option for Kelly. New Zealand hospitals were only doing straightforward bone marrow transplants at the time.

The financial implications of such a course of action were frightening. For overseas medical attention, the government would contribute a maximum of $80,000; the rest had to be raised by the family. $360,000 (including the government funding) had been raised to get Anna Keegan to Paris for her transplant.

The subject of obtaining a suitable donor was discussed. A family donor was ideal, giving the procedure a higher success rate, and the best chance of finding a match was amongst the patient's brothers or sisters, each of whom had a 25 per cent chance of being a perfect match. Other family members only had a slight chance of being suitable. In Kelly's case, Daniel was her one chance ... if he was free of the disease. Following Daniel, it was up to Jan and Richard. If they weren't suitable, the bone marrow registries around the world would need to be searched for a suitable unrelated donor.

The three major risks with a bone marrow transplant were spelt out clearly. First is the chemotherapy and radiation needed to eradicate the diseased marrow before the new is introduced. During this period, the patient is very susceptible to infections: even a minor one can prove fatal. The second area of potential problems is that the new marrow may not 'take', may be rejected by the patient's system. The third area of concern is the risk that the transplanted T cells in the new marrow could attack the patient's cells, causing graft-versus-host disease (GVHD) in areas such as the liver, gut, skin and eyes.

Jan: It was extremely daunting sitting there with so much to absorb. We'd been looking for answers and now we were getting them in spades, straight from the hip, thank God. We - I - kept them coming, asking question after question. The doctors told me that there was no specific test in New Zealand to detect FA early in an unborn child. Amniocentesis (testing of the amniotic fluid) was available at 16 weeks of pregnancy. This could lead to a terrible dilemma for parents if they had to face an abortion. The chorionic villi test, a procedure involving taking and testing a sample of the placenta in the first few months of pregnancy, wasn't available in New Zealand at the time. So, how long had Kelly's bone marrow been failing? They couldn't give us an answer, but had already contacted National Women's Hospital for Kelly's records to see if they could find out. They told us that they weren't surprised the disease hadn't been picked up at birth. FA was so rare, there were only a few hundred cases in the world. Apparently a world register was held in New York by a Dr Arleen Auerbach, and Kelly's details would be sent to her.

On it went. Every answer seemed to produce more questions. There was no time-frame available for Kelly at this stage. The major danger was that her bone marrow could turn leukaemic at any time, and a marrow transplant had to be done before this happened. I cringed at that. It was bad enough knowing Kelly had one of the rarest bone marrow conditions on earth, without the threat of leukaemia.

The specialists examined Kelly. Apart from her usual crop of bruises, she was fine. They met Daniel for the first time and commented on how healthy he looked. It was a fact, he had hardly had a sick day in his life. We then went to the laboratory for blood tests, and were told that the results would be a fortnight away. Daniel put on a brave face at the needle after his little sister showed him how easy it was. He figured he'd better act brave in from of her. It was quite light-hearted in the lab. I'd been given my share of jabs over the years and it didn't bother me. Richard, on the other hand, hated them and he took it much harder than the rest of us. However, soon it was over and we headed home. So many questions now had answers. That at least was a hell of a relief.

Back in Taupo we talked it through with the children. Daniel was Kelly's only real hope, and he didn't like the idea of being a donor. We still hadn't told them that Kelly could die if she didn't have a transplant, we just said that she could get very sick. I wasn't looking forward to the time we had to explain *all* the implications to them. As far as Daniel was concerned, I just told him that he mightn't be a match anyway and left it at that. I was taken aback when he arrived in from school the next day and declared that he would be a donor for Kelly.

'What made you change your mind?' I asked, curious to say the least.

'Well,' he explained, 'my teacher told me if I was Kelly's donor, I'd be a hero.' He had such a proud smile on his face. I felt tears rush to my eyes. All I could do was hug this brave little nine-year-old. Later I told him how proud I was. If only he were a match for Kelly, how much more simple that would make things. The thought of having to try and find a donor from amongst millions of unrelated ones frightened me. Sometimes it was literally a million-to-one chance. Many people had died simply because a suitable match was never found for them. I just couldn't bear to think of that happening to Kelly.

◆

The days that followed were very emotional ones for Jan. She was careful, though, to only fall apart during the day when the children were at school, or at night while they slept.

Looking back, she realised that she was caught up in her own grieving process. She jumped in and out of the various stages of denial, anger, bargaining and depression, trapped on an emotional roller-coaster. She tried talking to friends, but their children were healthy and they were uncomfortable with her situation. It was a lonely time. Eventually she made the decision to speak to Dale Keegan, Anna's mother. It took a lot of courage to make the call: she had no idea what reception she would get. As it turned out, contacting Dale Keegan was probably the best thing she could have done. Dale turned out to be both friendly and helpful. She told Jan Anna's story.

Anna Keegan's failing bone marrow didn't come to light until she was 13, three years previously. During those years, Dale and her husband had searched high and low for a diagnosis on what was causing the failure. None of the normal physical deformities were evident in Anna, although she had a short stature. It was only when Dale took her daughter to Seattle, Washington, that Fanconi's anaemia was diagnosed. She then visited hospitals in London and Paris in her search for a treatment. Hôpital St-Louis in Paris was running the most successful programme, under a Professor Eliane Gluckman. Dale had been impressed by the set-up and the professor. She explained to Jan why Fanconi's transplants were so difficult, as opposed to the comparatively simple treatment for leukaemia. Apparently, the normal dosages of radiation and chemotherapy used to destroy the

patient's bone marrow in other procedures are simply too strong for those suffering from FA, generally resulting in organ failure. Professor Gluckman had developed a technique whereby just one-tenth of the normal drug dosage was used successfully, resulting in her team having the best survival rate in the world for the operation.

Dale also warned Jan that if Kelly's donor was an unrelated one, there was a much higher risk involved. For Anna, the donor was unrelated and had been tracked down from the Anthony Nolan Bone Marrow Registry in England. Dale Keegan was completely frank with Jan. She explained that only a handful of unrelated donor transplants on FA children had been successful. Despite this, Jan felt very positive.

Dale also gave Jan the contact address for an FA support group in the United States, which put out twice-yearly newsletters. She also promised to send Jan the latest copies. Then they talked about fundraising. The Keegans had tried to raise a lot of the money privately, but in the end had had to launch a public appeal. Dale explained that they had left it as late as possible, to protect their privacy. She described the fundraising process as a 'terrible ordeal'. But their efforts had been successful. She and Anna were scheduled to leave for Paris in the New Year.

Jan: Dale and I must have talked for a half-hour. There was much more I wanted to know, but the call was going to cost a heap anyway. I gave her our address for the newsletters, and we closed our (first) conversation.

I got off the phone feeling so much better. Dale had been wonderful to talk to. Just what I needed, someone who had experienced what I was going through. As for the sobering warning about an unrelated donor transplant, I was sure in my mind that Daniel would be a match for Kelly. It was going to be all right!

❖

With this in mind, Jan and Richard faced the wait for the test results. Jan was a lot calmer now that she had many of the answers she had been seeking. Once again, however, fate was to deal them a blow.

CHAPTER 8

The good news, the bad, and the maybe

❖ **DR MAY TELEPHONED Jan a few days after her initial contact with Dale Keegan. He started with the good news. Daniel didn't have Fanconi's anaemia. The bad news was that Daniel wasn't a marrow match for Kelly, neither was Richard. The maybe was that Jan could be a match; it was close enough for them to run a further test on her at the Department of Immunology at Auckland Hospital.**

Jan: I was so relieved that Daniel was clear. It was a big disappointment that he wasn't a marrow match, but I clung to the hope that maybe I would be. I was Kelly's last hope of a family donor. On the day of the appointment, Kelly and I travelled to Auckland to meet Dr Cairns at the hospital. The entire procedure took a quarter of an hour at most - after a four-hour drive. One thing I was learning, when it came to medical matters, was patience. Once again we would have to wait for the test results. On arriving home, there was a lovely letter from Dale Keegan, together with a copy of the latest FA newsletter and a contact list of FA specialists and hospitals around the world. She finished her letter with, *'We wish you all the best in your pursuit of the best thing for your daughter. We certainly have every sympathy for you and know it is not easy, but keep on, don't give up. Please write and let me know how you get on-I will certainly be thinking of you. Kindest regards, Dale Keegan.'*

I was extremely touched that she had taken time out of her hectic schedule to put together all this information, and to write me such a warm and touching letter. I eagerly devoured the American newsletter which was full of stories of other families with FA children, many born with deformities similar to Kelly's. Sadly, the newsletter also contained dedications to children who had died. One of the things that kept cropping up was fundraising, as the American group were continually raising money for research into FA. For once, I had so much to think about that I wasn't preoccupied with waiting for the test results.

However, on 15 December the bad news arrived: I wasn't a suitable donor. We were back to square one. There would be no family donor for our little girl. I was so very sad, my emotions in danger of plummeting to an all-time low. But I couldn't let that happen: Christmas was almost on us. I was determined that this Christmas would be as happy, if not more so, than all our other ones. I threw myself into making it special, it was a distraction that almost worked, but I still couldn't help wondering if Kelly would be alive to share the next one with us.

❖ **Through a supreme effort, Jan and Richard worked hard at making this the best Christmas yet for Kelly and Daniel. The medical problems, although never far away, could be almost forgotten.**

Although pale and covered in her usual array of bruises, Kelly's last platelet count had been 50, still well clear of the danger zone On top of that, she was full of energy. The yard and house echoed to the sounds she, Daniel and their friends made. Jan took a lot of comfort from the racket, wishing that it could go on forever - but it couldn't.

At the end of January 1990, the holidays were over. Dreading having too much time on her hands, Jan took a computer/clerical course at the Waiariki Polytechnic.

She knew that she would have to get back into the work force eventually. In the meantime, the daily course helped to provide an escape from the thoughts of doom and despair that went with Kelly's FA.

Newsletters with valuable information arrived from the American FA support group. Some of what Jan read was full of hope; some was depressing. From 1985 onwards, there was not one mention of a successful unrelated marrow transplant. The related transplants, however, showed a high success rate. There was still one faint glimmer of hope that they could achieve a related transplant.

Reading the FA newsletters, I was amazed at how many families were lucky enough to have a sibling match. There was an article about a major breakthrough in the treatment, using umbilical cord blood from a newborn baby to provide transplant blood. Apparently this blood is very rich in marrow stem cells. The success rate was very high, with a quick recovery rate for the patients. One family had decided to have more children in order to find a sibling match. They were well aware of the one-in-four risk of having another child with FA, but went ahead under careful monitoring. They had one daughter who wasn't a match, then one who was. When this little girl was born, the cord blood transplant option had just become available. She was also a perfect tissue match to the eldest child with FA. This option was a back-up if the other failed. The earliest that bone marrow could be harvested from a baby was six months, although the cord blood transplant could be done immediately after birth. They were so lucky to have two chances for a successful related transplant.

I didn't know if I was grabbing at straws again, but here was an option to give Kelly the best chance for life. It wasn't going to be that easy. Richard's vasectomy had seen to that.

Richard: Jan and I had always wanted another baby, but Jan had feared that we would be tempting fate. Now there seemed to be a way of hopefully having another child *and* providing a sibling transplant for Kelly. To minimise the FA risk, we would go to the United States for the early testing procedures. We would find the money from somewhere. The thought that kept coming back to us both was, 'What if the baby tested positive to FA?' The thought of Jan having an abortion was horrifying to us both. I decided to have the reversal operation. Our haematologist, Steven May, was definitely opposed to us having another child, but in the end the decision was ours. It was in the hands of the gods whether or not the vasectomy reversal would work.

Therese: Jan had been so despondent at finding there was no chance of a related transplant for Kelly. The option of having another baby was really the last chance. Poor Richard: he had to go to Taumarunui to have his vasectomy reversed, knowing that even that didn't have a great chance of being successful.

My heart went out to them once again. They were prepared to go to any lengths for Kelly. And even then people were critical. There was always the chance of having another baby with FA. But until parents are faced with the possible death of a child, how can they judge what is right or wrong? Desperation makes its own rules.

❖ **The operation to reverse Richard's vasectomy was carried out, but things didn't go well. The day after the operation, a trainee nurse mistakenly removed the stitches. Richard was forced to spend several days in the hospital while the wound stabilised.**

Richard: The pain was something else! After my vasectomy I was riding my motorbike the next day. Not this time. Compared to the original operation, the reversal attempt was quite a complex procedure. Because the girl took the stitches out far too early, I was bed-ridden. We don't even know now if the operation was successful. Even today, almost six years later, I sometimes end up almost doubled over with pain because of it.

❖ **There never would be any last chance for a related donor: Jan never became pregnant, and she and Richard faced the fact that there was now only one chance for Kelly's survival. The decision was made to contact Professor Gluckman in Paris, through Dr May. They needed to know if the professor would be willing to undertake the transplant if a suitable donor could be found.**

While they were with Dr May, there was yet another bombshell. He told them that he had received copies of Kelly's medical records from National Women's Hospital. These revealed that a chromosome test had been done soon after Kelly's birth. The test had failed because 'there was something wrong with the chromosomes'; the hospital hadn't pursued the testing any further

Jan: When Dr May told us about the failed test, both Richard and I got very upset and angry. To us it was absolutely, totally, unbelievable! Not only had they not bothered to do a follow-up test, they hadn't even told us that 'there was something wrong with Kelly's chromosomes.

That night was one of the worst yet. As we lay in bed, the children asleep, I almost went completely out of control. I couldn't believe this latest revelation. 'What the hell have they done to Kelly?' I was sobbing, yelling, almost screaming. Richard tried to comfort me, but he was extremely angry himself. If we could have got our hands on the people responsible at that moment I hate to think what would have happened. There's a lot written about medical incompetence, but this really was beyond belief. They tested her, Richard. They found something wrong. Why the hell didn't they tell us?' The *why? why? why?* cycle had started again.

In the morning I was calmer. My first reaction was to write a letter of complaint to National Women's, but after seven years would anything be gained by doing this? Who would accept responsibility for not informing us? I couldn't help but think that maybe parents should be allowed to read their children's medical notes while they're in hospital so that they can be assured of knowing everything that is going on. And while many mightn't understand the medical jargon, they should have the right to ask for it to be explained. Boy, was I angry!

❖ **At the time, Jan wasn't aware that parents do in fact have the right to have things explained to them in language they understand. They also have the right to view medical and nursing notes, if they apply to do so through the hospital**

management. Sadly, however, at that time many parents and patients were not aware of these rights. Some health professionals had not bothered either to inform them or indeed to uphold their obligations regarding those rights.

CHAPTER 9

A time of searching

❖ **DR MAY CONTACTED Jan several weeks after their last, traumatic, meeting to tell her that Professor Gluckman had agreed to perform the transplant on Kelly. The professor had found three possible donors on the French Bone Marrow Donor Register. The first step was to obtain a sample of Kelly's blood so that the professor could determine which donor was most suitable. She also did not want to perform the transplant operation until Kelly's blood counts showed more of a decline. This fact gave Jan a boost. Obviously the professor didn't consider Kelly to be in any immediate danger. But always at the back of Jan's mind was the threat of Kelly developing leukaemia.**

Suddenly Jan and Richard realised that a 'concrete' decision on Kelly's treatment had been made: Kelly was to have the transplant. There was now so much that needed to be done: not least, was organising the fundraising.

Jan: 'Where are we going to get $360,000?' I asked. Richard and were sitting at the kitchen table having a coffee. It was such a normal everyday setting: thousands of people all around the country would have been doing the same thing. But we were different to every other family in the country at that moment. Here we were, a normal Kiwi couple with a mortgage, and a few hundred dollars in the bank, and we had to find all this money to save our daughter's life. 'We'll get it somehow,' Richard replied. He looked so positive as if we just had to write out a cheque and we'd be there.

Richard: Strangely enough, I really thought we would get the money. It was such a huge amount, quite unreal in a way, but I just knew we would find it from somewhere. Jan looked scared, and I guess I just sort of bluffed it out, but inside, I knew we would get it from somewhere.

Jan: 'God, I hope so!' I said, unable to even visualise the amount. What did $360,000 look like? Where did we start? I was scared. It was now May, my course at the polytech was due to finish in June. I wouldn't be starting work at the end of the course: I never knew when we would have to go to France. We sat there at the table trying to work out how we were going to do it.

It was on this morning that we heard some news about Anna Keegan: her transplant hadn't been successful and they were attempting another. It was horrible. Our hearts went out to the Keegans. It also made me wonder if we were doing the right thing for Kelly, now that the decision had been made. But, in the end, I knew that whichever way we went it was going to be a risk.

❖ **Faced with the fact that Kelly's death was more than a possibility even with the transplant, Jan found herself becoming preoccupied with thoughts of death. Up to this point in her life she had never lost anyone close to her. Now it was something she had**

to face up to. The death of a four-year-old boy from a brain tumour during her student nursing days had effectively finished her nursing career for her.

In my training, death was confined to the occasional elderly patient in the geriatric ward. Although it wasn't pleasant, it was acceptable at the end of a long life. I wasn't prepared for it in a dear little red-haired, freckled-faced boy, so weak he could hardly lift his head from the pillow. He would look up at me, with beads of perspiration on his brow, and tell me his head hurt. I felt helpless: apart from trying to comfort him and giving him endless pain-relief drugs there was nothing any of us could do. My training hadn't prepared me for this. I dreaded the thought of him dying on my shift, I just didn't know how I would handle it. As it happened, he died during one of my days off, and I tried to pretend that he had gone home. It didn't work. I quit nursing shortly after that. I could never admit it to anyone then, but I knew inside I couldn't face seeing another child dying. In my dreams I still see that poor little freckled face screwed tight with pain.

I had no belief system when it came to death, and this scared me. I had been preoccupied for years with keeping Kelly alive. What if she couldn't be saved? How would I cope with her death? I had all the usual questions, the age-old one being, 'Where do we go when we die?' The people I spoke to on the subject were very uncomfortable with it. So, once again, I tackled the shelves of the public library, being careful that the children didn't see the books I brought home to read.

❖

Jan tackled the subject of death with the same intensity she had shown when studying everything else to do with Kelly's condition. She discovered the writings of Elisabeth Kübler-Ross, and found her images of death comforting. She also gained strength from the advice Kübler-Ross gave to those with a life-threatening condition: 'Never give up hope until the very last breath, because if you give up hope then you have nothing.' Therese managed to obtain a cassette where Kübler-Ross spoke of her experiences. Jan agreed that the doctor made it all sound so acceptable that there was nothing to be afraid of.

Therese: I was very familiar with Elisabeth Kübler-Ross and her theories on death and dying. I had been for a long time. It came as no surprise when Jan started reading her. I'd never mentioned it to Jan, but for years I had found myself analysing all the drawings and paintings that Kelly gave me, looking for the tell-tale butterflies and other pictures associated with Kübler-Ross's images. Kelly had been drawing the pictures of a dying child for years. I felt so sad whenever Kelly proudly presented me with a drawing or painting she had done, and I saw death there.

I went into my own denial. I'm a coward and I just couldn't face the thought of Kelly's death. My heart ached for Jan and Richard, and all the time I thanked God it wasn't me in Jan's shoes.

The thing was, as Jan read the Kübler-Ross books, she recalled some of Kelly's earlier drawings and paintings, and she knew I had known all along. Now she, like me, didn't want to give power to the thoughts by talking about them. One day, as we were standing at her kitchen window watching the kids playing outside, she said, 'You know, Therese, I just can't bear the thought of Kelly not skipping in the door every day after school.' As always, I just jollied her out of her mood. I was all bluff and she knew it, there just weren't any comforting words you can say to the parent of a dying child. The real miracle of it all was that, from somewhere, Jan kept her hope so strong. It dragged her along with it through everything that happened.

❖ **After Kübler-Ross, Jan read everything she could on people who had near-death experiences, books on reincarnation. She devoured anything and everything in a bid to try and understand what was going to happen to Kelly if the transplant failed.**

Jan: The more I read, the more life seemed to make sense. The irony is that, in reading about death, I was learning about life. Of course the two go together, but we conveniently push this to the back of our minds until the end becomes inevitable. My father had been a carpenter and undertaker, the words associated with death had been with me all my life. But, as a child, the reality of death had never touched me. Now I was faced with the very real, possible death of my little girl. I devoured everything I could find on the subject, and when I had exhausted this section of the library I began reading about clairvoyants and mediums. Perhaps looking beyond death, I don't know.

One weekend a famous medium was due to be at the Spiritualist Fellowship on Sunday afternoon. Whether it was because of the reading or some other reason, I felt a real urge to go along. I'd never been before and had no idea what to expect. There was singing and prayers, not necessarily religious, but spiritual, pleasant, relaxing. I remember a saying: To be religious you have to be spiritual, but to be spiritual you don't have to be religious. I was fascinated when the medium began working with the audience. She had all sorts of messages for people; some were so involved and descriptive that I'm sure there was no way she could have made things up. Just as I thought she was finished, the medium stopped in front of me.

'I have a message for this young lady.' I was completely taken aback when I realised she was talking to me. 'I keep getting something about overseas. Are you going on a holiday or something soon?' I was baffled, shaking my head. Holiday? That was a joke. The medium spoke to the audience then. 'I must explain that this is a psychic message, not from anyone in the other world. This is a message from the universe in general, and it happens every so often.' She started talking to me again. 'It's definitely something about overseas,' she insisted, and then I thought about Kelly and Paris. I told her about the bone marrow transplant operation, quite astonished by what was going on.

'I'm to tell you that everything's going to be all right. That's a message from the universe for you.' I was dumbfounded, Therese had grabbed my hand in excitement. This was truly amazing - now I could see why I was meant to be here this day. It wasn't enough to make me run around saying that Kelly must have a transplant because 'the universe told me'. But it sure was strange enough to give me a certain confidence in what was becoming my new belief system.

❖ **Jan continued her reading, trying to find books about bone marrow transplant survivors - but couldn't find any. Most were stories that ended in the patient's death. She needed a book about someone who had lived, one that would give her hope. That was when she discovered *In the Absence of Angels,* written by Elizabeth Glaser, wife of Paul Michael Glaser, a Hollywood director/producer and former television actor from the**

Starsky and Hutch television series. The story was of the Glaser family and their fight against HIV. There was so much Jan could relate to, but, by the end of the book, she had a definite sense of gratitude for their own situation - there were worse conditions that Kelly could be suffering from. The book became a reminder for her not to cling to the 'poor me' syndrome.

From this point on, Jan looked at the various alternative healing options. She felt that she couldn't rule anything out as a 'waste of time', and was prepared to try anything and everything for Kelly It was at this stage that she encountered a crystal healer, and took Kelly to him for regular sessions. Kelly adored the crystals and enjoyed the experience; Jan found the sessions calming. When the healer left Taupo, he presented Kelly with a purple crystal that she still sleeps with today.

Jan was still running on hope as May came to an end. They all knew that the time was rapidly approaching when they would have to start fundraising. After Dale Keegan's warning, neither Jan nor Richard were looking forward to it - Jan in particular.

CHAPTER 10

The fundraising nightmare begins

❖ **IN EARLY JUNE 1990, Jan was talking to a friend who had been a former neighbour. In the course of their conversation, Jan mentioned the dilemma of shortly having to start trying to raise $360,000 for Kelly's transplant. The friend told her that her husband was a member of a local Lions Club, and she thought that they might be able to help raise the amount needed. She would get back in touch with Jan.**

At the next appointment with Dr May, he confirmed that this would be the time to start raising the funds. There was a chance that Kelly might have to travel to Paris for tests, and they would need to have the money available. The doctor said that he would apply on their behalf for the $80,000 government grant, in the meantime.

Jan and Richard had no idea where to start trying to raise the money that Kelly needed. The fact that they didn't have any definite dates was a hindrance, it was impossible to plan and create workable deadlines. They were saved by the telephone bell. It was their former neighbour: the Lions were interested in helping!

Jan: I was so relieved. It all sounded so positive. I remembered how quickly they seemed to be able to raise money in telethons and for other causes. If they could do that for Kelly it would be wonderful. A meeting was arranged, we were advised to have our family doctor present and a letter from Kelly's specialist explaining why the transplant had to be done overseas.

We were very nervous about the meeting because we knew that the Lions would be studying us to decide if Kelly's cause was a worthy one for them to be involved with. The Lions' District Governor was there, along with other representatives. We had our family doctor with us and a letter from Dr May. The meeting seemed to go well. We explained that the $360,000 figure was based on what the Keegans had raised for Anna to have the same transplant. We gave them all the information, including a complete profile of Kelly's medical history so they could put it forward at their next meeting.

They left then, having told us that they would contact us when they had made a decision. So here we were again, holding our collective breath, hoping the Lions would say yes. Meanwhile, there was some relief in the fact that Kelly didn't have to go to Paris for tests. Instead it was a matter of Professor Gluckman's team sending samples to New Zealand, and the tests being done here. Drs Cairns and May felt Kelly mightn't be strong enough to stand up to the trip. I didn't want to think about that too much.

❖ **The Lions came back to Jan and Richard later that June: the answer was yes. The Wairakei and District Lions Club had agreed to handle Kelly's fundraising appeal. Apparently they had been reluctant at first, but when the president met Kelly personally he was touched by the pretty little girl who seemed so full of life, while death hovered over her.**

The long experience of the Lions in fundraising efforts once again brought home the words of Dale Keegan; Jan and Richard were warned that not only was the

amount required a daunting one, even allowing for the government grant, but also that they were going to be 'living in a fish bowl'. People would be watching them and judging them, sometimes cruelly.

I remember thinking at the time, 'How could people judge us? Why would they want to?' We were just an ordinary family trying to save our daughter's life. I couldn't imagine people being cruel. I wouldn't do it, and I was naive enough to imagine others would feel like I did. Did I have a rude awakening ahead of me!

Murray Kemp was appointed the designated Lions organiser for the appeal. It was stressed that Murray should be contacted about any and all upcoming fundraising events, to coordinate them and keep things running smoothly. We agreed. Now, where to start?

I had just graduated from my polytech course, and my new clerical skills were going to be kept in full use on a word-processor. There were letters to write, lots of them. People started coming forward with ideas for raising funds. The first was from one of my fellow students. She was involved with a local car club, and was Keen to arrange a fundraiser. I put her in touch with Murray. The ball had started rolling eight months after Kelly was diagnosed with FA. There was still a long way to go.

❖ **The Lions wanted a target date to work to; but, as before, there was no fixed time-scale. The signal to move was when Kelly's platelet count hit 20. The tests to select a donor still hadn't been done; the samples hadn't even arrived from Paris. So, to have a working date, January 1991 was selected as the target for raising the total amount.**

In amongst all the discussions, Jan was facing her fears on a daily basis. Her emotional roller-coaster was in full swing, but she struggled to put the brakes on it. The fundraising was all-important; it had to be carried out in a business-like manner. It was unfortunate timing in that, just days before Kelly's appeal was officially launched, another was started in Taupo. It is only a small town, as the Turners were about to find out. Jan is a shy person in public; Richard is quiet. The effect of the next months was going to be devastating, particularly on Jan. Her stomach turned every time she had to appear in public - but she had to do it for Kelly's sake. She became an expert at explaining Kelly's problem in simple English. She fielded questions like: why can't Kelly just go to Australia? why can't it be done here? when is the operation? who is the donor?

Jan: The one question that kept coming back again and again was, 'Why does this operation cost $360,000?' This was asked at the very first fundraising event, and kept coming back at every one that followed. 'Why so much?' - from the very first time it was voiced, I felt like crawling into a hole. What had we let ourselves in for? The cameras flashed away. I hated having my photo taken at the best of times. I don't think any of us really knew what to expect. Dale had warned us, and so had the Lions - even then we weren't prepared. I don't think there is any way of preparing anyone for what came next.

CHAPTER 11

Life in a fish bowl

❖ **THE TRANSITION FROM 'private' to 'public' family was virtually an overnight one for the Turners. The announcement of the appeal appeared the day after they had attended the first publicity event, a 'birthday party' at a local supermarket. The front page of a local newspaper read, '$360,000 needed to save Kelly'. There was a photograph of the family, details of the first fundraising event, and a list of places where donations could be left. It had begun.**

Jan: Until now we had been invisible, except to our friends. Suddenly, in what seemed like an instant, most people in Taupo knew of our ordeal. I felt like I had been publicly stripped naked -it was the strangest feeling I have ever experienced. This was our plea to people to help us, our family was now officially a charity case. How I wish there could have been another way to raise the money.

Once Daniel and Kelly saw that first newspaper article, they began to ask questions. Daniel's first one was, 'Could Kelly die, Mum?' There it was, the cruncher! I had to answer as honestly as I could, yet give them both hope, because Kelly was there, listening.

'Yes, she could, but we're taking her to Professor Gluckman in Paris because she's the cleverest doctor and we're sure she can save Kelly. That's why we have to do all this fundraising, but we know it will be worth it in the end.' I had said it. I watched their faces anxiously, but they both accepted my explanation and went out to play. I felt I had handled it okay. I don't think there's a right or wrong way to do something like that. It's simply not the sort of situation any parent is ever prepared for - you just do the best you can with what you know.

I'd always tried to protect my children from any unnecessary pain, and I certainly didn't want them to have to go through the emotional pain that my fears put me through. They would find out more along the way. In the meantime, I just wanted them to keep their childhood innocence for as long as possible. I remember thinking, for the hundredth time, how I would have loved trading places with them at times.

Therese: When Jan showed me that first newspaper cutting, she had such a sad look on her face. Reality was there in big bold letters. '$360,000 needed to save Kelly'. Our little Kelly - she really was going to die if they couldn't find that huge sum of money. All I could say was, 'Isn't it cruel to see a price put on a child's life?' Kelly's life had its price-tag: $360,000. Some people would see that amount as peanuts. To Jan and Richard it was an almost impossible amount. How could so much cash be raised in such a short time?

In the coming months, I was to see Jan become utterly exhausted and terribly sad at times, as they struggled to get the money together. I felt very frustrated for them. I just kept wondering, and still do, why there is not a special fund set up by the government to help families who may need to seek treatment overseas? Why should New Zealanders like my sister be reduced to literally begging because our country can't provide certain life-saving treatments? In so many other countries, people needing assistance are automatically granted funds.

❖

The local chapter of the Lions decided to write to the other clubs around New Zealand for help in raising money for the appeal. Because Jan had a computer and the necessary skills, she wrote a letter and did a mail merge to create hundreds of personalised versions.

I am writing to ask your club for help to keep Kelly Turner of Taupo alive and enable this young seven-year-old girl to grow up into a young woman and mother of the future. Kelly suffers from a rare chromosome disorder called Fanconi's anaemia. In layman's terms, she needs a bone marrow transplant at an estimated cost of $360,000. The only place where Kelly can have this operation is Paris, France. You may ask, 'Why can't she go to Australia like most *of the others needing a transplant?' Well Kelly has a high sensitivity to the drugs used with the transplant, and Paris is the only place where a professor has had success with a drug programme that Kelly needs. We have a tentative date of January 1991 for Kelly to have this operation, or sooner if her health deteriorates. Without this operation Kelly will not survive.*

You might be saying 'Not another appeal, we have just had one for someone else.' I'm afraid health doesn't have a timetable, and it's unfortunate that this appeal comes on the heels of a similar appeal. Kelly wishes she didn't have this sickness. The $360,000 needed for Kelly's operation is far beyond the Turners' financial resources. The Wairakei & District Lions Club are hoping your club can become a part of the extended Turner family and help give Kelly the chance of life, because I am sure Kelly's life is worth a lot more than $360,000.

I hope you can look favourably on assisting us. I await your reply.

The letter was signed by Murray Kemp as Appeal Organiser, and mailed out on Wairakei & District Lions Club letterhead that Richard had had printed by an Auckland printer - who supplied the paper and did the printing at no charge as a donation towards Kelly's appeal. This was the first example of the generosity of total strangers that Jan and her family were to experience. There would be many more such instances. However, there would also be deeply hurtful words and acts of callousness and outright cruelty to contend with, now that the Turner family was public property.

Jan now was working part-time at the polytechnic as a computer tutor and relieving tutor and, as Kelly's family became a household name in Taupo, Jan used her time at the polytechnic as her escape. There she was Jan Turner, tutor - not Jan Turner, Kelly's mother.

Jan: Of course we all knew that the publicity was necessary, there can be no denying that. It's just that for a 'normal' family, suddenly going under the microscope is tough to take. Because I'd always been shy, very private and terribly self-conscious, I found the public appearances truly nerve-racking. Home life was terribly disrupted, and because we were all amateurs at fundraising, there was often a serious lack of communication. The Lions were wonderful, but the problem was enormous. The local branch had never been involved in such a huge fundraising venture before, and the stress on them was tremendous - both as an organisation and as individuals.

Often it seemed that everything we were involved in was a last-minute decision. We were scrambling at times to get to where we had to be. It was having to get Kelly prepared for photographs at the last minute that prompted us to get a publicity photo done. A local photographer agreed to do the sitting for free. We had Kelly sit on a tree stump with the lake and mountains behind her. She had on a lovely black-and-yellow spotted jumpsuit, she looked delightful. We selected the best of the bunch and used that where possible. Later someone criticised us for dressing Kelly up in a 'flash outfit' that must have cost dollars which could have been spent on the appeal. In fact, Kelly's outfit was borrowed just for the photograph. We didn't have money to spend on luxuries: we were all trying to raise money for our little girl.

Richard: Once we had made the decision for Kelly to have the transplant, all I could think of was getting the money to save her life. I suppose I didn't really allow myself to feel anything. I just drove myself to find money. I felt that was all I could do under the circumstances. I practically dreamed about it. It dominated everything, because it was the difference between life and death for Kelly.

I felt relieved when the Lions accepted the appeal. They are such a big organisation with so many contacts. When we hit the public eye, I was so conscious of doing or saying the wrong thing that I probably got a reputation for being aloof, or something. I was just scared of putting one of my big feet in things. We were all very conscious of being watched and judged. Call it paranoia, but unless you've been there . . . it's far from pleasant. Despite that, it was part of the price we were prepared to pay to save Kelly's life.

All the time, money-making schemes were flying around in my head-I tried to be as involved with all the fundraising events as I could. It was tough, though - as the appeal dragged on, my confidence got knocked back time and time again. It's tough approaching businesses, literally begging for donations, for prizes for events, especially when the answer is so often a definite 'No'. Our friend Yvonne was amazing here, somehow getting donations from just about everyone, time and time again.

As the pressure came on the family, I became more and more on my guard to protect Jan and the kids. We certainly found out who our real friends were through all of this. A lot of people were quick with advice about what we should be doing - most of those same people weren't willing to help rattle the collection buckets.

❖ **It quickly became obvious to all involved in the appeal that the media makes its own rules. Invitations to top television shows to participate in events or run items were declined. Some media had their own agendas, and very harsh slants were put on the fundraising and the reasons behind it. Others, if not necessarily sympathetic, at least stayed with the facts.**

A photographer for one magazine asked Murray Kemp, the Lions' representative, 'how can the family afford to do up their barbecue and grounds while trying to raise money for Kelly?' This was Jan and Richard's first experience at being judged by strangers and, as always, the question was never directed at them. If it had been, they would have found out that Richard was using the landscaping as a release

from the pressures of fundraising. He and friends were doing all the work themselves. It was a labour of love, not a financial exercise.

Following the publication of an article in the *New Zealand Herald,* people started sending in donations. Jan was given the accompanying letters.

Jan: I wanted to personally write and thank each and every one of the people, as it was the least I could do for their kindness. I was soon to find just how difficult that task was. Typing the letters wasn't hard, but reading some of the ones we received was. Some were so touching that I would cry my eyes out. It was an experience I'd never had before, and one that was truly humbling. It made me realise how many caring people there were around. Many of the letters had no return addresses. To those who had included them, I started sending out little passport-sized reprints of Kelly's publicity shot. Sometimes people even wrote back thanking me for the photos.

❖

So, with the good and the bad, the Turner family were heavily involved in the fundraising. The appeal was moving along well locally, with many small events running each week. The Taupo and district newspapers were very supportive, regularly printing photographs and generally keeping the public informed of the fund total. The Department of Health grant for $80,000 had been approved. By November 1990, the fund was up to $100,500. On the 25th of that month, a Charity Golf Classic was held. This was a great success, and raised a further $12,000 for the appeal. The catalogue of fundraising events ran from street appeals during the Taupo Christmas Carnival, to raffles, a rock 'n' roll evening, a mountain-bike trek, and musical concerts. Local schools - and others - raised money for the appeal. One school in Tauranga corresponded regularly, incorporating Kelly's plight into their social studies lessons. Kelly Turner had captured a lot of hearts. Despite the exhausting round of fundraising events, Jan and the family received another boost. Dale and Anna Keegan had arrived back in New Zealand from their ten-month stay in Paris; Anna was doing well since her second transplant. Dale had a lot of information for Jan to absorb.

CHAPTER 12

Breakdown in communications

AFTER JAN'S CONVERSATION with Dale Keegan, she decided to write to Professor Gluckman directly, in part to thank her for accepting Kelly as a patient and also to find out where the donor cells were. The months were passing, and still the cells hadn't arrived for the vital compatibility tests. The reply from Professor Gluckman was prompt.

Dear Mrs Turner,

Thank you for your very nice letter and the picture of your daughter. She looks really nice. Her blood counts are very good and I don't think that she is now in great danger. I think that it would be better if the MLC test was performed as quickly as possible, because we have to know if this donor is suitable for a transplant. If not, we have to continue the search in the French registry and also in other European registries.

Could you contact Dr May to make arrangements for the shipment of the cells, as I indicated in a previous letter?

If we find a donor we will discuss together the best timing for the transplant. Do not hesitate to contact me if you have any questions.

Sincerely yours,
Professor E. Gluckman.

Jan: So there it was, my answer to the question of why the donor cells were taking so long to come to New Zealand: there had been a total breakdown in communications. New Zealand thought Paris was sending the donor cells here, and Paris thought New Zealand was sending Kelly's cells over there. What a mess! Precious time had been wasted just waiting for nothing to happen. I hated to think how long it might have been if I hadn't written to the professor. I immediately telephoned Dr May and told him what I had just learned. He was as shocked as I was. There had obviously been a complete misunderstanding.

Dr May arranged for the tests to be carried out at the Wellington Department of Haematology. Apparently, at the time, Auckland Hospital was having problems working in with Paris.

It was now mid-December, so there was not much that could be done so close to Christmas. Once again for me, it became a time for reflection. We headed north to Tauranga and over to Whangamata Beach were Mum lives. It was a relaxing time. Daniel, Kelly and their cousins were on the go the whole time we were away. There was a playground right beside Mum's place. I wondered if I should be restricting Kelly from doing some things, such as climbing high - if she fell, she could have suffered a massive internal haemorrhage because of her lack of platelets. In the end I decided that it would be more damaging to her if I killed her spirit. She was going to need every little bit she had to help her through the transplant. I couldn't treat her as an invalid at this time. We all needed to grab whatever 'normality' we could for the moment. After the holiday, it would be back to the fundraising.

❖ **When the Turners returned from their holiday, there was one very welcome donation to their appeal. The Regan Chibnall Trust announced that they would donate $20,000 to the appeal. One of the French Lions Clubs that had been sent a circular early in the appeal had replied, saying that they would help in any way they could.**

That was the good news. There were, however, problems at home. Kelly began to have fits of rebellion about having her photograph taken or attending some fundraising events. She was fed-up with all the public attention. After all, she was only a child: she didn't understand the fundraising fully, or even her own condition. As far as she was concerned, she felt fine, so why was there such a fuss?

Jan: The public, nonetheless, expected Kelly to be on show. Fund-raising is really a form of marketing, and Kelly was the product on sale. Much as we all hated to put it that way, it was fact. All of this was a necessary evil to save her life. We also had to appear grateful for whatever was being done - not that we weren't, but we had to make sure we expressed our gratitude by thanking everyone who had done something. I always worried that I would forget to thank an organisation and that they would label us ungrateful. It was so hard to try and do everything right all the time, particularly with everyone watching every move. I understand now why some of the celebrities in Hollywood lose it in public - just one too many photographs, one too many autograph hunters. Being on show and being 'perfect' all the time was an impossible task, but we were expected to do just that.

Therese: I felt the family was being treated like a travelling road show, not like a grieving family with a dying child, which is what they were. Jan used to tell me how exhausted Kelly got. I got angry, knowing how frail Kelly was. I got angry at Jan, yet knowing all the while that Kelly had to be at these things. And I got as angry as hell at the government: a measly $80,000 for a child's life, and millions for stupid bloody advertising campaigns to tell everyone what a great outfit they were. They should have been hanging their heads in shame at putting distraught parents through the humiliation of fundraising, all the time risking the life of a desperately ill child.

Jan would always say how generous and kind people were. We would sit and read letters from people who had sent donations. Sometimes we both cried our eyes out at all the kind wishes. Dear little kids sending in their pocket money. This was really gut-wrenching. Pensioners giving what they could barely afford. Just ordinary people - these were the people who ultimately saved Kelly's life.

❖ **It was at this stage that friction developed between Richard and some of the Lions. Unused to the close scrutiny of life in the 'fish bowl', and frustrated at being prodded and poked like a captive animal, Richard wanted to break out of the mould. He had ideas of spreading the fundraising out of the Taupo area. Only a few of the other Lions groups in the country were willing to help, because of their own fundraising commitments.**

The amount of money required was a constant source of extreme frustration to all concerned. The figure of $360,000 was the cost of Anna Keegans's transplant and expenses during her ten month stay in Paris. At every turn, the size of this amount was queried, and each time this happened, Jan and Richard took it personally. They hated having to rely on 'charity', and even today, the scars are there.

Jan: I feel as if I have incurred a debt for life. Today, we are back to being an ordinary family struggling along like so many others. Yet I feel as if there is a mortgage on my soul. This is a sensation that has never gone away. When we recently sold our old house and moved, we insisted that there be no sign outside and no open homes. We didn't want any public focus at all. I have this deep-seated distrust of what people are thinking. I realise that most aren't judgemental and nasty. They are only a minority, but they tainted everything, then and now, with nasty aspersions, questioning everything, casting doubts, saying so many cruel things (but never to our faces). The bitter taste of that has never left me. Seeing us move into a new house, I can imagine what they said. The final irony of it is that I believe that these people never made a donation anyway. That is their nature. All they have succeeded in doing is fuel my paranoia, and belittle the generosity of all the other wonderful people who did help.

Richard and I were seriously investigating the possibilities of moving to the United States through this period. Richard's parents were running a tourism business from Seattle, Washington. We were beginning to wonder if the transplant would ever happen - and if it didn't, where would we go from here? We had written to the Seattle Hospital Dale Keegan had been to, to discuss the alternative androgen treatment. The financial problems involved in shifting were enormous, but we were prepared to do whatever it took to keep Kelly alive. In the end, we had to admit to ourselves that the transplant was the only viable option open to us.

❖ **By February 1991, the appeal total stood at $140,000, including the government grant and the anticipated $20,000 from the Regan Chibnall Trust. This meant that approximately $40,000 had been raised publicly. The total was a long way from the $360,000 target.**

It was February and still we were waiting on the donor cells from Paris. It was so hard to keep the appeal moving without a transplant date. We couldn't even say there *would* be a transplant, because we didn't have a donor established for definite. Things were very messy, time was hanging heavily. As always, the amount needed was being questioned constantly, even by the Lions themselves. Richard's grandfather was involved behind the scenes, stirring things up, casting some nasty aspersions about Richard and mo to some of the Lions. When Richard found out about this he disowned his grandfather, but some of the seeds of doubt his grandfather had sowed started to spread roots. He had succeeded in damaging the appeal right at its heart.

Doubting the figure required, the Lions wrote to Professor Gluckman to attempt to cost the operation. The professor wrote back saying that the approximate cost would be $US50,000, or $NZ95,000. That rocked me; it looked as if we had been aiming for something else again. But what shocked me more was the fact that the professor was still waiting for us to send Kelly's blood cells to her, when the donor cells were supposed lo be coming to us!

I immediately contacted the Department of Haematology in Wellington to find out what was happening. Dr Carter, who was to handle the testing, said that he had been dealing with a member of Professor Gluckman's team, a Professor Rabain, and there had obviously been another communication breakdown. The doctor asked me to send a copy of the letter from the professor down to him, which I did. He wrote in turn to Professor Rabain, with copies to

Professor Gluckman and Dr May, stipulating that the blood from Paris was to be forwarded to Wellington as soon as possible. The letter was couched in very polite terms, but it left no doubts and no room for misunderstandings. Frustrated and angry, I went back to the fundraising.

It was at this time that Richard told a reporter that he hoped the whole family would be going to Paris when Kelly had the transplant. Talk about putting the cat amongst the pigeons! It was our infamous timing again.

Richard: I was fuming at the incident with the reporter. I rarely said anything; I left it to Jan. Then, when I did say something because she wasn't around one day, it all got blown out of proportion. It was just an innocent comment. I got a severe rap over the knuckles from the Lions over that.

It came at the same time that I found out about my grandfather's stirring. Eventually, when the smoke cleared, I no longer had a grandfather. As a father fighting for the life of his daughter and as protector of my family, I wasn't going to let *anyone* throw a spanner *in* the fundraising works, not even a member of my own family.

❖

The figure Professor Gluckman had quoted for the operation did appear to raise serious doubts in the minds of the Lions. Jan was sure that the professor had quoted for an average, uncomplicated operation, and she took great pains to point out that the risks of an unrelated transplant were high and extra costs had to be anticipated.

***In fact,* Anna Keegan had needed two transplants, and her family had actually run out of money after their ten-month stay in Paris. It cost $2000 a day for Anna to be in St-Louis. This was totally separate from accommodation and Jiving costs for her mother- living costs in Paris are amongst the highest in the world.**

The fall-out from Richard's newspaper comment really brought out the nastier side of being in the public eye.

Jan: Reports from the Lions about what some people were saying about our 'holiday in Paris' brought me to tears. I just couldn't believe they could be so ignorant or so hurtful. As to us all going to Paris, Richard and I *had* to be there, there was no question of that. As for Daniel, the cost of an airfare just to keep us all together wasn't much. Feeding a ten-year-old boy wasn't a great extra expense in the scheme of things. Daniel and Kelly were great friends as well as being brother and sister. It was important for Daniel to be there, both for himself and for Kelly, especially if Kelly were to die in Paris. He would need to be able to say goodbye. I'm sure that a lot of the people who criticised us had never imagined their family in the same situation. It's so easy to intellectualise when you're on the outside looking in.

We had a meeting with the Lions, and they pointed out that because of the very large amount of money involved we had to be seen to keep costs to a minimum. We understood that, and we agreed. We were told of .some of the criticisms passed on by people, to illustrate just how precarious the public relations side of fundraising can be. Both Richard and I became upset when we heard some of the comments. Some people were suggesting that we sell our very modest little home. What would we do when we came back - go on a council-house waiting list? Then there were a few little old ladies complaining that we could still afford to buy groceries while they struggled by on their pensions. They were basically insinuating we weren't as poor as we made out. If only they knew.

We were caught between a rock and a hard place at this time. There was no way we could win. If we went around looking too well-dressed, we'd be judged one way, if we dressed in sack-cloth and ashes, we'd be labelled no-hopers. One thing, though: no one ever came up to us and criticised us to our faces. They were all too gutless for that.

So, from that point on, there were no more interviews with reporters; media releases would be made. The appeal would be slowed down until a donor was confirmed.

Therese: Jan phoned me up after the incident with the reporter and the meeting that followed. She was crying when she told me what people had been saying about the family. She told me how she felt people were watching everything she did, even down to what was in her supermarket trolley. I was dumbstruck. I just didn't know how people could treat others that way, especially someone as caring as Jan. I told her to hold her head up high and stuff the lot of them.

❖ **From this point on, Jan admits that she was paranoid and bitter, as well as being totally exhausted. In public, she put on a brave face; inside, she was a mess. At her job she had wonderful support and home was more of *a* retreat now than ever before. She found it increasingly hard to go to the fundraising events. Now, instead of being humbled by the efforts of all those who were helping, she looked at them through different eyes, wondering who amongst them was sitting in judgement on her family? She was hurt deeply, a lot of her faith in the essential goodness of people had been badly battered - and meanwhile Kelly was slowly dying, her platelet counts beginning to drop after holding at 50 for such a long time.**

Jan: When I went to the supermarket, I found myself taking only the most basic items. Sometimes I would take something I needed from a shelf and then put it back again, glancing around to see if anyone had seen me. I always tried to find an empty check-out and get through before anyone got behind me. I found myself shopping at odd hours, when there were fewer prying eyes around. Sometimes I would sit in the car afterwards and cry at the frustration, knowing I had got only a fraction of what I needed -scared to get the rest because someone might think I was extravagant. It was a horrible feeling.

❖ **The stress was beginning to show through the facade that Jan and Richard maintained in public. But, as if that weren't enough, there was another bombshell to come.**

CHAPTER 13

Why? That accursed word, again!

JAN AND RICHARD were watching the television news when an announcement was made that Anna Keegan had died. The shock was total. Anna had apparently been doing well, and Jan and Richard had high hopes for her because she led the way down the path that Kelly would shortly follow. Now this!

Jan: Richard and I just sat there looking at each other. After all Anna had been through. Why? Why had this happened? The last time I had spoken to Dale, Anna had been fine. What went wrong? What were we going to tell Kelly? She had been following Anna's progress closely. What about Anna's parents - what pain must they be going through? It all seemed so unfair. I broke down. 'Why? Why?' I sobbed. I remember grabbing Richard's hand. 'I don't know, I just don't know' - he put his arms around me and tried to hug away my tears.

'Poor Anna. Poor Dale. There can't be a God for this to happen.' I was angry at the loss, the waste. There had to be something, or someone, to blame. I ranted and raved and cried myself out. All the time Richard just held me: I don't think he trusted himself to say anything. It was a long, sleepless night for us both. The tears kept on coming, my pillow was soaked. *Why?* - that damned word had been constantly on my lips since Kelly's birth, and the answers were still out of reach on so many things. I hated the word and everything it represented - the not knowing, the ignorance, the games fate played on us all.

The next morning I felt as if I was full of broken glass. I was so brittle; there was a lot of hurt inside. I was dreading what I knew was going to happen. Kelly was helping me around the house when she heard the news on the radio. She came through to me in the laundry, looking confused, not sad: she still didn't understand death. 'Mummy. The man on the radio said that Anna has died. Why?' Poor Kelly, she was just asking the question that I had been asking most of the night. I hadn't found an answer then, I didn't have one now. All I could do was give her a cuddle.

'Anna was just too sick, darling. Sometimes that happens,' I said, groping yet again for some answers. As yet, I had no idea why Anna had died. It wasn't the time to be phoning the Keegans. God knows they would be needing time alone. Kelly was just looking at me, waiting for what I didn't have. 'Why couldn't they cure her?' she asked. I tried to find words that would make sense to her.

'Doctors are very clever people, Kelly, but sometimes they just can't save everyone.' I waited for her to ask 'why?' again, but she didn't. I had to keep her calm; I had to give her more. 'Anna's transplant was a very difficult one. Sometimes, darling, people just aren't meant to live, and when it's their time to die, nothing anyone does can save them. Professor Gluckman is the cleverest doctor at doing transplants, and we think she will be able to save you. You have a good chance as we haven't waited until you get sick.' With the acceptance of a child, Kelly put on a sad face and went back into the kitchen. I just leaned on the washing machine with my head bowed. We had to stay positive. As Elisabeth Kübler-Ross said, 'Never give up hope until the last breath you take.' We had all been looking forward so much to the day Kelly and Anna met - now this could never be. It was so cruel.

❖ **Although she managed to hide it from Kelly and Daniel, Jan was more scared than ever before. She had started doubting the decision for Kelly to have an unrelated transplant. There was still no evidence in the newsletters from the American FA support group of any successful transplants of this type. The fundraising had turned into a living nightmare, and they still didn't know if they even had a donor.**

When Jan and Dale Keegan finally spoke, Dale explained that Anna had contracted a virus that caused shingles. By the time it was detected, it had caused too much damage to the new bone marrow. They had considered doing a bone marrow 'top-up' from the donor, but Anna's condition had deteriorated too quickly.

Dale called in to see Jan unexpectedly one day, shortly after their telephone conversation. Kelly was playing outside.

I took Dale out to meet Kelly. I was amazed at Kelly's reaction once she knew who Dale was: Kelly just looked up at her and asked, 'Why did Anna die?' My eyes filled with tears: here was my little eight-year-old sounding more like an adult than a child. Dale was marvellous. She explained about the virus that had taken Anna in such a gentle way . . . all the time she must have been grieving so deeply inside. Later, she and I spent a couple of hours together and she told me a lot about what is involved in the transplant; some of it was far from pleasant. The thought of Kelly losing her beautiful long hair was bad enough, but some of the drugs would bloat her face and distort her features. There were other side-effects as well, but these varied from patient to patient. Fortunately, the side-effects were mainly temporary. Dale also told me about Alain Silverston, a Frenchman with twin sons suffering from FA. Alain had been very helpful towards her and Anna. She suggested I contact him later.

When Dale left, my head was swimming. There was so much to think about, particularly the alternatives to transplant. Dale had recently attended an FA symposium in the United States, and had the latest news on treatments. Apparently, the use of low doses of androgen drugs was meeting with some success. Also, the cord blood transplants were proving very successful.

That night Richard and I had a lot to talk about. All the doubts re-surfaced. Was an unrelated transplant a death sentence for Kelly? We didn't see the androgen therapy as a permanent solution, because at some stage the drugs would stop working and we would be back to square one. In the end, we came back to the transplant. It needed to be done while Kelly was still in good physical condition. But when? We had been trying to get me pregnant since Richard's vasectomy had been reversed, but nothing had happened - we still had a faint hope that it would though.

❖ **Life settled into a holding pattern for the Turners. The faint hope that Jan would become pregnant, and that the baby they both wanted and dreaded could provide the solution to the unrelated donor problem, remained with them. The thought of having to abort an unborn child because of the one-in-four chance of it being affected by FA was a major factor in their reluctance to force the pregnancy option. They relied on faith to make that decision. Richard did not have a fertility test to see if his vasectomy reversal had worked; he still hasn't.**

Shortly after Anna's death, Kelly developed bad hay fever and began to suffer massive nose bleeds caused by damage to the capillaries in her nose. It took a long time for her blood to clot, and at one stage her nose had to be cauterised to stop the bleeding. Her platelet count, however, was holding.

In July 1991, Kelly entered Waikato Hospital for tests needed for Professor Gluckman's team. Her platelets were down to 24, approaching the danger level. In August, more than a year after they had first been requested, the donor cells arrived from Paris. With relief, the Turners headed south to Wellington, where many blood samples were taken from Kelly. The immediate good news was that her platelets were up to 36. The test results would be ready in a week.

Jan: That week passed like any other. The knife edge we had lived on for so long had almost become our normal state. How many times had we waited for vital test results of one sort or another to come in? It never got any easier.

I got the phone call at the end of the next week as promised. The news was good: one of the donors was an excellent match. There had been a total lack of reaction between the French donor cells and Kelly's. It would be risky, but Kelly would have a chance - more than some people ever had. Now all we needed was to get the rest of the money together as quickly as possible. The thought of hitting the fundraising trail once more scared me, but at least we now had a donor, and Professor Gluckman would soon give us a firm date for the transplant.

❖

The appeal fund stood at $160,000, but $200,000 was still needed. As Richard had already pointed out, it would be impossible to raise all the money in Taupo, a small town with a population of only 20,000 people. Where was the money to come from?

CHAPTER 14

Waiting . . . always waiting

IN LATE SEPTEMBER 1991, a letter arrived from Professor Gluckman confirming the donor and stating that the transplant could be done any time after 1 January 1992. However, the professor required two months' notice to make all the arrangements. Kelly would need to be in Paris a month before the operation for tests, and would be admitted to the hospital two weeks before the transplant date. The professor concluded with a request that Jan let her know their plans as soon as possible. A reply was sent to Professor Gluckman, saying they would come to Paris in December for the transplant to be performed in January. Towards the end of October, the Turners still hadn't heard back from Professor Gluckman, concerning a finalised transplant date. Jan decided to telephone the professor and speak to her directly. After a lot of confusion with French-speaking telephone operators, Jan and the professor were eventually connected, and Jan soon learned why there had been yet another delay.

Jan: It was wonderful to be speaking to Professor Gluckman finally. She had a very strong accent, but her English was good. I told her I was becoming concerned about not hearing from her. It was then that she told me she had been sending faxes but none of them were going through. She had decided to write instead. As soon as she mentioned the problems with the faxes, I knew what had gone wrong. New Zealand had just changed to a seven-digit telephone numbering system, and I had never thought to tell the professor. I had assumed that there would be a carry-over time between old and new numbers. I was wrong, and I was embarrassed: this time the delays were my fault. I explained what had happened, the professor accepted my apology, and then told me she had set the transplant for 13 February, with Kelly being admitted to St-Louis Hôpital on 29 January. I told her the dates were good for us.

As soon as I got off the telephone, I felt extremely relieved both to have spoken to her directly and to have established a firm date. The fact that we still had so much money to raise didn't bother me at this point. Half of me was scared; the other half elated. We had our date, we had a donor and we had the one woman in the world who could give Kelly a chance at life. Having actual dates would also make the fundraising so much easier.

Professor Gluckman's letter arrived shortly after our telephone conversation. We contacted the Lions with the confirmed dates. Labour Weekend was approaching. Richard and I had talked about inviting the Keegans down for the three days. We knew that Paris was going to be difficult in so many ways, and we needed their expert advice on how to cope once over there. There was no one else to turn to who had the kind of experience we would need. I didn't know what their reaction would be . . . I was worried about bringing back so many painful memories for them. I gave Dale the chance to decline but they were amazing, accepting the invitation immediately. I next wrote to Monsieur Silverston in Paris, and asked if he could help find accommodation for us. Dale had mentioned a new McDonald House in Paris, I asked if he could check that out.

❖

The next few days were spent arranging correspondence schooling for Daniel and Kelly, and attempting to sort out their financial affairs. Social Welfare advised that they would probably be granted an emergency unemployment benefit, but they had to apply closer to their departure date.

The Labour Weekend meeting between the two families was everything that Jan and Richard had hoped it would be. The Keegans had their 13-year-old son with them. Far from being all doom and gloom, the families did the tourist spots; and they talked. Kelly saw photographs of Anna without any hair. Dale helped answer that and many other questions for Kelly, Jan and Richard, She also supplied them with one answer that they didn't want to hear.

'What is Daniel going to do when you go to Paris?' I looked at Dale. 'He's coming with us,' I replied, wondering what she was getting at. She looked at me, and I could see she was about to tell me something I didn't want to know. We had planned on Daniel going, on keeping us all together. Dale was shaking her head, 'it's not a good idea, Jan. Children under the age of 15 are not allowed to visit the bone marrow unit. Not being able to see Kelly is bound to upset Daniel.'

I was dumbstruck. This was all news to me - bad news. 'To be frank, Jan, you and Richard are going to be spending most of your time at the hospital. Believe me, I know. Leaving Daniel alone in a strange city is going to be cruel, and you won't have any option but to do that if he goes. You simply won't have the time to spend with him. Sorry.' She gave me a sad smile of understanding, and I sat, trying to contemplate being in Paris without my son. The thought of being parted was bad enough after our plans, but to be parted from Daniel for such a potentially long period was simply unbearable. I knew, though, that it would be foolish not to consider what Dale was saying. She'd been through it all. With those few words, my dream picture of the two kids spending a lot of time together with me being able to help them with their schooling was shattered.

It just hadn't entered my mind that Daniel wouldn't be allowed in the unit. Now that damned disease was making me compromise yet again. I had to separate my children. I was so angry at the thought of them being apart. I mean, they were normal kids when it came to brother-sister things - they fought, they did all of that -but they were also best friends and I just never saw them being separated at this time when Kelly was going to need all the support she could get.

❖

Before the Keegans returned home on the Monday of the long weekend, they agreed to attend a meeting at the local radio station. The meeting was between the station manager, the Lions' representative, and Jan and Richard. Once again, the subject was money: $360,000, to be precise.

The meeting was a frustrating one for both the Keegan and Turner families. Despite Dale explaining in depth the kind of expenses they had encountered in Paris, and insisting that the fundraising appeal target be maintained at $360,000, Professor Gluckman's $95,000 quote was constantly referred to throughout.

The next article in the local newspaper gave the target figure for Kelly's operation as $250,000, stating that $160,000 was already in trust and only another $90,000 was needed. The reason for the changed target figure was put down to the fact that

free accommodation and transport had been arranged. This was not true: there had been no guarantees of either.

Shortly afterwards, Jan and Richard received a letter from Alain Silverston in Paris. The McDonald House option was not a possibility. This had been reserved for another hospital, and was in any case far from the St-Louis. The good news was that the hospital itself had six accommodation rooms for family members, and one had been reserved for them. Monsieur Silverston also said that the rooms were small. He suggested that perhaps Daniel would be better staying at home. He added that if the hospital accommodation wasn't suitable, they would find another solution when the Turners arrived in Paris. It looked as if this aspect at least could be worked out. Jan and Richard now had to tell Daniel that he couldn't go with them. It was something they both dreaded. They had to find the right moment.

Jan rang Therese to talk it all through. She wasn't aware that her 'big sister' was way ahead of her.

Therese: The thought of leaving Daniel behind had been making Jan really anxious. When it was first suggested, she got really angry. I knew in my heart that I would have to be the one to persuade her to leave him. I had already, unbeknown to Jan, talked to Mrs Keegan about it, and she had explained just how difficult it was going to be in Paris. When the moment was right, I told Jan that I would love to have Daniel come and stay. I meant it too - Daniel was a favourite of mine. With us, he would have his two cousins to play with, he could bring Chloë (his beloved dog), and he could attend the local school just up the road. I'd already worked things out, so that, when Jan objected because of my shifts as midwife at Waikato Hospital, I had an answer ready. I had arranged to go on permanent night-duty while Daniel was with me. I would be home during the days and my partner would be there at night. Reluctantly, Jan agreed. I felt a bit mean in a way, because I had been 'organising', but from what Dale Keegan had told me, life would have been much more difficult with Daniel in Paris. I knew that Jan, Richard and Kelly were going to be really stretched just getting by. With hindsight, I'm glad I got in there and meddled.

Jan: Now that the decision not to take Daniel had been made, I at least felt that he would be with the best person to look after him. He was very close to Therese, and if he had to be back here, that was where he would be happiest. Despite this, it was not easy breaking the news to him and I hated doing it. It took a lot of talking before he reluctantly agreed. Kelly wasn't happy with the new arrangement either. She had prepared herself for us all going.

Now that we had the dates a new reality had arrived, and things became very unsettled. I had great difficulty keeping my spirits up. I cried more and more often at nights. Daniel and Kelly were now openly fearful, and would cry at bedtime. Anna had died, Kelly knew that the operation was dangerous. Daniel had to stay behind. There were so many things that could no longer be ignored or hidden away. The only thing we could do to help was to encourage them to talk. Daniel's big fear was that Kelly would die in Paris and he would never see her again. Kelly heard this and came running in, crying and talking about dying. I just hugged them and tried to appear strong and stay positive, but it was so very hard. Life can really be a bitch sometimes!

◆

To attempt to ease the children's fears, Jan and Richard made contact with a family whose child had had a bone marrow transplant about the time Kelly's appeal was launched; they felt that it was important for Daniel and Kelly to see another child who had come through a successful transplant.

The family lived a short distance away. The local newspaper was there when the children met and posed together. Kahn and Kelly were pictured sitting at Jan's computer, playing a game. The picture printed in the paper carried a caption explaining that Kahn was the recipient of a transplant, and Kelly was waiting to have one. The only sour note came when someone suggested that it hadn't been a good idea to show Kelly at a computer, in case it made people think they weren't poor. Despite this, the exercise was successful, sending a positive message to the public, and to Kelly and Daniel.

Jan contacted Air New Zealand Koru Care Club in Auckland, and told her story to the president of the club. He said he would see what he could do. Shortly afterwards, he rang to say that they would pay for the family to visit Disneyland on their way to Paris, as well as for accommodation in Los Angeles. Jan was delighted: this meant that they could have some 'special time' as a family. Daniel could fly to Los Angeles with them, then return to New Zealand while the others carried on. Little did Jan know that even this simple thing would be difficult to accomplish.

November arrived, and with it Jan's worst time in public; the pressure had finally got to her. They were to make an appearance at a Lions convention. It was a day when Kelly and Daniel were both being difficult. Daniel didn't attend the convention. Kelly didn't want to go, but as she was the 'star of the show', she virtually had to be forced into it, which made Jan very angry. She stumbled through the event, and went home to collapse and cry her heart out.

CHAPTER 15

Total chaos

❖ NOW THAT DATES had been established, there was a frenzied rush of activity. The small town of Taupo was going to be totally saturated with events for Kelly's appeal. Once again, Richard was determined to get things going outside the town itself.

During November, Jan and Richard met someone who was to become a very important friend. Louise Carroll of KIDS (Kids with Immune Deficiencies Foundation), from Auckland, passed through Taupo. Louise offered to help in any way possible, and suggested that KIDS offices be used as the drop-off point for donations in Auckland. Other people came to the fore, including Roger McClay, the local MP, who took charge of arranging visas, personally taking the Turner passports to the French Embassy in Wellington.

Airline tickets were booked. The itinerary was: depart New Zealand on 5 January, 1992; stay in Los Angeles until the 9th; arrive in Paris on the 10th. Alain Silverston would meet them at Charles De Gaulle airport.

The fundraising entered a new phase. A dramatic poster was printed free-of-charge by a local newspaper that had supported the appeal throughout. The recurring target figure of $90,000 still made Jan and Richard cringe. Based on the original estimate from Dale Keegan, they needed something like $200,000.

Richard travelled to Auckland to deliver posters to Louise Carroll. The visit proved very fruitful. He visited a cousin who worked at a country radio station, and was interviewed on air. The station management decided to hold a fundraising day for Kelly on 22 December. Richard also had a telephone interview on radio with personality Paul Holmes. Everywhere he went, he left posters for people to distribute.

Jan: Once again, the Christmas Carnival was held, and, once again, we did a street collection, running up and down the parade, rattling a tin. It was soul destroying, particularly when people grumbled things like, 'Not that damned appeal again, I've already given!' I just kept on going, knowing that soon it would be over and I'd never have to do it again.

It became increasingly obvious that the stresses and strains of running such a large, long-term appeal were affecting everyone, including the Lions. The wife of one member told us that, because of the appeal, she hardly ever saw her husband. We were all suffering from pure overload, exhausted, tempers fraying. We had been trying to raise funds for seventeen months now. We were also attempting to raise the money for Daniel's airfare to Los Angeles, separately from the appeal itself. We had absolutely no personal money at all: everything had gone into the fund. At the next Lions meeting, we were told that if we didn't reach the target figure soon, Richard wouldn't be able to go to Paris. We were devastated. Quite frankly, I don't think I could have coped on my own. As it turned out, my premonition was right. We *had* to get enough for us both to accompany Kelly. The alternative didn't bear thinking about.

It was at this stage that we applied to the Department of Social Welfare for the emergency benefit to help with our living expenses in Paris. We had to submit written estimates for the cost of airfares, accommodation and other expenses. Once again, Dale Keegan came to the rescue, writing down her daily accommodation costs in detail. There were no luxuries there, I can tell you - it was all basic necessities. Alain Silverston gave us weekly estimates for food and transport. The expense of living in Paris became very clear to us. We were going to need every cent we could get. We submitted all the costs and a letter from our doctor stating why it was important for both parents to be with Kelly.

❖

The reply from Social Welfare was a long time coming, and Christmas was just days away. Jan had been hounding the local office of the department, knowing that with the holidays everything would close down. Eventually, the office gave her the Private phone number of the Assistant Director-General. He said that he had just received the application and would ring as soon as he had made a decision. True to his word, Jan received the call a day later. They had been granted money towards airfares and accommodation. The amount was far more than they had ever hoped for: $36,553. This meant that Richard could now definitely go to Paris as planned. The accompanying letter stressed that the money 'must be used for the purposes for which it was granted'. Since the money raised publicly wasn't being used for Richard's travel or accommodation, it was a huge relief to them both.

Christmas was almost upon them, but both Richard and Jan were simply too busy with last-minute fundraising and personal arrangements to even think about it. Once again, Therese stepped into the breach, inviting them all to Hamilton for the holiday.

Therese: I was so looking forward to Jan and the family arriving that I kept an eye out the window for their car. Once again, I wasn't prepared for what I would see. Jan looked so thin, as I hugged her she felt all bones . . . I was scared I would break her. She looked pale and tired, her left eye was red and weeping. She was so exhausted she could barely manage a smile. I found it really difficult to give her my usual jolly-up. I had serious doubts that it was going to be 'all right' this time.

Once things settled down and the kids were playing, I vowed that my little sister was going to get as much TLC as I could give her. I ran her a big, hot bubble bath and made her a long non-alcoholic cocktail (she no longer drank alcohol). We sat and talked. Jan was beyond crying. She had to face the fundraising event in Auckland the next day, the last one, the one Richard's cousin and the country radio station had arranged. I bathed Jan's eye, it looked so sore. She was worried about facing all these people and looking 'terrible' - problem was, she did at that moment.

Later, as we sat talking about 'tomorrow', I couldn't help thinking that it wasn't tomorrow that was the problem. It was all the yesterdays. I know I sound like an over-protective big sister, but looking at Jan sitting there, so tired, her fingernails bitten until they bled, I honestly don't know how she had made it this far. She'd fought; God, how she'd fought. From the moment Kelly was born, she had had no peace or peace of mind. The final straw was the fundraising, it had stripped her totally bare emotionally' physically and spiritually. She was as close to breaking as I had ever known her to be. There was a haunted look in her eyes that I had never seen before, and it scared the hell out of me.

I actually prayed for her that night, asking God to give her the strength to get through one last day of fundraising. It was my turn to cry myself to sleep.

Jan: As we drove over the Bombay Hills heading for Albany for the fundraiser, my eye was hurting like hell. What a day for this to happen! I told myself to stop feeling sorry for myself. All these people had been working so hard to make this last one effort a great one. I didn't realise how hard, or just how good it was going to be. As we drove in, we heard the announcer talking about the appeal. It seemed really strange to hear Kelly's name on air. Through all the fundraising we'd done, I still hadn't got used to hearing her being mentioned in that way.

At the radio station everyone was flat-out, very friendly and very busy. There were bands and singers, stalls, auctions and other events in Albany, and people came and went all day. Girls in Santa suits collected money on the streets, the phones were busy with people taking donations. A French airline phoned up with the offer of a return children's air ticket to Paris for Kelly. Because we already had our tickets, they later gave us a credit against an adult fare if we needed it. Louise Carroll was there supporting us throughout the day, for which we were very grateful. A local Taupo reporter had come all the way up for this event - again we were grateful, he'd become so well known to us over the last eighteen months.

There was one particularly touching moment. One of the singers was David Reid: his daughter Nicole had died earlier in the year before she could get to Canada for a bowel and liver transplant. It all came down to money again. The cost of Nicole's transplant had risen by an obscene amount during their fundraising efforts. They'd struggled to find the extra funds, to no avail. Now David was here doing what he could for us . . . it was totally humbling.

Late in the afternoon, we were told that something important was going to happen and we were to wait outside. We did so, totally baffled. People started to gather around us, and then Robyn, the announcer, came out with her microphone and introduced us all on air, before turning to a lady who had been standing beside us. The woman was Kay Reid, Nicole's mother. When asked why she was here, Kay replied, 'I've come today to donate $10,000 to Kelly's transplant.' I couldn't believe my ears, and when Kay explained where the money had come from, I ended up a blubbing mess. The money was from Nicole's transplant fund - because Kelly needed it, it was hers. It was that simple to this brave lady and her husband. Kay finished her short speech by saying words that I heartily endorse: 'We know all about fundraising and we know how hard it is, especially when you have a child needing a transplant.' There were a lot of hugs and a lot of tears when we were off-air. Kay told me the full story of Nicole and how she died, all because of the lack of money. How absolutely tragic!

On the way back to Hamilton after this very emotional day, I couldn't get what had happened to Nicole out of my mind. Money. It was so obscene that a child's life - anyone's life - could have a price tag slapped on it like that. There was $360,000 on Kelly's life, the price some people paid for a car or a holiday home. I started questioning it all, prefixing every thought with that damned word that haunted me: why? Why should lack of money cost a life? Why couldn't medical institutions and governments worldwide simply link up to provide a service where no money need change hands? In Europe, Kelly's operation would have been free under the EEC rules. If we had been British, or German, or whatever, it simply wouldn't have been a problem. What about all the huge companies making obscene profits out of every soul in the country? They grandly announce their results, everyone congratulates themselves and looks smug. The executives drive their BMWs and Jaguars, which cost as much as Kelly's transplant. What a waste. These people and companies have no concept of what life for 'ordinary people' is like. Their petty cash could save a child's life. They weren't there for Kelly, Anna, Nicole, or the countless others who through necessity had to go overseas for medical treatment. It was the 'ordinary people' who were busting their guts, many donating what they could ill afford for Kelly and others.

I was shattered, and bitter. I don't think I've ever been so low, mentally or physically, in my life. On top of that, I felt so very, very humble. Once at Therese's, I just collapsed and slept the sleep of the dead. I had totally had it!

❖ **Over the rest of their time in Hamilton, Therese insisted that Jan and Richard take it easy. Therese had made a huge effort for this very special Christmas. Money had been no object to her: her family's needs came before anything else.**

Therese: I was absolutely determined that Christmas Day would be wonderful for Jan and her family, just like the ones we'd always had together. I'd opened a credit account at a local department store, and loaded it to the hilt with anything and everything I thought would bring a little happiness - to hell with the cost. I would worry about that later. It was worth every cent to hear Kelly's squeals of delight and Daniel's 'Wow!' Jan and Richard both had smiles on their faces at their gifts. We had a lovely Christmas dinner, with all the trimmings. I couldn't help wondering what they would eat 'over there', and if little Kelly would be eating Christmas dinner with us next year.

❖ **On their return to Taupo, there were a lot of last-minute things to be organised. There was still the problem of finding the money for Daniel's return ticket to Los Angeles. They were due to leave in just nine day's time. Jan rang Louise Carroll for a talk, and she flew down to see them the next morning. With her long experience of fundraising and trusts, she expressed surprise that all the trustees on Kelly's account were in fact Lions. She explained how important it was that the trust be well structured, with a representative of the patient and family, a medical person, and a lawyer, to ensure a fair balance.**

Jan and Richard approached Richard's brother-in-law to represent Kelly, and a friend who was a bank manager to represent them. Their family doctor agreed to act as the medical representative. One of the Lions was a lawyer. They all agreed that they had fair representation now.

A business friend of one of Kelly's new trustees donated an airline ticket for Daniel: finally it was done. The Turner family would all be going to Los Angeles together. It remained to be seen if they would ever be together again after that.

CHAPTER 16

From fight to flight

LOUISE CARROLL, VERY aware of the strain on the Turner family, invited them to leave Taupo as soon as possible and stay with her family in Auckland for a few days. She recommended that they give themselves some time together, out of the limelight, before they flew out to Los Angeles. Initially Jan turned down the offer, but after discussing it with Richard they decided it was wise to leave town and get a 'change of air'. They all needed to calm down a little.

Jan: It was strange leaving home, not knowing when we would see it again, not knowing under what circumstances. We left Taupo after sorting out the care of the house and section and our finances for the trip. We had been issued with credit cards on which to draw our living expenses. We had an allowance of 2000 French francs (FF), or $NZ650, a week. The statements were to be sent back monthly for payment by the trust. The trustees would send bank drafts directly to Hôpital St-Louis for Kelly's medical expenses. As far as accommodation was concerned, we just didn't know for certain until we arrived.

Louise, her husband John, and children Emma, John-Paul and Katie, made us feel so welcome. They had a lovely big home, and the kids soon spotted the swimming pool. The atmosphere was really relaxed. Louise made it very plain that she just wanted us to 'blob out', which we did. Louise vetted all our calls so that we could have a rest. It was she who suggested that we make arrangements for press releases to keep the media informed about Kelly's progress. Dale Keegan had told me that she had been pestered dreadfully while in Paris. Louise offered to be the middle-person to pass information on. It was decided that I would fax once a fortnight with a press release. She would telephone our families to give them the details, then lax the material on to the Lions and the media that had helped us with the appeal. It was important that all the people who had contributed knew what was going on. We also had to work out a plan to follow in case Kelly died.

One day Kelly asked if she could have her hair cut short, in *a* bob. We all knew that she would lose it during chemotherapy, so I readily agreed. Louise arranged an appointment at her hairdresser, and we all made a big fuss. The new hairstyle did look lovely. One night we had chicken for dinner and, as usual, Kelly claimed the wishbone. Louise made her promise to come back after her transplant and break the wishbone with her. Kelly agreed. Louise had given her another little incentive to keep her spirits up.

On the day of our departure we had two lots of television interviews to get through. The setting was around Louise's pool, where we had been spending most of our days. I thought I'd become reasonably good at judging the media - wrong again! The first film crew were great, and there were no problems; the second interviewer, however, was something else.

As the interview went along, she started to ask Kelly some really insensitive questions, before I could register what was happening. It was Louise who picked it and called out to me, asking if I had been told that these sorts of questions would be asked. I of course said no. Louise stepped in then, and told the reporter to tone down her questions or the interview was over. The reporter gave in reluctantly, but realised that Louise was far from naive when it came to this particular circus. When the reporter came over to me to continue the interview, I was astonished when she leaned over and whispered, 'If you want our help, you have to play the game our way.' My chin must have hit the floor: I couldn't believe what I was hearing. The woman was cunning enough not to let Louise hear what she was saying. If it hadn't been for the fact that we were still short of funds, I would have finished with her there and then. What an absolute bitch!

We watched ourselves on the early evening news, and it was quite an emotional time for us all. Both channels screened the stories at the same time, so we watched one and videoed the other. It was our story, a story of hope. One began, 'An eight-year old Taupo girl begins a long; journey tonight. Kelly Turner is flying to Paris for what is hoped to be a life-saving hone marrow transplant.' It then showed us around the pool, and some segments of our interviews. They mentioned that we were still $72,000 short of the amount we needed. There was also an interview with Louise; the reporter started that segment with the introduction, 'The support group KIDS said the burden is too great.' Louise then came on. Her piece finished with the words, 'We can't expect those parents to get out on the fundraising trails any longer.' I was so glad they showed that, to outline the pressures on families such as ours.

There was no time to dwell on it any longer: we were off to the airport. Once again, Louise came to our rescue. She had arranged a private room so we could say goodbye to our entourage, which included a lot of family members who had come to see us off. My mind was whirring. 'What have I forgotten?' I kept asking myself. Then came the question of our departure tax: we had changed all our money into US cash, and didn't have any New Zealand currency left! Everyone did a quick whip-around to help us out. That's what you call fundraising to the very end,' we joked. A TV cameraman turned up, as arranged, as we booked our luggage in - then that was it. The four of us tried to be brave as we said our farewells to family and friends. I felt more sorry for them, being left behind, than for us. We would be there on the spot knowing - they would be here wondering. Then we were away into the boarding area. This was truly it!

❖

The 12-hour flight passed slowly, the adults finding it difficult to sleep in the cramped conditions. Kelly, being the smallest, had no such problems. At Los Angeles, Richard's parents, who had a business in Seattle, were there to meet them.

They all squeezed into the elder Turners' car and drove out to the hotel, which was situated near Disneyland. For two days the weather didn't co-operate, although they visited Disneyland in the rain on day two. The children just had to get inside the Magic Kingdom. Day three was a true Disney day, bright and sunny. The kids knew what they liked, heading straight for their favourite rides. It was a day to be remembered, and Richard captured much of it on video. Neither he nor Jan dared think that this might be the last time they would film Kelly and Daniel together. All too soon, it was time to farewell Daniel and Richard's parents, and board the flight to Gatwick.

Daniel: I enjoyed Disneyland, but at night I thought about how we were going to be separated and I was scared. When the time came for Mum, Dad and Kelly to get on the plane, I think it was the worst moment of my life because I didn't know when I would see any of them again - particularly Kelly. I was old enough to fully understand the dangers.

My flight back to New Zealand was very lonely. I tried not to think of them; instead I focused on going to Therese's house. I kept remembering all the neat times I'd had with her and my cousins. When I arrived at Auckland Airport, I felt very lost until I saw Therese. Then I felt safe, especially when she gave me a big hug.

Jan: Poor Daniel! No matter how I tried, I couldn't shake off the image of him standing there waving, looking so sad as we went through the boarding gate. I knew he would be fine with Therese, but that didn't change the fact that we as a family had been separated at a time perhaps when we should have been together for mutual support. My fears regarding this were going to be realised many times in the months ahead. All through our long, uncomfortable flight, that premonition nagged away at me, but there just wasn't anything we could do about it now.

We arrived at Gatwick Airport at a few minutes to ten in the morning. We had to change to Dan Air for our final journey into Paris. The weather was dismal. We transferred from one terminal to another, and with the time we had to spare I went into the airport shops. I was kicking myself: I had forgotten to bring that most important Kiwi item, Vegemite, with me. I'd heard that you couldn't get it in Paris. I couldn't find any in the airport shops. What I did notice, though, was the price of everything - very expensive. We boarded our 40-minute flight, and even got served lunch before we touched down at Charles De Gaulle, in the fog.

The language difference was beginning to bother me even before we got off the aircraft. Most of the people on board were speaking French. It wasn't that we hadn't tried to brush up. We'd had a few crash courses from a local lady, but it had been very basic. She gave us an English/French dictionary - it was to become my bible.

It was 12.30pm as we cleared customs, all our baggage on a trolley. Now we just had to find Alain Silverston. I had seen a distance photo of him in an FA magazine, but apart from that I didn't have a clear idea of what he looked like. No one was holding up a card with our name on it, and because there were so many exits we walked around looking at them all. Maybe he was at one of the others?

❖ **By 2.00pm, the Turners still hadn't located Alain Silverston and were starting to get very apprehensive. Kelly was virtually asleep on their mountain of luggage. Jan decided to phone the Silverston home. They had no French coins, and the currency exchange wouldn't oblige; however, a barman understood their predicament and gave change. Eventually Jan got through to the house, and was faced with another problem. A young boy answered - he couldn't speak English, while Jan couldn't speak French. It was the situation she had been dreading. She and the boy got nowhere fast, and eventually Jan hung up, none the wiser. She decided that they would have to get a taxi to Alain's house. It was then that a man in a striped suit appeared, holding a card with *Turner* on it.**

What a relief: we hadn't been forgotten. But who was this man? After shaking hands, we realised that he spoke only French. Using sign language, he signalled for us to stay where we were while he got his car. He returned with a large station-wagon that easily took all our luggage. We still didn't know what was going on; I was desperate for some explanation in English.

The driver then handed Richard a letter written on New Zealand Embassy letterhead. It was from Godfrey Payne, the Consul. The letter introduced Samba, the driver, and explained that he would take us to our accommodation. Alain would contact us there at 3.00pm. It was almost that now; however, it was such a pleasant surprise to have this support from the New Zealand Embassy.

As we drove through Paris I couldn't help but notice the pace of life, narrow streets and cars parked everywhere. The buildings were much taller than I had imagined; many looked very old.

It took us an hour from the airport to Les Citadines, our temporary home. We had to wake Kelly to get her to walk into the lobby. Immediately, we noticed a very smart looking man in a long dark coat, who looked very agitated. This was Alain Silverston. It was marvellous to meet him in person tor the first time. Alain's English was quite good. He introduced a young man standing nearby as Alexis. Alexis had been an exchange student to New Zealand and had stayed with Bob Powley from the Lions; Bob had said he would tell Alexis about us. The young man's English was excellent, and he explained what had happened. There had been a mix-up between the various exits, which was why we and Samba hadn't connected sooner.

Alexis told us that Alain had arranged a reduced rate at this hotel, and was anxious for us to view the apartment to see if it was suitable. It was! Although tiny, it was nice, everything was quite modern. There was a self-contained kitchenette, a single bed and a lounge suite that folded down into a double. As soon as Kelly saw the bed, she flopped onto it and was asleep in seconds. We reassured Alain that the apartment was indeed fine. He gave one of his own cheques to the receptionist as a bond, and said he would fax New Zealand to tell them that we had arrived okay. He had to rush off: he worked in a bank and today, Friday, was always very busy. He promised to contact us the next day, and left with our thanks ringing in his ears.

While I unpacked, Alexis took Richard and showed him the shops, helping him buy some basic food items. We would need a snack for Kelly when she woke. Poor kid, she was sound asleep. We thanked Alexis for his help, and after he left, got to taste real French bread for the first time. After I had had a very hot bath, Richard and I crashed out on the settee bed. 'We've made it.' I said, not really believing we were actually here.

'Yeah - finally!' he replied, and for perhaps the first time I realised that, behind his confident mask, he had had doubts all along. He had been strong for us all and never let on, even to me. I gave him a big hug of gratitude and love. The hug might have turned into something else, but sheer fatigue and relief had taken their toll. We fell asleep like that, wrapped in each others' arms.

Kelly and her family launch the fundraising appeal: Kelly cuts the eleventh-birthday cake for My Pickwick’s Bakery, Woolworths, Taupo, July 1990

More fundraising with the Lions, a poolside barbecue at a local hotel, 1991.

Daniel and Kelly spend valuable time together in Disneyland,
on the way to Paris, January 1992.

Staying germ-free: Kelly masked-up for a trip down the Sienne River, Paris, with Marie-Pierre Bichet and Jan and Richard, August 1992.

CHAPTER 17

Even the air feels foreign

AFTER SLEEPING OFF their travel fatigue, it was time for the Turners' first solo foray into the unknown, as they went on a shopping expedition to stock their larder.

Jan: We woke at 9.30, looking at least half-human after the very long, previous day. We decided to go shopping, and because the day was quite cold, we bundled up. Out in the streets everything was so different to home. There was no way that you could pretend you weren't in a foreign land, not even for a moment - even the air felt foreign. The supermarket was a difficult experience. It took us two-and-a-half hours to buy basics such as cereals, veges, toilet paper, meat, and so on. The difficulty was in trying to decipher the words on the items, and we were also constantly converting prices to see which was the best value. We were so aware of just how careful we had to be with our funds, and had made the decision to start off as we meant to carry on. Dale's warnings about the expense of even basics wasn't in the least exaggerated.

When we arrived at the check-out, we realised that somehow we had accumulated five bags of groceries. It was going to be a problem getting them back to the apartment without a car, as we were some distance away. Then we spotted the solution. We had noticed that many people had their own little shopping trundlers, and came upon a display of them in the supermarket. We decided it would be a wise investment. They cost 288FF ($NZ95), but the little cart was to prove its value time and time again over the coming months. We wheeled our way home like tourists.

It gave us a sense of security to have some food in the apartment. Our first solo flight had been a success. We hadn't been back at the apartment long when Alain rang, and said that he would come and take us out for a drive.

We found the driving, and the city, fascinating. To a total stranger, it appeared that there were no driving rules other than 'Stop for the red light'. Cars ducked and dived all over the place, and parked bumper to bumper in parallel parks. I wouldn't have tried to park a motorbike in the spaces where they fitted cars. I swore to myself that there was no way I would ever attempt to drive here. I also couldn't help noticing the fashions that Paris is so famous for. Some of the women looked exquisite. I felt I looked like a hill-billy in comparison.

As he drove, Alain pointed out many of the historic landmarks. The sense of history in the city was amazing. New Zealand is such a new country by comparison: even the Maori and Moriori histories only seem to go back a few centuries. Paris oozed age. As Alain pointed things out and gave us a brief account of their significance, I found that my school history lessons on the Revolution came back - and made sense. It had taken all those years, but finally seeing these places with a French guide made me understand.

It was during our drive that Alain told us his story with FA. His twin sons, Benjamin and Thomas, have FA, but there is a twist to the story. Although Benjamin's bone marrow had begun to fail, Thomas' had shown no signs of doing so. This is quite inexplicable, considering that they are identical twins. The twins' older brother Julian is a tissue match for both of them, and 18 months previously, Benjamin had had a bone marrow transplant at St-Louis. Alain told us that he had done very well since then, and despite the fact that he was now a lot shorter than Thomas because of the medical treatment, he was at school and enjoying a normal life again. It gave us all a lift to hear this.

Alain returned us to the apartment late in the afternoon, promising to take us to his home at Vitry, an outer suburb of Paris, for lunch the next day. We were all looking forward to meeting his family, and seeing how a French family lived.

That evening, as I cooked our meal in our tiny kitchen with its two electric rings and tiny bench top oven (far too small for a Kiwi roast even if we could have found one - let alone afforded it), I thought of Daniel and wondered how his trip back to New Zealand had gone. I hoped he wasn't fretting too badly. I was missing him terribly. I think I shed a tear or two, but blamed it on the onions I was preparing. Unfortunately for Kelly, the television wasn't working and couldn't be fixed until Monday. Dale Keegan had given us a Nintendo game she had bought in Paris for Anna; Kelly was keen to get it going. None of us had any idea just how important that game was going to be later.

Sunday arrived: washing day. We bought tokens for the washing machine and drier in the downstairs laundry. A 20FF token for the washer, 2FF for the drier. Each lasted about five minutes. I worked it out: it cost about $18 to do one load! I was horrified. I thought back to 'normal' family life at home in Taupo, and how I did one wash a day just trying to keep up with the two kids. The cost of the wash served to remind us that here nothing was free - not even drinking water. We had been warned not to drink the tap water, and had been buying bottled.

A nice surprise this morning was a call from Godfrey Payne at the embassy. He reminded us not to hesitate to call him if we needed help. I thanked him for sending his driver to meet us. Godfrey was very friendly and helpful, and told us he would like to bring his family to meet us and visit Kelly in hospital at some stage.

Alain arrived as arranged, and took us out to Vitry. While a long way from the centre of Paris, there was no clear division: the area was still very built-up. The Silverston home was a quaint two-storey house, a hundred years old and, like most of the French homes we had seen, it had shutters on the windows. Alain told us that he and his wife Sylvette were in the process of restoring it.

Sylvette Silverston greeted us at the door. She was very welcoming, with a lovely warm smile. She immediately apologised that her English wasn't good. I felt awful. Here we were in her country, and *she* was apologising. I should have been the one apologising for my lack of French. It didn't matter, though. In just minutes my instincts told me that she and I would become good friends. We next met the boys. Julian had been learning English in school, but Alain translated between us and the others. I couldn't help wishing that Daniel was here with us to meet them.

Lunch with the Silverstons was a typical French meal of bread and cheeses, meats and, of course, wine. We communicated as best we could. I learned an important lesson that day - to keep my language simple, with no clichés or Kiwi phrases. I However, it was fun, and we got by. Kelly was quiet and didn't eat much; she was absorbing all the differences around her. At about four in the afternoon Alain said that they would drive us to Hôpital St Louis to show us around. Until now, St-Louis had only been a name to us: shortly it was going to become a reality, and I was nervous and a little apprehensive. After all, this was why we were here.

As we drove back into the city, Alain tried to explain how the *métro* worked. We were going to have to use it to travel to the hospital on our own. Both Alain and Sylvette worked during the week, and would not be available to drive us around - not that we expected that anyway, especially as they lived quite a long way from the centre of the city.

As we approached St-Louis, I couldn't help but notice just how big and old it was. The transplant unit was in a new section of the hospital, the Tréfle 3, and I remember thinking how familiar this would all seem to us in six months' time. I knew I was going to have to prepare myself for a life of patience, hanging around the hospital. It might be a foreign hospital, but a hospital is a hospital no matter where you are.

The main doors of this hospital opened automatically to let us in. The entrance was huge, and the warmth hit my face as we entered. To the left was a cafeteria; straight ahead was a beautiful fountain, and on the far wall I noticed a magnificent stained-glass window. I'd been in a few hospitals in my life up to this point, but never had I seen one with such striking architectural design. The place certainly didn't have a gloomy atmosphere. We caught an elevator to the third floor and went to the doors with the sign *Unité de Greffe de Moelle.* We were there!

Alain pushed a control button and the doors swished open; we walked in and they closed behind us. We were in a sort of airlock. Alain showed us how to put plastic covers over our shoes. When we were ready, Alain opened another set of doors into the unit. As these swished open, we entered another world.

Richard: When we first entered the bone marrow unit, I was blown away. Up until this point in time I had concentrated so much on raising the money for Kelly to have the transplant that I hadn't really stopped to think about what it would be like in the hospital. I guess I just expected it to be an ordinary hospital scene with white walls and flowers, and the odd patient wandering around. What we walked into was nothing like I'd imagined. The walls were bright colours, lots of yellows. The ceilings were very low, and there was the constant buzzing and beeping of electronic gear. It reminded me of the sounds in the Critical Care Unit at Auckland all those years before. I was fascinated by the technology, though, and also quite over-awed by it. Each room had a control panel outside which operated its own individual air filtering and temperature system. When Jan, Kelly and Alain went into one of the patient's rooms I stayed outside with Sylvette. I didn't want to go in: I was as scared as hell about this place. I just wasn't mentally prepared for it.

Jan: I could see that Richard was finding it all mind-blowing. I wasn't scared, just curious. We all entered the outer part of the room where we left our coats and washed our hands. Sylvette explained that this was where all the drugs and IV fluids were prepared. There was a laminar air-flow area for the staff to work under. They would sit right up to it, with their hands in the sterile air to avoid any contamination. We went on into the second room. There, a young woman was sitting in a chair, and behind a clear plastic curtain was a young man of about 20. He was in a totally sterile tent, lying on his bed watching television. Alain introduced us, and the young man gave us a bright smile. He had a lovely face - and not one strand of hair on his head. He'd had a transplant to combat leukaemia five weeks previously. It had been an unrelated transplant. His blood counts were increasing, and he was now playing the waiting game. He and Alain talked in French for a short time. Alain translated his comment that it was very important to be strong mentally to be able to handle the isolation. I noticed that there was an exercycle crammed into his small living area. Kelly was very quiet and 'all-eyes'. Even so, she didn't appear to be scared. We thanked the young man and wished him luck. As we left, Alain pointed to a plastic blood-product bag taped to the wall. He explained that it was customary whenever someone had a transplant to save the bag that the bone marrow came in, write the date on it and put it on the wall for all to see. When the patient left the hospital, they took it as a memento. I hoped that this would happen with Kelly.

Tomorrow we would return to see Professor Gluckman; we would need to use the mé*tro.* To prepare us for that, Alain took Richard home to our apartment using the Underground, while Sylvette drove Kelly and me back in the car. That night we went to bed early in preparation for a 'big tomorrow'.

CHAPTER 18

The countdown begins

NEXT MORNING JAN, Richard and Kelly set off for their first trip on the *métro.* Jan was a little apprehensive, while Richard was confident he had it all figured out, thanks to Alain who had given him a map and written directions. Richard had never been on a train before his trip with Alain the previous day.

Jan: I was scared that we'd get lost, but Richard's one trip with Alain had convinced him that it was easy. He was right. Once underground, we just followed the name of our line, which was printed on the walls. The train was ultra-fast: we arrived at our stop - République - in only 15 minutes. Very impressed with the efficiency of the system, we made our way back to the streets. The only problem was that there were two exits going in opposite directions - luckily we chose the right one. The hospital was well signposted, and we were there in ten minutes. I think we all felt quite smug about how well we'd handled our first trip on the *métro.*

In the transplant unit we met Isabelle Hirsch, the clinical research nurse. Isabelle spoke fluent English, and was very helpful. She phoned Professor Gluckman to let her know we had arrived. At last, we were going to meet her in person.

The small woman with the lovely smile who came to us looked just as Dale Keegan had described her. After the introductions, the professor went straight to the point, setting up blood tests for the next day and a consultation for the coming Friday. There was no time for more before she left, obviously very busy. At least now I had a face to focus on: that was a help after all those long months. I had no doubt that we would be seeing a lot more of the professor in the future. Isabelle took over to arrange the appointments, and gave us an information booklet that thankfully was in English.

Richard: That first trip to the hospital by ourselves was a bit of a nightmare for me. The *métro* was okay, and even on only my second trip I could see just how essential it was to life in Paris. It was fast and very efficient, not like driving in the streets above. At the hospital, though, I felt totally out of my depth. I couldn't understand a word the nurses were saying, and was totally dependent on Jan. She was more familiar with medical procedures in general, and had a better grasp both of the language and what was going on.

On meeting Professor Gluckman I did feel reassured. I felt that all we had heard about her wasn't exaggerated. She was the sort of person who commanded respect. There was no 'dressing things up'; she was a straight shooter. I came away from that meeting feeling a lot of hope. If anyone could save Kelly, the professor could.

- **After this first meeting with Professor Gluckman, the Turners went to arrange a bank account. Little did they suspect that they were about to embark on the first of the seemingly never-ending 'money-go-round circuses' that were going to become a constant thorn in their sides while in Paris.**
- **They had with them a bank draft for their first month's living expenses, with the intention of cashing it and opening an account. They had noticed many Crédit Lyonnais**

branches around the city; it seemed a logical choice. Jan and Richard soon found out that it wasn't as easy as they had hoped. The bank staff said that they had to go to the Head Office branch, and wrote down the address and *métro* information. Two changes later, they arrived at the bank and cashed the draft. The next problem came when they attempted to open an account: they had to go to another branch to do that. The cashier wrote down the instructions; it would require a further three *métro* changes. Kelly was exhausted. The decision was made to head home. From this point on, they intended using their credit cards to draw living expenses, as originally planned. They would tell Bob Powley in Taupo not to send bank drafts in future.

Jan: Back in the apartment after a long day, it truly felt like home - our refuge. We had a replacement TV, and Kelly was pleased about that. There were nine French language channels, two Spanish, and one English. This last was an American cable channel with lots of music clips, plus a few movies and sports items. Already we were missing any news about New Zealand. The whole country could have been blown off the face of the earth and we would have been none the wiser. We had given our families Alain's address, because we hadn't known definitely where we would be staying before Kelly was admitted into the unit.

When night came, I sat and reflected about what was to come. The next day was the true beginning of the build-up to 'T-Day' -transplant day.

❖

During their appointment at St-Louis, Isabelle Hirsch conducted them through their first test experience in Paris. Because a large amount of blood was going to be needed, Kelly would have to return the next day to give more. Professor Gluckman had commented to Isabelle that Kelly appeared very pale, and thought that she might need a red-cell transfusion.

The next morning at the laboratory, the nurses had a great deal of trouble finding a vein. Eventually they did manage to draw off the blood they needed. Although there was a language problem, the nurses made a fuss of Kelly, kidding her along with toys and lollies. She was happy. Jan, however, was concerned at the blood counts - platelets 27, red cells 8, white cells 2.8. Isabelle informed her that a red-cell transfusion was normally given if the count dropped below 8.

The following day, Thursday, was a rest day. Their appointment with Professor Gluckman was set for 8.30 the following morning. Jan wrote letters and sent her first media fax to Louise in Auckland. She noticed that Kelly was now looking very pale, the worst she had yet seen her, with big, very dark, blotches under her eyes. Jan suddenly found herself feeling even more grateful that they were here in Paris under Professor Gluckman's wing. She shuddered at the thought that they could still be in New Zealand waiting to get here . . . waiting until it was too late.

Sitting in the clinic waiting for Professor Gluckman the next day, I browsed through some French magazines. I couldn't read any of the articles, but as I looked a! the pictures I thought to myself, 'This is what it must be like for children before they learn to read!' The observation made me wish once again that I had paid a hit more attention to French during college: I could sure use it now. I ultimately, though, Professor Gluckman's English was excellent. She asked routine questions at first, and said that Kelly didn't need *a* transfusion yet. She was pleased that Kelly had not had the androgen treatment or any blood transfusions to date, as this meant that she was in good physical condition to have a transplant. The professor gave Kelly a thorough physical examination, which confirmed she was indeed in good condition. That at least was a relief for us. The professor went on to discuss the transplant itself, explaining that while unrelated ones did carry a higher risk of rejection, with a patient in good health there was an excellent chance of success. She explained that there were a lot of tests to be done, starting with a cardiac one the following week at another hospital. The professor was going to a conference in America that week, and volunteered Isabelle's assistance with any problems that arose. Kelly would be admitted to St-Louis on the morning of 29 January, as per schedule.

After our meeting with the professor, it was back to the laboratory for more blood tests. Poor Kelly now had many bruises from all her tests. I hoped that for the next 12 days she could have a break from them, before she entered hospital. Poor kid, she was so brave about the needles. They had been a part of her life for a long time now. I prayed that one day soon, they would stop.

Back at the apartment, I still hadn't heard from Louise following my fax. I needed a list of New Zealand fax numbers I'd left behind. I was beginning to feel very cut-off from home. In the end, on the Saturday, I placed a call to New Zealand. Louise was at a wedding, and her husband John said he would get her to call. I felt quite homesick when I hung up. With this beautiful city all around us, I couldn't even relax enough to go out and enjoy the sights. There wasn't an hour went by when I ever forgot why we were here, or that Daniel was at home. How could I relax? I broke down in tears. Homesickness might he a state of mind, but anyone who tells you it doesn’t hurt has never experienced it at full force. I was a mess, and it was another tearful night before I finally fell asleep, all cried out.

❖ **On the other side of the world, Daniel too felt the strain of being separated from his family.**

Daniel: I missed Mum and Dad and Kelly at night, especially in the beginning. It was really hard when I got any mail from them, or when I spoke to them on the phone. The rest of the time it wasn't so bad, because I was always busy doing something. It was the nights that were the worst time, though.

Jan: Louise rang on the Sunday morning; it was great to hear her voice. She'd sent a fax on Friday, and it was a mystery where it had got to. She also explained that Murray Kemp had sent 80,000FF to St-Louis and that Les Citadines had been paid for up until the 29th, when we were to check out and move into the parents' wing at the hospital. I was worried that money was flying around all over the place while we had no idea what was happening.

On Monday I got the fax from Louise with all the fax numbers I needed. I felt so much better knowing that the lines of communication were now open. I faxed Murray the hospital account and details of how the accounting procedures were dealt with. I also asked him to fax us every time he sent money.

- **Jan and Richard now settled into the roles that each would maintain for most of their stay in Paris. Jan kept up with Kelly's day-to-day care, interpreting the medical procedures and looking after Kelly directly, while Richard assumed the housekeeping role. Compared to a 'normal' Kiwi house, the apartment was tiny. Originally intended for tourist visitors who were in Paris for short stays and who would normally eat out, the facilities were stretched to the limit accommodating a 'live-in' family of three - but they coped.**

CHAPTER 19

God, I wish I could speak French!

❖ THE WEEK BEFORE Kelly entered St-Louis was as close as the Turners got to their 'holiday of a lifetime'. They actually took Kelly to see the Eiffel Tower. The day was cold, and the price of going up the tower was too expensive, so they contented themselves with taking some photographs and a video. When they returned to their apartment, they found a message that Kelly had been booked for her cardiac test at another hospital. Isabelle was definitely their saviour when it came to translating French to English.

The problems Jan and Richard encountered through not speaking French grew daily. They were dreading the thought of the difficulties they would face when Kelly was admitted to St-Louis.

Through all of their time in Paris, however, support came to them from a great variety of sources. Alain Silverston was working hard on their behalf behind the scenes. Pierre Loiselet, a Parisian Lion who had been contacted at the beginning of the fundraising, now got in touch with the Turners. Through an oversight, he had not heard back from the Taupo Lions. When he found out that the family was in Paris, he invited them to lunch and offered his chauffeur and car to help them shift from their apartment to the hospital. Another group of Lions from a separate club invited Jan and Richard to one of their meetings. One member was the father of Alexis, who had met them on their first night. The Lions enquired into the Turners' finances and were told that they had funds for six months. The club agreed to help if there were difficulties later on; Alain would contact them if there were problems. Jan and Richard left the meeting very impressed and reassured by the fact that, so far from home, this international brotherhood shared the same ideals and concerns as their counter parts in New Zealand.

Regarding the medical expenses, everything had to be paid for immediately. The trusty credit card was found wanting at Kelly's cardiac test: although the bill was 966FF, credit cards could not be used. Instead, Jan had to find a bank and get cash. This scenario, and a dozen variations, were becoming commonplace.

Their first mail arrived at Alain and Sylvette's the Saturday before Kelly was to be admitted to St-Louis: Daniel was fine! Jan, however, suffered, her homesickness coming back at full force.

On the Sunday they kept their promise to take Kelly to McDonald's before she went into the hospital. It was ironic that, while trying to ask for sweet 'n' sour sauce for Kelly's Chicken McNuggets, it was an English- and French-speaking Chinese man who came to their rescue. Unfortunately for Kelly, the sauce wasn't available. Despite this, they enjoyed their first restaurant meal out in Paris, albeit in an American clone.

Then Tuesday, 28 January, arrived: Kelly was to be admitted into St-Louis the following morning.

Jan: The day rushed by so quickly. I was very apprehensive now that the moment was upon us. I wanted to keep Kelly up all night; I didn't want tomorrow to come. Part of me wanted the transplant to be over, another part wanted it never to come. The fears would have paralysed me if I had let them. It was obvious that Kelly was scared too. She didn't go to sleep until well after ten. Richard and I lay in bed talking for a long time. 'Thank God I've got you!' I said. Richard gave me a kiss. Thank God we've got each other,' he replied. That was it, the heart of it all. I finally went to sleep knowing that we had each other, and that together we were going to fight to keep Kelly alive and get our little family back together again.

❖

The next morning, the chauffeur promised by Monsieur Loiselet arrived 40 minutes early, and in a hurry. Chaos reigned. Although the account for the accommodation for Les Citadines was paid-up, there were extras to be paid. Jan and Richard found that the receptionist insisted that the amount be paid immediately, and not via fax from New Zealand. Once again the credit card was used; both the 'Turners were worried about having reached their monthly limit of $NZ1500 already.

The car was too small for all of them and their baggage, so Richard caught the by now familiar *métro* to St-Louis. Their new home was a tiny bedroom in the parents' wing of the hospital. Suddenly the apartment they had just left didn't seem so tiny. The process of admitting Kelly was long and complex, and once again Jan and Richard were grateful that Isabelle was there to act as translator. At the hospital cashier a bank draft was waiting for them, and they both breathed a sigh of relief.

For her first few days, Kelly had to share a room until a single one became available. The woman in the other bed was friendly, but spoke no English.

When I knew there was no hope of a conversation, I felt very frightened. Over the years, when Kelly was in hospital I had kept my sanity by talking to other parents and whoever else was around at the time. Now I didn't have that luxury. If Richard hadn't been there it would have been a total nightmare. I hate to think how I would have coped by myself. We all sat by Kelly's bed waiting on that first day. If it had been New Zealand, I would have known the routine. The admission nurse would have come in and done all the usual tests. Here, I didn't know what to expect.

'I don't want to be here,' Kelly said at one point, and started sobbing - I joined her. We all sat there hugging each other. We must have been a pitiful sight. Deep inside my fear was churning away. I was plain scared but I tried desperately not to let Kelly see that.

We had been waiting for about 15 or 20 minutes when two nurses came in to take some blood tests. Poor Kelly: I had never seen so much blood taken at one test before - about 20 tubes. They weighed her and did the usual tests, before bringing her lunch. It was a nice meal, with a lamb chop, macaroni, bread, cheese and chocolate mousse, but she wasn't interested, she was too upset. Later, the unit psychologist, Madame Alby - a friendly, middle-aged woman who spoke very good English - came to see us. She showed us a video on transplants that they had performed, and translated for us. I think that helped calm Kelly a little.

The transplant procedure itself was a simple one, and Kelly was used to needles anyway. Madame Alby had a nurse watch Kelly while she took Richard and me to one side for a talk. I broke down when we discussed Daniel being on the other side of the world. I admitted that I missed him so much, and was feeling contused, scared and lonely. I think it was good to have someone other than Richard to open up to. Madame Alby was very understanding and I felt better after our talk.

Richard then went back to see Kelly, and I went on to our new home to sort out our luggage. There was a code lock on the door to our area; it took me some time to get it to work. The parents' unit had obviously been an old ward, with utility rooms down one side and bedrooms down the other. As I entered, there was an Arab man by the door. He spoke no English, but led me to a noticeboard by the telephone half-way down the hall. There was a list of names and room numbers. He indicated that his name was Monsieur Kodifa. Our name was there too, and I pointed to it. We smiled at each other - he had *a* lovely smile - I just wished we could have conversed. We were all here with one thing in common, we had all experienced similar things - it was so frustrating not being able to talk.

Monsieur Kodifa showed me around the living area. There was a kitchen, a tiny lounge, two toilets, two showers, and a washing machine and drier. In our room there were two single beds with pillows and blankets, but no linen. Monsieur Kodifa didn't understand my questions regarding this. Bewildered, he disappeared for a moment and came back with another man who introduced himself as Cesar de Leon Lucero. He spoke English with a strong accent, not French (we found out later that he and his wife Irma came from Argentina). Cesar's English didn't include 'sheets'; however, he took me across to the *'l'hôpital'* and the unit linen room, where I gathered some sheets and pillowcases. There were no towels: a nurse told me that they didn't issue towels. I had to go and buy some; this was another unexpected expense, as at Les Citadines they had all been supplied.

After sorting out the luggage and making the beds, I returned to the hospital. Richard had managed to cheer Kelly up, and she had settled into her room. A nurse told us that Kelly's red-blood-cell count was down to 7, and she would be having a red-cell transfusion the next day. I was shocked at how quickly the count had dropped since we had been in Paris. The timing, once again had been quite uncanny.

It was tough leaving Kelly that night. She cried, and I felt terrible. We explained why we had to go, and gave her the telephone number for the parents' wing so that she could ring us if she needed to. On the way out, I told the nurse that Kelly was upset and asked her to keep an eye on her. As we left, Richard and I talked about how hard we were finding things, how we wanted to be able to rescue Kelly from all the painful times, and how it just wasn't possible. It was an awful situation for any parents to be in.

Richard: Once Kelly was settled into the unit, I realised quite suddenly that the transplant was damn close. Until now I had found it easy to be positive, but reality was setting in and, like Jan, I felt very real pangs of fear. I wasn't good around hospitals anyway. It's a male thing I think: you see a member of your family in pain and you want to make the pain stop, but you are helpless to do anything. Watching the nurses trying to find a vein on poor little Kelly's arms just about drove me over the edge: it is against any natural instinct to let it happen. I had to really fight myself to keep from lashing out, telling myself that everything was being done for Kelly's good, not to knowingly cause her pain. I'm not normally one to run from difficult situations, but I was always relieved when tests were done when Jan was with her and I was away doing the shopping or other things. To see your child suffering while not being able to prevent it is a nightmare.

I was glad when we moved into the parents' wing. For the first time in Paris, there was the company and support of other parents. I was to become good friends with Cesar.

Despite the fact that we were from different cultures, it was great to have another man around to talk to. Because of our situations - us with Kelly, and Cesar and Irma with their daughter Morena, both girls suffering from FA - we were bound together into a small, unique group.

I soon became aware of the roles that both parents played, roles that Jan and I had already assumed. The women looked after the medical and emotional needs of their children. We men seemed to have difficulty in these areas, so became the housekeepers and supporters to our wives, allowing them to focus entirely on the children. It was the same for all the parents, and now I wasn't alone in thinking that I was somehow 'different'. The roles just seemed natural.

❖ **That first night, Jan and Richard weren't up to cooking. They found a restaurant and had a quick meal. No sooner had they walked back into the parents' wing than the telephone went, it was Kelly needing reassurance, and 'checking out' the telephone. Richard went to her. Cesar de Leon Lucero introduced Jan and Richard to the other parents. As Cesar spoke Spanish, French and English, he became the translator for the little international group. Jan and Richard were to learn the stories of the others, and to realise how lucky they were in comparison. Cesar and Irma's daughter Morena was due for a transplant in a few days, the donor being her 12-year-old sister, Ximena. They also had two boys, neither affected by FA, but had lost a teenage son to it the previous year, following a long fight during which he received androgen treatment and many transfusions. When they heard of Professor Gluckman, they were determined to save Morena and had come to Paris. Another young couple, from Algeria, found out that their daughter had leukaemia when she was three months old. The mother was a half bone marrow match, but was still being used as a donor. The Turners were to hear many other tragic - and heart-warming - stories in the long months that lay ahead.**

CHAPTER 20

Needles, needles and more needles

THE PERIOD LEADING to the transplant itself was perhaps the hardest of all for Jan and Richard to cope with. The 'nasty stuff as Jan termed it, began on Kelly's first day.

Jan: Kelly was quite happy on the first morning, that was until we came back from Radiology to find a woman waiting to do a bone marrow aspiration. She was going to do it using a local anaesthetic. Kelly had always had it done under a general in New Zealand. I explained this, but was told that here it was done with local anaesthetics and took only moments. 'I don't want that, Mummy!' Kelly started to cry. 'It'll be over in a moment and it won't hurt very much, darling!' I gave her a hug and a kiss, but who was I kidding? I didn't even believe it myself. I knew the aspirations were extremely painful, but there was nothing I could do. When the nurse pushed the needle into Kelly's tail bone, the poor little thing screamed and sobbed. I felt like screaming along with her. The need to protect your child is so strong. I had to fight myself not to slap the woman away and cuddle my little girl and keep her safe. I bit my lip until it bled, trying not to curse the nurse.

Eventually it was over. The nurse put a plaster on Kelly, rolled her over, pricked her finger to smear some blood on some slides; then was gone. I've never seen anything like it: she had been quick all right, and had hardly spoken a word. I hugged Kelly, hoping that was it for the day. It wasn't. A nurse came in and told us that Kelly would have a red-cell transfusion after lunch. 'I'm going to make sure lunch takes a long time!' Kelly announced to the nurse. We did drag it out, but eventually we just ran out of time. Two nurses came in armed with all the equipment. Once again they had trouble finding a vein, and every time they moved the needle, searching for one, Kelly yelled and cried. I didn't know where to look. I could see Richard was trying hard not to cry. It took ten minutes for them to find a vein. We gave a big sigh of relief and comforted Kelly, and the transfusion began to run slowly. This was her first transfusion of red cells since she was 15 months old. It took nearly three hours; Kelly had to lie there, motionless, all that time. When Richard went outside for a break, Kelly and I had a good talk.

'I hate the needles, Mummy. They hurt, and the nurses are not nice!' She was so angry at them, and I knew that this was only the beginning. Kelly had to learn to trust them.

Reasoning with a child so young can be difficult at the best of times. Under stress it can be a nightmare, but I tried.

'You know the nurses don't like having to do these painful things to you, Kelly,' I began. They don't like hurting little children, but they know that these things have to be done to save your life. Dad and I don't like seeing this happen to you either, because we love you very much. But we know there's no choice if we want to save your life. Do you understand what I'm saying to you, sweetie?' Kelly nodded. She had always been a brave little soul, and she was digging deep. 'One day this will all be over, and we'll be back in Taupo with Daniel and can put this all behind us.' It was easy to say because I liked the sound of it myself. In fact, by saying those words to her, I was also helping myself: I needed some reassurance too. I desperately needed to keep reminding myself that one day this would all be over and there would be a happy ending.

After our talk, Kelly perked up a bit and even started making jokes about things. She now had a new room-mate, but unfortunately that was making things worse. He was a little boy named Mokhtar who came from Algeria. Mokhtar was about 18 months old, and cried almost continually. It was pitiful and made things so difficult, but there was nothing that could be done: he was just too young to understand what was going on.

❖ Now that Kelly was faced with bed confinement, Jan and Richard knew that they would have to find her as many distractions as possible. Sylvette Silverston also realised that, having been through the experience with her son Benjamin. She arrived with a solitaire board game, a colouring book and pens. She also brought mail from New Zealand: a parcel from Therese with wonderful gifts, including a jar of Vegemite. It was just like Christmas, Jan joked.

Therese: The parcels I sent to Paris were my way of trying to cheer everyone up, to brighten their far-away days. Whenever I felt guilty because it was Jan and not me going through it all, or just got depressed thinking about it all, I would do what I always do when I'm feeling down: go shopping.

I used to have a box that I would add things to whenever I went shopping. Into it I would put all the family favourites, all those things that would remind them of home - but didn't weigh too much because postage was expensive, generally about $50 a package. I sent little things like potato crisps, packet soups, Vegemite, and salt-free peanut butter. There were hair rinses for Jan, exercise books for her daily diary, chocolate bars, all manner of things. Often I would take off the outer packaging to cut down the bulk and weight. Other things I loved to send to Kelly were little trendy hats, scarves, cute pyjamas, knicker sets, books and toys. We taped her cartoon favourites; Daniel knew them all.

It was great taking Daniel shopping with me so that he could help choose things that Kelly would like. We weren't wealthy by any means. I had the usual stack of credit cards, and used them to the best of my ability. I used to think Too bad about the money', it was one year out of our lives and all I wanted to do was help them through it the best way I could, and make Daniel's stay as happy as possible.

When the money from the trust came through for Daniel's keep, I used it to send parcels to Paris. I felt a little guilty, but we received very little and when it stopped I just let it be. I felt happier not taking the money. Daniel was being well provided for in any case. It was the very least I could do.

❖ During that first stage of Kelly's confinement there was one little bonus: she was allowed out of the hospital for the weekend. Unfortunately, they had to go through the entire discharge Procedure and would have to go through admittance again when she returned on Sunday, but it didn't matter.

Kelly met the other parents in the family area, and Cesar and Irma's donor daughter Ximena. Despite their language problems, the two girls settled down with toys and played. Kelly slept on a fold-up bed in Jan and Richard's room. It was cramped, but none of them cared.

On the Saturday night, Alain Silverston arrived to take the Turners to a feast organised by the French FA Association and a post-transplant organisation, EGMOS 3. When introduced to the other families, Alain invited them along as well. Cesar de Leon Lucero and the Algerian couple, Karimou and Nassera, joined in.

Jan: It was fun as we all walked along the avenue together, a little league of nations. We chatted as we made our way through the busy streets to the hospital where the feast was being held. Kelly was skipping beside me holding my hand. It was so 'normal'.

At the feast there were about 175 people, including Professor Gluckman and some other staff from St-Louis. There was entertainment, and a lovely buffet. The noise level was high; most people spoke French, but it was good to meet them. Kelly was pleased to see Professor Gluckman and Isabelle, and spent a lot of time with them. It really was a night of fun. We played bingo - with the numbers called in French, of course. Looking around at all the people, I knew that many of them were only there because Professor Gluckman had saved their lives. We were very late to bed that night, but it was worth it. We had thoroughly enjoyed ourselves.

The next day we slept late, ate fresh French bread for lunch, then went walking by a canal, feeding the pigeons and watching the boats. It was so relaxing. There were couples strolling along arm-in-arm: this was the romantic Paris of the movies. As time went by, we began a slow walk back to the parents' quarters for Kelly's gear. As we walked to the hospital, she was crying but saying nothing. She wiped away her tears and sniffed, to force herself to stop crying before we went into the unit. She was a brave little soldier and it tore my heart out.

No sooner were we in Kelly's room than the nurses came to do another blood test. Once again they had trouble finding the vein: it took ten long minutes. One of the nurses told us that Kelly would be going to the theatre the next day to have a catheter placed directly in her chest, so that all her future IV treatments and blood tests could be done through that. That was a relief. 'Thank God! I thought; I didn't know how many more of these sessions I could go through, and I knew Richard was just about ready to blow up. Fortunately, this time he had been out buying dinner for us all when the nurses arrived.

We had now established another routine, one that would stay with us for the rest of our time in St-Louis. At 7.00pm I went back to the parents' area for dinner while Richard stayed with Kelly. When I returned, Richard went for his dinner and I settled Kelly for the night. The nights were always the hardest, with tears and sobs from her; the mornings were the complete opposite. I guess it's just life that you've got to go through the nights to get to the mornings.

❖

The operation to insert Kelly's catheter took only 30 minutes. Jan knew from experience that she came out from under the influence of anaesthetics well. This time, she looked particularly bright. She told Jan, 'I'm glad I've been to theatre because now I don't have to worry about going any more.' Jan and Richard endorsed that sentiment whole-heartedly.

Tréfle 3 had its own schoolteacher, Jacqueline, whom Jan described as 'lovely'. Kelly had also decided so, and she and Jacqueline soon became friends. Jacqueline gave Kelly an exercise book and it was arranged that she would call on Kelly every weekday, to give her French lessons. Kelly was keen to do this with her. When she

noticed that Kelly didn't have a television, Jacqueline loaned her one. This was just another of the little personal gestures that helped make life for Kelly - and in turn for Jan and Richard - that much more bearable. With the television installed, Richard connected the Nintendo. The game was going to prove an invaluable distraction in the weeks ahead.

Routines established, the waiting began again. No one was looking forward to the first real step in the procedure. This would be the chemotherapy required to kill off Kelly's infected bone marrow.

Jan: We thought we were finished with needles now that Kelly had her catheter in: wrong again! One day Kelly had to have a barium meal, and while she didn't like the stuff, she put up with it. It was only when I saw a nurse with a syringe that I realised there was more. They were going to do a dye test, and the catheter was no use. No one had mentioned this. I had gained Kelly's trust by telling her 'No more needles'. I was so angry. Kelly sat there with both arms folded across her chest while the woman asked me which arm she should use. Eventually, I managed to coax Kelly into releasing one of her arms and the nurse started trying to find a vein. It was the same as before: every time she moved the needle, Kelly started screaming. Fortunately, the nurse realised that there was a problem and called a technician over. He decided to use a vein in her hand instead. It was very quick and soon over, but I was really angry. Afterwards, I told the staff in Tréfle 3 of Kelly's ordeal, and they said they would ensure that we were informed before any tests like that were done again. Trust is such a delicate thing; I couldn't have stood it if Kelly had lost her trust in Richard and me.

Talking of trust, we were lucky to have some very wonderful people in the unit; and some of them spoke English, which was marvellous. There was Dr Richard, a research doctor who was studying DNA; he was French, and married to an Australian woman who was a film producer. His English was good, and he was a nice man. There was an English doctor, Annabel, and Dr Thomas, a Hungarian: both were in Tréfle 3 to learn about transplants. Dr Thomas was assigned as Kelly's resident, following her case with daily examinations, and talking to us. I could tell he was extremely dedicated to his patients; his examinations were very thorough and his manner easy. His English was good enough to explain most things to us. He was having trouble with French but knew more than us. Also like us, he was a foreigner in Paris, experiencing the same basic problems as we did - all of us strangers in a strange land with Kelly as our common link. Richard and Dr Thomas, in particular, became good friends. It was good for Richard to have another man around whom he felt comfortable talking to. I think they each learned a lot from the other through their very different backgrounds.

❖

It was another irony that, just as Jan and Richard had everything sorted out as to how they could best support Kelly, the announcement was made that the parents' wing at the hospital was going to be closed down in three weeks for redecorating. This was a real blow for them: they were living there rent-free which enabled them to spin out their tight budget. The plan had been to move to an apartment just before Kelly's release from hospital; now they were going to have to get one much earlier.

Saving money where we could was absolutely essential because we just didn't know how long we would be in Paris. One godsend was that Professor Gluckman let us send our fortnightly media releases on her fax machine: the cost at the post office was approximately $NZ75 for two pages! The money problems were also the result of people at home not understanding the French systems, and because of bad communication between us and them. Despite the fact that we had asked that no more bank drafts be sent, another arrived. Richard went to cash it, but they wouldn't because it had *Mr and Mrs Turner* on it: they wanted to see the 'Mrs'. This was not one of my better days. I just wanted to go somewhere and scream.

Of course, there was nowhere to go. We just cashed the draft the next day, the day before Kelly was due to start her chemotherapy. I had great difficulty waking up that morning; stress was making me very tired. When Richard and I were due to leave for the bank, Kelly broke down. She didn't want us to go. She started talking about the chemotherapy that was about to start; she needed to talk about it. I realised once again, as she talked, how easily a child's viewpoint can be shaped. The 'No to drugs' message that had been run on television and posters and in schools at home had really got through to Kelly. She didn't want any drugs. I explained to her the difference between 'good' drugs and 'bad' drugs, and vowed not to use the word 'drugs' again if I could avoid it.

❖

That night Kelly was hooked up to an IV antibody solution called gamma globulin. This was to give her system some added immunity while the chemotherapy was destroying her bone marrow. It had begun.

CHAPTER 21

The chemical countdown begins

THE MORNING AFTER the introduction of the antibody solution, Kelly's chemotherapy began. The chemotherapy drip contained large amounts of glucose fluids to help reduce the toxicity of the drugs on her major organs. This resulted in her continually passing urine, which was measured in large jars. In the first 24 hours, she passed 2L of fluid. To prevent vomiting, Dr Thomas had administered an anti-emetic medication, which fortunately worked.

Jan: Poor Kelly. While she wasn't nauseous or vomiting, she was constantly having to go to the toilet. She no sooner got there (after the hassle of having to manoeuvre her drip line), sat on the toilet, washed her hands and made it back to bed, than she would have to go again. Madame Alby did a psychological profile on Kelly in those first days, and we were very relieved to hear her assessment. Kelly had told Madame Alby that she 'got mad sometimes'. Madame told her that she had every right to do so. She also said that Kelly had a lot of trust and good roots, and that she thought this would help her get through the treatment. She told us to call her anytime if things got rough. When we saw Kelly after this, she was really perky. She had obviously enjoyed her time with Madame Alby.

The thing that really scared me at this time was the thought of the radiation treatment that Kelly was going to have. The chemotherapy was bad enough. The reality hit me when I accompanied her to the Institut Gustave Roussy in Villejuif so that she could be measured for chest plates. These were necessary to protect her heart and lungs. She had to lie perfectly still while measurements were taken and lines were drawn on her body. These would remain until after the radiation treatment.

We started wearing masks on the Saturday as Kelly's immune system was becoming very diminished from the chemotherapy. There was still no sign of nausea, thankfully. Because the masks were uncomfortable to wear for any length of time, Richard and I had regular breaks from Kelly's room. By this stage, she was used to being in hospital and knew that we would always come back. She didn't get as upset at night when we left her, which helped relieve some of the pressure. By Sunday, she was still handling the chemotherapy well, and I remember thinking at the time how wonderful it would be if the whole transplant went as smoothly.

❖ **Kelly's chemotherapy finished on the Monday, and she was to be taken to the Institut Gustave Roussy on the Tuesday morning for the radiation treatment. She would be going into a sterile room as she would have no immune system whatsoever. Jan and Richard were informed that the transplant date had been shifted from Thursday the 13th to Friday the 14th. On the Monday night, Mokhtar was moved from their shared room so that Kelly could have a quiet night to sleep for what was to come.**

Richard and I would not be able to go with Kelly for her radiation treatment. Instead, we stayed behind and prepared all her personal items for sterilisation in the tent - and there were a lot of them! That night we stayed at the hospital until 10.00pm. Later, we talked to

Cesar and Irma about our fears of Kelly having the radiation. They knew exactly what we were going through: their daughter Morena had had it the week before. It was a very restless night.

The next morning, we went to the hospital at 7.00am. Kelly was given a sedative so that she would remain still during the treatment. We put a sterile gown, hat and mask on her, and went with her down to the ambulance. She was really sleepy, which probably made it easier for her, but it was horrible for us. I had trouble holding my tears back as they put her inside. Jean-Pierre, a male nurse, and Dr Thomas went with her. The ambulance drove off with its lights flashing; there were two motorcycle policemen escorting it, their sirens going as well. The drama just overwhelmed me: I fell into Richard's arms and cried.

It was a very solemn pair of parents who went back up to the ward where the nurses were already preparing Kelly's sterile room. Soon, thankfully, we were busy. Everything had to be placed on the bed inside the tent in such a way that the formalin gas could sterilise it. When we had everything set up, they put the gas machine in the room, sealed the door completely and turned the machine on. Through the window we could see the room filling up with gas. Nothing would survive in there, I was convinced of that. They told us that Kelly wouldn't be back before 10.30, so Richard and I gathered up her surplus things and went back to our temporary home feeling very, very apprehensive.

When we arrived back at the parents' wing, Cesar was waiting to pamper us. He knew exactly how we were feeling. He made us his special café, and his wonderful humour soon had us laughing. Despite everything, he was just the tonic we needed at that moment.

When we returned to the hospital, we arrived just moments after Kelly. Jean-Pierre told us everything had gone well and she was fine. We watched as he prepared to enter the tent. This was something that we were going to have to get used to. He put on a mask, hat, gown, boots and gloves before he touched anything inside the tent. It was scary, but total sterility was going to be a fact of life from now on. We could see Kelly lying on her bed, she was sleepy but happy. Jean-Pierre arranged her drip line, which was connected to IV machines sitting on a shelf outside the tent. This was so that the nursing staff could change the fluids or add drugs to the line without having to enter the tent. Kelly's toilet chair sat beside her bed, just inside the plastic curtain so that the pan could be slid out from outside the tent. A sterilising machine was in the outer room. This was where we were going to spend a lot of our time in the future.

Apart from frosted plastic where the toilet chair was, the walls of the tent were completely clear. Dr Thomas had explained that the fewer people going into the tent the better, in order to reduce Kelly's exposure to microbes. We had been warned to expect her to have some fevers; this was considered normal. Kelly soon went to sleep, and we just waited.

Professor Gluckman and her team called in at 4.30pm, and reported that Kelly had come through both the chemotherapy and the radiation well. She also told us that her donor was to be a man. We asked her to express our deep gratitude to him. Shortly after the professor left, Kelly awoke, and we saw more of how life in the tent went. A nurse, Valérie, gowned-up and went in to take Kelly's temperature. She helped Kelly to the toilet. When she came out, she showed us how to collect the pan, measure out the urine, sterilise the pan in the machine, wash it with a sterile solution and replace it in the toilet. Later, Kelly asked for something to eat. Valérie got her some biscuits that had been pre-packaged into meal-sized amounts. She also took a bottle of mineral water, pouring alcohol on the outside to sterilise that. She masked up, carefully put her hands into the tent, and unwrapped the biscuits so Kelly could take them out of the wrapping without coming into contact with the outside of the pack. Looking on, this was such a whole new and totally alien way of living, it was really intense. I felt helpless at not being able to see to Kelly myself as I had up until now. Watching Kelly try to pour herself a drink from the huge bottle of mineral water, I just wanted to run in and help. I was so frustrated. When her bedding started to fall off, I had to instruct her how to straighten it up. If anything touched the floor, it had to be taken out of the tent for re-sterilisation. I realised then that all those 'silly' little things had now assumed totally horrendous proportions. We had to live with the fact that Kelly now had no immune system: any little mistakes could be fatal. That was the terrible reality. Sitting there outside the tent watching, I shivered -and it wasn't just from the cold air that blew down from the ceiling vents.

That night, back at the parents' wing, I spoke to a French lady who had a three-year-old at the unit. Her English was very good, and it was a relief to be able to tell another parent of my frustration at not being able to look after Kelly in the tent. My new-found confidant turned everything around for me. She put her hand on my arm, all the time shaking her head. 'No, no, no. That is not right. It is so important that the parents go into the tent with their child. It is so much better for your baby to have you instead of a lot of different nurses. You must insist that you look after her. It is a far less risk of infection. You don't have contact with other patients, but the nurses do. You must insist!' She waved at me and was gone back to the unit, leaving me to think over what she had said. I realised the truth in her words: I would represent a far lesser risk to Kelly if I did most of her care.

I didn't have to insist at all, as it turned out. I talked to Valérie, and she agreed that it was good if I would help. She showed me how to gown-up. Everything had to be done in a certain order. The gowns were kept hanging up just inside the plastic curtain, and the boots were draped over the underside of the bed. I was quite apprehensive that first time. I put a mask and hat on before entering the tent. Next, I opened up the sterile gloves onto the bed, discarding the packet outside the tent. I carefully bent down and slipped my feet into the boots. At all times I had to make sure that my unsterile body didn't touch anything. Then I unhooked the gown, holding only the string ties, carefully eased my body into it and tied the strings. Lastly I manoeuvred my hands into the gloves. Richard filmed the whole process; it seemed to take forever and I was petrified. But, from that moment on, I was in and out of Kelly's tent all day long, every day. I took her temperature and blood pressure, washed her at the basin, played with her and did whatever else I could do. I was looking after my daughter again. The nurses were grateful, too: they had plenty of other patients to look after. They now only had to go in when we weren't there or to handle Kelly's catheter or drip-line changes.

There were so many little things that we normally take for granted. For instance, Kelly wasn't allowed to use a toothbrush because the bristles could break her gums and cause bleeding and infection. Instead, she had to use a mouthwash. She hated it, but I had to stress to her that it was necessary so that she would use it when we weren't there. We soon learned all the little tricks. Because linen was changed every day, we laid sterile sheets around Kelly's bed, so that she could walk around in her slippers and, if anything fell, it didn't need to be re-sterilised. Every day the schoolteacher would visit. She sat outside the tent and worked with Kelly. Madame Alby came by daily, as did Isabelle and Dr Thomas. We had established a routine and things were going smoothly, but Friday was approaching rapidly.

❖ **On the Thursday before the transplant, Kelly was started on a drug called antithymocyte globulin (ATG). This was to prevent rejection when the bone marrow was administered, and Jan and Richard were warned that it could cause fevers. Kelly was to have the drug on alternate days. It produced fever and chills, and she became severely fatigued as the effects of the diminished bone marrow began to be felt. Soon she couldn't lift her head to eat, and began wetting the bed.**

13 February: *Poor Kelly, the bed-wetting upsets her more than anything else. I explained that at this time it is perfectly normal. She accepted my explanation and could rest without fretting. Her temperature came down in the evening, and she has entered a kind of limbo. I am anxious, there is no going back now. Tomorrow, with the transplant, Kelly will live or die.*

CHAPTER 22

Life . . . the ultimate gift from an unknown man

APPROPRIATELY, PERHAPS, T-DAY was Friday, 14 February, 1992: St Valentine's Day.

Jan: When we came to see her in the morning, Kelly didn't seem as tired as she had the day before. I was thankful that she was only going to have the ATG drug on alternate days. We had no idea when she would receive the bone marrow, but we knew that it had been 'harvested' already at the town where the donor lived, and was on its way to Paris.

Once in the laboratory, all the red cells had to be extracted from the marrow, because the donor's blood and Kelly's were incompatible. All I could think of was an accident happening to the marrow before it was inside Kelly. The fact that this was Kelly's one and only chance for life was a cloud over everything. It *had* to work!

In the understatement of a lifetime, I said to Richard, 'This is going to be a long day.' We were told that the marrow would be ready at 4.00pm. Kelly was great, but understandably quite nervous. At the magic hour, the marrow arrived. It looked so innocuous, just like red food-colouring in water. Madame Alby and Dr Thomas arrived.

Valérie was Kelly's duty nurse, and she prepared the IV line and hooked the marrow up to Kelly's catheter. Kelly asked me to go into the tent with her. I had to wait until Valérie was finished. Madame Alby was wonderful, reassuring Kelly that she wouldn't feel anything. There was a real air of excitement in Tréfle 3. Even Dr Thomas was laughing as we all fluffed around - and he had seen the procedure many times before. I told him that this was a special moment, and he agreed. Richard was filming everything so our families could see it all.

As soon as Valérie had the bone marrow flowing, I gowned-up and went in with Kelly. I had to check her blood pressure and temperature regularly, in case she had a reaction. Fortunately everything went smoothly, and she relaxed when she realised that the procedure didn't hurt at all. We'd all talked about the transplant for so long, that until it actually happened Kelly, Richard and I didn't fully believe it was so simple. The complications were in the treatment before and after.

As I watched the marrow flowing into Kelly, I really was taken with the wonder of it all. I don't think the average person realises just how incredible a machine the human body really is. With all the reading I had done, I had a good insight by this time. I just marvelled at what was taking place. I could picture the stem cells finding their way to the bones, and settling in and beginning to work. They have an in-built homing instinct. Before a baby is born, it doesn't need its own immune system. The marrow stem cells simply float in its blood, and at birth they find their way to the bones, settle in and get to work. In a way, that was exactly what was happening to Kelly - she was being reborn.

Richard: This was such an exciting time, as Kelly's room was buzzing with people full of hope that this was going to be a successful transplant. I can still hear Dr Thomas's words when he pointed to the bag of bone marrow hanging on the IV stand: he said, It's incredible that this is life.' I felt very humble that someone we would never know or meet had given this marrow for Kelly to live.

❖ **From this point on, the greatest danger to Kelly - barring outside infection - was the on-set of any rejection from the donor cells. Despite the fact that the donor was an excellent match, the use of an unrelated donor meant that some GVHD (graft versus host disease) would occur, hopefully to a lesser, controllable degree. Until the new marrow began working, Kelly would remain in limbo with virtually no immune system. Signs that the marrow was grafting wouldn't appear for at least ten days. She was now put on an anti-rejection drug called cyclosporin A, to suppress any rejection activity from what remained of her own immune system.**

Now it was a matter of time, time that would hang very heavily on them all, and the road ahead wasn't going to be all plain sailing.

Initially Kelly was fine, if constantly tired. Her reaction to the ATG settled, and she didn't get a fever or chills again. Her frustration at being confined to her tent was a constant, and Jan and Richard worked hard to keep her spirits up and keep her occupied. Kelly's correspondence lessons from New Zealand hadn't arrived as arranged. Her Nintendo was a blessing, but even that caused frustration when she played games at an advanced level.

There were other problems as well: at weekends, relieving nurses seemingly not fully conversant with the sterilisation procedures caused several instances where Kelly was in potential danger, particularly from unsterilised food wrappers.

Jan: I was so conscious at the end of the first weekend that this was just the beginning of Kelly's stay in the tent. The temporary nurses were a worry, and Richard and I both had run-ins with them. The language barrier was never more frustrating. We made sure that we watched them closely. There were some close calls, silly things that so easily could have led to a crisis. I don't think some of them realised just how vulnerable children in Kelly's situation were to the risk of infection.

❖ **Now began a long period of watching and waiting for Jan and Richard. It was going to be far longer, and far more traumatic, than either of them had dreamed it would be.**

CHAPTER 23

Watching, waiting, waiting, watching . . .

THE FIRST FEW days after the transplant Kelly was tired, but there were no initial chills or fevers, and the verdict was that she was progressing well. She was being fed intravenously, and spent most of her time playing with her by now beloved Nintendo. On the Sunday, Jan prepared a chicken casserole for Kelly, which delighted her.

Jan: It was great to get some solid food into her. But even a simple task such as preparing a meal was quite complicated in our present situation. First I would cook the meal in the parents' wing, sometimes not an easy thing to do with the pressure on the very limited facilities. Once cooked, I would take it into Tréfle 3 in a foil dish with a cover. In the kitchen there it would be sterilised. The problem was the kitchen staff. Unlike the nurses, who were marvellous and very kind, the kitchen people were really officious and often quite difficult. If a meal wasn't in the kitchen by 5.30pm, they simply refused to sterilise it for you. They didn't like parents upsetting their routines. I, and many of the other mothers, had frequent run-ins with them.

Richard: Apart from the occasional hassles with the kitchen staff, the only real problems occurred at the weekends. Then, some of the silly mistakes that the relieving nurses made were very hard to take. Jan and I became paranoid, distrusting them, watching everything they did like hawks. We trusted the usual team: it was too difficult to trust the 'part-timers'.

Jan: On the Monday, Dr Thomas examined Kelly and said that she was in good health apart from diarrhoea. She was given pills for that. There was still no sign of her beautiful hair falling out yet. I secretly hoped that she would be one of the rare exceptions to this. We did have one scare that day. Kelly was quite perky and bright, but she was also bored. Lucille found that she had taken the protective covers off her catheter lines and turned off the drip. It gave us all a hell of a fright. She had her first platelet transfusion that night because her count was down to 10. I had no idea that, from now on, I would be monitoring her blood counts like a Lotto player waiting for the lucky numbers. We knew it was going to be many days before the transplanted cells took, if they did, and Kelly started producing her own white cells. Until then we could only wait.

❖

On the Tuesday morning, the 'nasty stuff' started. Kelly's temperature soared to 39° C. Her mouth and throat were sore; the diagnosis was Candida or mucositis. Mouth washes were prescribed, and swabs taken for analysis. The fevers were to stay with her for the next few weeks as her body was ravaged by the after-effects of the chemotherapy and radiation. Kelly's system was a battleground where the many drugs she was on and the life-threatening micro-organisms fought each other for her very survival.

It was on the Thursday that I saw the first strands of hair on Kelly's pillow. She had had a terrible night and wasn't at all happy. She had noticed the hair herself. I tried to hide my feelings, as I didn't want to scare her. I explained that hair loss was normal with chemotherapy and it would grow back better than before. It was at this time that the arrival of Godfrey Payne from the New Zealand Embassy provided a very welcome distraction. It was lovely to finally meet him in person, and - what a treat - he bought with him the latest New Zealand newspapers and some Vegemite.

After Godfrey had gone I received a shock: I was handed the tiniest pair of scissors in a sterile pack and told to cut off all of Kelly's hair. I was horrified, and so glad I was wearing a mask so that Kelly couldn't see my face. She joked about it as I cut, or rather hacked, her beautiful hair off. It was one of the hardest things I have ever had to do. It took so long; with the tiny scissors it was like slow torture. When I had finished, Kelly wanted a mirror. Poor thing, she tried to appear brave. She told me she looked 'like Daniel, but my ears slick out!' I replied that she looked cute, and I wasn't lying, she really did.

Later, I ended up having a good cry in Madame Alby's office, and when I arrived back in Kelly's room a nurse had shaved her head with an electric razor. We found a scarf and covered her poor naked scalp with a turban. She'd been so brave.

❖ **Kelly was now on a drug regimen that included anti-fungal drugs and antibiotics, as the medical staff attempted to cover all the infection possibilities. The anti-fungal drug had side-effects that included chills, vomiting, and possible kidney damage. Close monitoring procedures were required. Kelly was back on IV nourishment. On Friday, day seven post-transplant, her temperature climbed to 41.8° C. The IV was used to introduce paracetamol to control it.**

Poor kid. The nasty stuff was going full-on. Kelly's little body was literally a battlefield for all those drugs. Without them she would surely die, but let's face it: there was also a chance that they could kill her as well. The knife edge is so fine in these things, as we were continually finding out. It was here that the incredible skills of Professor Gluckman and the team working in Tréfle 3 came in, as they found and maintained that most delicate balance. Despite everything that was happening to Kelly, Richard and I had complete faith in the professor.

On the Saturday, I awoke exhausted and Kelly was very tired and upset at not having any hair. Her fevers were down a little. We had another visit from Godfrey Payne and his wife and daughter. A lovely family, and so very welcome. They brought magazines and some home baking, a wonderful surprise amongst all the difficult moments. I rang Therese that night with a progress report, and started sniffling when Daniel came on. I gave them Kelly's telephone number and they promised to ring in the morning.

23 *February:* *The call has been a great tonic for Kelly. Her face was beaming as she spoke to Daniel. She was quite bight afterwards, although very tired. She has developed a rash all over her body and the staff don't know what it is. Because it's Sunday, we won't have the answer until Dr Thomas comes back on duty in the morning.*

The following day, there was no clear answer to the rash. Dr Thomas could only offer several possible causes at this stage. It could be associated with the low platelet count, GVHD, or a reaction to the drugs Kelly was on. Her temperature was 39°C, and she was really miserable. The next day, her fevers were still with her and the rash had absolutely covered her. Poor Kelly, she was itching all over and had a dry cough. All I could do was hug her. Dr Thomas was as puzzled as I was. Then she began to cough up bits of blood; I was told this was 'normal'. God, normal just seemed to cover so many things associated with the treatment. I wanted to scream out, 'Can someone give me some answers. What is happening to my daughter?'

I calmed down when Professor Gluckman and a big team of medical people squeezed into Kelly's room. There was a very vigorous conversation in French. After they left, Drs Thomas and Annabel stayed behind, and explained that they thought the rash was serum sickness caused by the drug ATG. They would stop that and increase the dosages of other drugs to compensate. It was then that we received some absolutely fantastic news.

25 *February:* *Madame Alby came in and told as that the new marrow was working well, and Kelly's white count was up to 1.3. How wonderful! The white cell count was confirmed next day, when the reading was 2.0. Kelly's temperature had been down all night. Had we turned the corner?*

Richard and I really didn't dare believe it. I gave Kelly the news. I told her that her soldiers were building their army and she had 2000 white cells. I mentioned the soldiers because I had read her a story about Louis Pasteur, written for children, in which the white blood cells were likened to an army. It made it so much easier for a child to understand the workings of their immune system.

The staff in Tréfle 3 were absolutely delighted by the news. Dr Thomas was as excited as if Kelly had been his own child. And Kelly was hungry, that was a great sign. She wanted an egg, her first solid food after eight days on the IV. Richard and I went home at 9.30 that night, the earliest we had done so for days. We felt wonderful. What a relief alter the roller-coaster ride of the last few days.

Were we through the worst? I didn't dare say it out loud, but inside I was praying it was so,

❖ **The roller-coaster ride was far from over. Kelly's temperature continued to hover between 37° C and 38°C. The drug dosages were being continually juggled. Her moods began to swing more and more violently. She missed Daniel badly; she was frustrated, bored and full of drugs. Because the steroids had pushed her blood glucose levels into the danger zone, she was being administered insulin through her IV.**

Richard came down with a heavy cold, and was not allowed into the ward. The burden of caring for Kelly fell squarely on Jan's shoulders. The only piece of good news was that Kelly's white count continued to hover at 1.8.

It came as a surprise to Jan when Dr Thomas announced that they were happy with Kelly's progress and that if it continued, they would look at releasing Kelly at some stage soon.

I was more than surprised at Dr Thomas' announcement - I was shocked (yet again). I had always thought that this would be a long way off. However, Dr Thomas did say that he would want Kelly to remain close to St-Louis, and was pleased that we had allowed for a six-month stay.

One other cheering thing that happened the same day was that Morena, Cesar and Irma's daughter, was discharged and they were to leave the parents' wing. We were going to miss them, miss our talks and Cesar's special *café.* They were both happy and scared about taking Morena out of the sterile environment into the 'real world'. Hygiene is so very critical, as it takes up to two years for the new immune system to be safely matured. The mortality rate during the first year is the highest. I thought then, the way it's all heading, in a few days or weeks it might be us leaving St-Louis with our baby. What a wonderful, scary, thought.

I remembered as I went to sleep that night that I hadn't got Kelly's white count today. Because it had been hovering around 1.8-2.0 for so long, I really didn't worry. If I had known what ft was, I doubt I would have slept at all. Ignorance can indeed be bliss.

CHAPTER 24

How nasty can it get?

ON THE MORNING of Tuesday, 3 March, Jan and Richard began to get an idea of just how nasty things could get. Kelly's white count the previous day had been only 0.6. This day, it was down to 0.3. Not only that, there were fears that Kelly's liver had become enlarged, and a liver scan was scheduled for the following day, along with another bone aspiration to see what was going on in her marrow. The fevers hadn't abated.

Jan: I didn't tell Kelly she would have to have another of the dreaded needles on the Wednesday. I knew that if I told her, she would have another bad night. As it was, I did plenty of worrying for us both. The bone aspiration actually wasn't as bad as the others had been. The technician was very quick, and Kelly handled it much better than she had the others.

Shortly after the test was done, we received a call to Professor Gluckman's office. Both our hearts skipped a few beats. Richard and I entered her office praying that it wasn't bad news. Far from it: the professor was quite happy with Kelly's progress. She told us that, because the white count was dropping, she wanted to start Kelly on a white-cell-growth factor (GM-CSF). Apparently it had worked well with other patients, but because it was a trial drug she needed our consent to use it. The drug would tell us whether the marrow had rejected or not, so at least we would know. We agreed to use it: it's the not knowing that is the hardest thing of all to take. Kelly was to have a daily injection. As it turned out, her liver was enlarged but its function was fine.

❖ **Over the following days, the bone marrow tests showed that Kelly's marrow was working. However, the fevers persisted until three weeks after the transplant. Then Kelly began to have them at night but not during the day, which was another mystery. Kelly developed a cough, which slowly became more persistent. She had to collect the phlegm samples in a jar for analysis. Her white-cell count varied between 0.3 and 0.6 for another week.**

There was so much going on, but always I kept my eyes on those magic numbers. One thing I noticed about this stage was the fact that every face in Tréfle 3 told a story, ours included. There was a constant death cloud hanging over us, and none of us knew where the cloud was next going to stop. Over the months we were there, it was going to touch many of those we had come to know, and many more we didn't know.

Mokhtar, the little boy who cried all the time would die, as would another little boy, named Thomas, who was in the room next to Kelly. Fatima, the Kodifa's little daughter, would have one last chance at life, a bone marrow transplant from her father. The transplant would fail, and the poor parents would take her to a hospital closer to home for her to die. There were many other deaths as well, but amidst all of these there was a wonderful feeling of joy for every life that was saved. Life was never more precious than in this place. When there was a success to be celebrated, the members of staff would dance for joy, and I mean it. They would grab each other - and total strangers - and dance. God, I hoped they would be dancing for Kelly.

We kept the deaths from Kelly; she was oblivious to what was going on. One thing that was becoming harder and harder to do was keep Kelly's spirits up. Richard and I both had to keep smiling, when it was the last thing we wanted to do much of the time. Apart from feeling unwell and having no hair, Kelly was going stir-crazy. She had been a month in a tiny tent bedroom, unable to venture outside it. Imagine the effect on an adult who knew the reasons for everything that was going on. That would be bad enough, but when the patient is a child with no complete understanding of why, it is so much worse.

Richard: The days dragged as we stood by helplessly and watched Kelly lying there, waiting for the marrow to work. She had been so drained of energy, and Jan and I had a great deal of difficulty in accepting that what Kelly had been going through was normal. We got excited when the counts went up and dejected when they fell again, time after time after time.

❖Their time in the parent's wing had now come to an end, and Jan and Richard moved back to Les Citadines with the assistance of Godfrey Payne from the embassy. The long-awaited correspondence school lessons and equipment arrived, another vital distraction. Kelly threw herself into her school-work.

Jan: We joked about the fact that Kelly had never been so keen to do school-work before. We now had another small apartment in Les Citadines, on the fourth floor this time. When it came time for Kelly to come home, we would move to *a* two-bedroom one. Thank God for Alain's influence: the normal room rate was 590FF but, because of him we paid 383.50FF a night. We had to get a telephone line between St-Louis and the apartment, and that alone cost 500FF. Despite the fact that Kelly's hospital was 8340FF a day, nothing else was free - that was a fact of life in Paris.

❖Wednesday 11 March was a red-letter day for Kelly. In three days her white-cell count had soared from 0.8 to 6.5; her platelet count was up; and so was her red-cell count. The new marrow was working well. Dr Thomas announced that they would give her two more doses of GM-CSF and then stop, to see if the marrow would sustain the white-cell count. Already Kelly was receiving antibiotics orally in preparation for her release.

Jan and Richard had settled on a new routine now that they were commuting again. Richard set off in the morning to get to St-Louis early, while Jan would come in later with Kelly's lunch. At the end of the day they would travel home together on the *métro.*

On the Thursday, I arrived at Tréfle 3 with a great sense of expectation. Kelly was in a good mood, she thought she might be out of hospital in time for her birthday on the 22nd. It really did look as if she might. Richard wasn't with her when I arrived. He had gone down to the blood bank to donate platelets. He hated needles, but this was his one way ol helping others. Despite the fact you are only supposed to donate them twice a year, he managed three times in five months before they caught him out. Isabelle came in and announced that Kelly's white count was 18: it had tripled overnight. What incredible news! Kelly did need a red cell transfusion, but no platelets because she had 40 of her own. I was daring to think it was almost over.

Richard: My way of trying to help others was by donating my platelets to the blood bank. The whole process was an ordeal for me because of my very real fear of needles. The entire process took about two hours, with a needle stuck in each arm. I used smaller ones on horses back on the farm. However, it was a very small price to pay, and the only way I could even attempt to pay a tribute to all of those who had helped Kelly.

13 March: *Today was Friday 13th, bat it was a good-news day. Dr Thomas announced that if all goes well, Kelly can be released next week. He wants her to start eating properly because the IV is being stopped. Her white-cell count is 11. Kelly isn't very happy at that, she is worried that when she gets out of hospital her white-cell count will drop. Poor kid. I sometimes forget just how much awareness she has about what is happening to her. She decided to paint a picture of the day she leaves hospital. It is a beautiful picture, with green grass, lovely coloured flowers, a blue sky and a sun with a happy face on it.*

Jan: The next day, Saturday, was exactly one month since the transplant. Kelly was tired because she had been coughing all night. We decided that it was possibly because of her big dinner and the problem with her stomach position. Her white count was still drop-Ping, it was 6.0 that day.

Over the next few days, the coughing continued and Kelly's white-cell count slowly continued to drop. We were slightly distracted as it was her birthday on the following Sunday. Alain rang to say they had received parcels from New Zealand, along with lots of cards and letters. Kelly was so excited by the thought of her special day. I hoped the cough was nothing, and prayed that the white count would stabilise and climb again.

❖ **On Tuesday 17th, Kelly's cough was revealed to be more than just that. She had pneumonia. Her white-cell count was 3.4, and her oxygen level had plummeted so low that an oxygen mask was put into the tent in case it was needed.**

I felt so scared. My bubble had been burst yet again. Whenever I dared to think that Kelly was out of the woods, something came along to destroy it. Murphy's Law, some people would call it: what-ever can go wrong, will go wrong.

18 March: *Wednesday: when I arrived at the hospital, more than a little apprehensive, Kelly was oat of her tent having a lung scan. This is the first time she has been out since February 11th. She was transported wrapped in sterile sheets, masked and hatted. She came back really tired and slept the day away. Tomorrow she is having a CAT scan to check there is no abscess on her brain, apparently that is always a risk with lung infections. Kelly's white count is 3.3 today and she had another nose bleed. Once again I was told it was 'normal'. I'm beginning to hate that word.*

The next day, the CAT scan wasn't scheduled until 7.00pm. It would have been a long day had I not heard from Graeme in Taupo before I left the apartment to take Kelly her lunch. The trustees had just had a meeting. They had granted a weekly allowance towards Daniel's living expenses at Therese's, and some people had come forward offering to back the trust with more money if it were needed. Great news! On top of that, the trustees wanted us to buy a present for Kelly's birthday on their behalf.

When I got to the hospital, Kelly was still sleeping. She had had a rough night because her catheter had played up. Dr Thomas still didn't know what was causing the lung infection, but they were trying to find out. In the meantime, they were hitting Kelly with anti-fungal and antibiotic drugs to cover all the possibilities.

19 March: *At a few minutes to 7pm, Kelly was taken away and I sat not daring to even think what might be. I don't want to give power to the thoughts. 'I'hnt phrase from so long ago again. Stay positive, Jnn! When Dr Thomas came back from the CAT scan. I could tell by his beaming face that the result was clear. Mv spirits climbed up from my boots again - the old emotional roller-coaster is working again!*

The next day, Kelly's white count had fallen to 1.7 although her lungs were sounding better. It was so depressing watching the white count dropping again, however. I was introduced to a French family who were desperately searching for a donor for their little girl. That helped shake me out of my own depression. Whenever I thought we were hard done by, I always seemed to meet others so much more worse off than we were. This turned out to be a terrible day for some of the others in Tréfle 3. Mr Kodifa was very upset, trying to tell us something about Fatima. Damn the language barriers! The poor man needed so badly to talk to someone. We found out later that the bone marrow transplant had failed. There was also great panic in Mokhtar's room in the late afternoon. The poor little soul had died, the first death of someone we had come to know in Tréfle 3.

Next day, I was speaking to Thomas's mother. She said that his transplant hadn't taken, despite it being a perfect match from his older brother. It's just so bizarre how some take and some don't. The high point of the day was the arrival of a big package for Kelly from EGMOS 3, the wonderful bone marrow transplant support group. Kelly was really excited about her birthday tomorrow. I went to sleep that night praying that it wouldn't be her last birthday.

I was half-asleep, in a semi-dream state, when something Kelly had said to me a day or two ago came back to me. She had been watching *Flipper,* her favourite programme on the French TV channels - mainly because when Flipper communicated, he sounded the same in any language. She looked at me and said, 'I want to play with the dolphins before I die.' Under my mask, my mouth fell open. I immediately jumped to the obvious conclusion, and stumbled for the right words. 'You're not going to die, you're going to get better, you are getting better!' Kelly shook her head. Not now, Mum,' she said, exasperated, 'I mean before I die when I'm old!' What a relief! For a moment I had thought she was talking about the present that was all *I* was living for. So this night, I saw the picture in my mind of Kelly playing with her dolphins. she couldn't die before she played with them!

CHAPTER 25

Happy birthday, Kelly

Sunday, 22 March. Kelly's ninth birthday had arrived. It was indeed a special day.

Jan: I never in my wildest dreams thought Kelly would be spending her birthday in a hospital in Paris. I remember thinking, 'God, I hope by her tenth we'll have seen the end of the struggles.' We went to the hospital early. Kelly was sitting up in her bed with a big grin on her face. We got all the sterilised presents from Isabella's office, took them into Kelly's room and blindfolded her while we wrapped everything in sterile linen. Everyone knows it's not really a birthday if you can't unwrap your presents. What a great day! Richard filmed Kelly unwrapping everything. I got extremely emotional, especially when Kelly read out her cards and letters.

This was the first birthday that Daniel hadn't been there, that hurt, but I couldn't let it show. We hung balloons with 'Happy Birthday' on them that Therese had sent over, and Kelly's little world definitely looked like a birthday in progress. Daniel rang at 11.00am to wish her a happy birthday, and there was a steady stream of visitors, all bearing gifts. Alain arrived with another parcel from New Zealand. There was a lot of chocolate amongst the gifts, and Kelly asked me to take some to Thomas next door. Poor little Thomas! Amidst all the joy and celebration, there was always a painful undercurrent in Tréfle 3. Some kids had birthdays, some died, some just sat in limbo, waiting. That was what was happening with Thomas. They were waiting for definite confirmation that his transplant had failed. Kelly's special day was made all the more special for me when I returned from the room next door. She was going to see her tenth birthday, and many more to come. She was going to swim with her dolphins! I threw myself back into party mode. Nothing was going to spoil this day - and it didn't.

The next morning, Kelly was very bright. The gift from EGMOS 3 was a big baby doll complete with potty, and she was enjoying it immensely playing 'mother'. Seeing her playing there, I couldn't help wonder if she would have children of her own one day. Looking back over the years, I was so aware that I had done that all the time. I would see some perfectly normal thing and apply it to Kelly. Would she" Could she? Will she? Always the questions.

Her white count was down to 0.5 this day, and I was horrified. Why did her count keep dropping? The good news was that the X-ray showed a slight decrease in the lung infection. They still didn't know what had caused it. When I went for a break, I saw Thomas' mother. She broke down, telling me the second transplant had definitely failed and there was nothing more that could be done for the poor wee boy. I hugged her, and held her while she cried. Then Thomas's grandmother came along, and she broke down too. We just sat holding hands. I felt so angry at the cruelty of the disease and the failed transplants, all that suffering for nothing.

I really had to pull myself together before I went back in with Kelly. She looked so bright and bubbly, and all around her was death.

Later in the day, we did have a lovely surprise. A big box of 20 video tapes arrived from New Zealand, sent from a radio station in Rotorua. The letter that accompanied it read:

Dear Kelly,
Gidday from Rotorua. We heard you didn't have much in the way of English-speaking videos to watch. So with the help of a local video shop, the people of Rotorua, and a courier company, we managed to get together a special video library just for you . . . hope you enjoy it. We are all thinking of you and hope you are keeping a smile on your face. Keep well, looking forward to having you home soon.

Another wonderfully generous gesture. Our friend Yvonne had approached a radio station after I had told her in a letter about Kelly's frustration with French TV. This was the result. The generosity of so many people was really touching, and what a lift to Kelly's spirits.

That night when we got back to the apartment, I rang Yvonne to thank her, and received the most terrible news. She told me she had been diagnosed as having stomach cancer and had a month to live. I went into shock, I didn't know what to say. I should have been there to give her a big hug. It was so cruelly ironic. Yvonne had worked so long and hard to help save Kelly's life, not knowing that she was losing her own. God, everywhere I looked at that moment there seemed to be death - death - death. Yvonne, Mokhtar Thomas, Fatima . . .

'It's so damned unfair!' I blubbed at Richard as we lay in bed that night. 'I know!' He was crying as well. He and Yvonne had become very good friends on that long fundraising trail. 'Why? Why? Why?' he asked, and I realised then that I wasn't the only one who had that bloody litany running in the back of my mind. We tried to sleep on wet pillows, but it was to be *a* terrible night with little sleep.

Richard: I didn't handle the news well when we learned that Yvonne was dying of cancer. I had worked closely with her through the fundraising. She was a very special person. There wasn't anything she wouldn't do for us. I just couldn't accept that someone so young and vital and caring had to be taken so soon. When she died, I was so terribly sad. She had been there to help save Kelly's life, and I was so far away and couldn't be there to help her.

24 March: *Kelly phoned at 3.00am and again at 7.00am. The nurses were having problems with her catheter. She was frightened she would have to go back to theatre again. What a hell of a day! They managed to unblock the catheter. I was completely worn out and my brain was just whirring with questions. So many questions - so few answers. I was thinking of the injustice of it all. Poor Yvonne, poor Thomas, just waiting to die.*

Kelly is having platelet transfusions again. Her marrow isn't working as it was a couple of weeks ago. I asked Dr Thomas for his honest opinion on what is happening to Kelly. He replied that either she has an infection they can't find, or her marrow is being rejected. The only way to find out is to see if the GM-CSF *works. It's so hard having to live through all of this again.*

I was feeling as it I was seeing everything through a tog. It was becoming more and more difficult to keep myself together in front of Kelly. Once again, I was grateful that I had a mask on. Richard was tremendous, more and more he was gowning-up and spending time with Kelly in the tent.

Richard: I hated the tent, and only gowned-up and went in as a last resort. I felt so big and clumsy in that tiny 2 x 3 metre space. I was scared of damaging things or carrying in bugs. It reminded me of a movie I had seen once about the *Boy in the bubble.* However, at times I had no choice but to go in. When I did, it was as if I were walking on eggs. I really was scared of screwing things up.

Jan: Madame Alby called me into her office. She told me that they had known what was happening to Kelly and had been concerned since Friday, but they wanted her to have her birthday and didn't want us to be miserable. They thought the bone marrow was being rejected. I began to cry. I felt as if everything was caving in. Our one chance was the GM-CSF. I left the office praying it would work. Somehow I went back into the tent, but at 5.00pm, I had nothing left, I had to get out, I had no strength left. I told Richard I had to go; I felt as if I were running out on them both.

All the way home on the *metro* I felt as if I was floating. There were people all around, but I wasn't there. I was totally spaced-out. The trip seemed to take forever. When I arrived at our stop, I became completely disorientated - I couldn't remember which exit to take. I walked around and around until I got my bearings, and at last reached the safety of the apartment. When I got inside, I just sat on the couch and cried and cried. Everything I had been holding inside just poured out. I cried for two hours, then I rang Louise and told her that Kelly's marrow may have rejected. I asked her not to tell our families yet. I couldn't bear to put them through that, not until it was definite.

Richard: When Madame Alby told us that they thought the bone marrow had been rejected, Jan broke down. I was terribly shaken, and I had to dig right to the bottom of my reserves then for her and for Kelly. I have never seen Jan in such a mess. I had to he strong for all of us. Hut that was the way Jan and I had managed to get through it all at this point: one being strong when the other lost it. By doing that, somehow we made it. I think the lesson for everyone is that you can't be strong all the time or you simply crack up completely.

Jan: The next morning, Dale Keegan telephoned. Louise had called her, knowing that Dale, more than anyone else, would understand what we were going through. Louise telephoned next, and then our doctor. They were all so concerned and so supportive. I did feel better because I had cried myself into a good night's sleep. It had been therapeutic, and the support from so far away was just what I needed. When I got to Tréfle 3, Richard gave me the good news: Kelly's white count was up to 1.0. Maybe my prayers had been answered.

❖ **Jan's prayers would not be answered for a long time to come. Kelly's white-cell count was back to 0.4 the next day, and for the next week it didn't climb beyond 0.5. Jan and Richard went to see Professor Gluckman, expecting the worst.**

They were amazed when the professor said she still had a lot of hope that the marrow would work.

'We must give the GM-CSF time to work. Last time it took a week. I am more concerned with the lung infection. We still do not know what is causing it,' Professor Gluckman said. Richard and I left her office feeling a lot better. There was still lots of hope for Kelly. Professor Gluckman had been through this so many times before. We had to trust her judgement, and we did, implicitly.

Two days later, it seemed as if one of our prayers had been answered. Kelly began coughing up a lot of phlegm. The duty doctor said it was her lungs clearing themselves. A week after the GM-CSF was started, however, her white count was only 0.5. Wait. wait, wait! My patience was being tested like never before in my life. Kelly had now been in her tent for six weeks.

CHAPTER 26

A month of lows and highs

1 APRIL - APRIL Fools' Day - and a crisis greeted Jan when she arrived at St-Louis.

Jan: When I arrived, Kelly was looking tired and upset. When I asked her what was wrong, she said Dr Thomas had growled at her because she had a headache but hadn't told anyone. It was so unlike the doctor to react this way, that I knew something was wrong. When I saw him, he looked worried. I soon found out why.

'When I examined Kelly, I found one of her pupils was sluggish, the same with one of her leg reflexes. I asked her how she was feeling, and she said she was "fine". She didn't tell me about the headache until later. Her platelet count is only 5. I think Kelly is on the verge of a brain haemorrhage. I have called for platelets, she must have a transfusion immediately.'

Brain haemorrhage! I couldn't believe it. This on top of everything else! Dr Thomas rushed off and I was left pacing the floor, feeling sick. Richard came in; he had been to the cashiers, trying to sort out yet another of the ongoing problems concerning bank drafts. He was angry that a draft we thought had gone missing had in fact gone directly to the cashiers, and they hadn't told us. I told him what was happening with Kelly, and all thoughts of money - or anything else - went out the window. We both paced, praying. After half an hour, the platelets still hadn't arrived. Dr Thomas returned; when he discovered the platelets hadn't arrived, he rushed to the telephone to hurry the laboratory up. Within minutes, someone came running in with the bag. We grabbed the nearest nurse and the platelets were attached to Kelly's line. When the bag was empty, Dr Thomas sent her for a brain scan while we waited, and wailed.

Thank God! It was a miracle, or as near to one as it could have been. There was no sign of haemorrhage or infection.

I sat with Kelly, and explained to her why Dr Thomas had growled at her, and I made her promise to tell someone if anything like that ever happened again. There was one bonus to the day; her white count was up to 1.1. So ended one of the worst days. Happy April Fool!

The next day, I received a letter from Yvonne's mother telling me how she was, and I cried as I read how she was on large doses of morphine and would not be able to write to us any more. It was a terrible way to start the day. When I got to the hospital, Dr Thomas had just finished examining Kelly, and was much happier with her condition. Her white count was 1.2. Wonderful news! But in the room next door, poor wee Thomas was in a coma, deteriorating fast.

As the day passed, I saw more and more of Thomas's family file into his room. It was so difficult to sit laughing and joking with Kelly, knowing what was happening next door. When I got home, I wrote to Yvonne. This was probably the most difficult letter I have ever had to write in my life.

When I arrived at St-Louis the next morning, I was told Thomas had died at 6.00am. I asked the nurses to tell Kelly that Thomas had been moved to a hospital closer to his home, if she asked about him. Shortly afterwards, an English lady who had been a frequent visitor to Thomas phoned. She said that Thomas's parents were very sorry they hadn't been able to see us before they left. They wished us all the best for Kelly. God, how humble I felt -they had lost their precious child and they still took the time to consider us. This sort of caring and compassion seems to be a unique thing that binds families with children suffering as ours were. Looking back, I know I am so much richer for having experienced that.

Dr Thomas told us he thought Kelly's lungs were 'almost right'. He was going to take her off some of the antibiotics, and schedule another lung scan. Kelly's white count was down again to 0.93, and the platelets were down to 128 from 205 the previous day. The platelets only have a life of a few days. The good news was that the chromosome tests they had run showed that half of Kelly s white cells were from her old marrow, and half from the new. I was confused. I thought the chemotherapy and radiation had killed off all of Kelly's old cells. Dr Thomas explained that wasn't the case. The therapy was designed only to kill off enough of the old cells to make room for the new. Total eradication of the bone mar-row often led to death. Once the new healthy cells took, they would then grow to force out the old. I couldn't wait for that to happen.

It was next morning, when I was on my way to St-Louis, that something took place which illustrated, yet again, just how wonderfully caring and very special the staff at St-Louis were. I ran into one of the nurses who worked in the nurses' pool and often looked after Kelly and Thomas. She asked after Thomas and I told her what had happened. She sat and cried, and I comforted her. She told me she didn't like nursing children with life-threatening conditions because she found it so difficult. I understood exactly, having been through it myself.

When I arrived in Tréfle 3 Kelly was asleep, but when she awoke she looked better than at any time for weeks. She had pink cheeks and was in a giggly mood. Was this a sign for the future?

❖ **Over the next few days, Kelly's physical condition continued to improve. Her white-cell count continued to climb slowly. The lung scan showed that the lung infection had decreased dramatically. The major problem emerging now was a mental one. Kelly was extremely depressed, and Jan and Richard had a very difficult time trying to raise her spirits. She was bored; she missed Daniel terribly; and, most of all, she was sick of life in her tiny, transparent cell.**

Madame Alby spent more and more time with Kelly, who told her that she had dreams of dying. She complained of aches and pains, and cried for long periods of time, smiling less and less often. Kelly was also having great difficulty sleeping at nights, and this resulted in Jan and Richard receiving calls at night, breaking their own valuable sleep. The irony was that Kelly would in turn sleep through much of the day when they were in the hospital.

The calls at night added to the stress on Richard and I, but the Poor kid needed to be able to speak to us at anytime. In an effort to get her spirits back up, Richard and I resorted to pure bribery, buying her little treats. One of the most successful of these was a musical yo-yo that lit up. Such a simple little thing. Madame Alby thought that most of Kelly's aches and pains and her depression was simply because she had been in the tent too long. It was now almost two-and-a-half months. A hell of a long time for anyone doubly so for a nine year old.

To try and help alleviate the situation, we managed to exchange the half-frosted tent for a completely clear one. That helped, because it increased Kelly's visual world by almost 50 per cent. Her white count continued to rise and fall totally unpredictably as the GM-CSF struggled to do its work. So, the waiting game continued. I was very, very worried. I had never seen Kelly so depressed before.

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Kelly's extreme lethargy meant that now she wasn't interested in her correspondence or French lessons. She would only do something if Jan or Richard went into the tent and did it with her.

A physiotherapist began treatment to help clear the loose secretions from her lungs. Kelly's aches and pains continued, and she suffered fluctuating temperatures. As always, the drugs were adjusted to compensate. On 16 April, Professor Gluckman called Jan and Richard to her office. She told them that because Kelly was so depressed, they thought she would be happier if she were released.

I was quite astonished when the professor said that. I told her I had thought Kelly's blood counts would have to be much higher before that happened. Professor Gluckman said not. Because Kelly's white count was low but stable, she could be released. I would have to administer the GM-CSF injections. The professor continued saying that if the blood counts were still stable on the Tuesday, five days away, they would 'top her up' with red cells and platelets and she could go home on Wednesday. She would need to return to St-Louis twice a week.

'Wednesday!' My mind went into a spin. 'I won't tell Kelly until it's definite.' I couldn't bear to think of the effect on her if it didn't happen. The professor shook her head. 'You must tell her now. She needs to be able to prepare herself. You can open two of her curtains.' Professor Gluckman smiled, probably at our expressions. We thanked her and went back to Kelly's room.

When we told Kelly the news she didn't get excited. In fact, she didn't seem to believe us not until Richard gowned up and opened the two tent curtains. Poor Kelly, her eyes opened wide with fright. she knew that the only time the curtains were opened was when someone was to be released. Now she believed us and suddenly she was transformed, back came our old bright, smiling Kelly. She jumped out of bed and began walking around. One of the first things she did was go to the window and stand looking at the world outside that she hadn't seen for so long. The *métro* was on strike and it took Richard and me two-and-a-quarter hours to get home, and it was a couple of scared but happy parents who finally crawled into bed.

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The following day, Dr Thomas gave Jan and Richard some vital 'good-bad' news. After many weeks, their tests had finally identified a virus in Kelly's urine. The virus was called cyto-megalovirus (CMV). They were sure that this was the cause of Kelly's white cell struggle. The good news was that CMV was treatable. Further good news was that it wouldn't affect Kelly's release: it simply meant that they would have to find a means of administering an IV at home.

I never saw a doctor so happy to find a virus. They felt they had the key. I was so glad that they'd found it before Kelly came home. Now, Richard and I needed to work out what had to be done to prepare a place for Kelly outside the sterile environment of Tréfle 3. It was scary.

There were no two-room apartments available in our present Les Citadines, but one was found for us at Bastille Les Citadines. It was the same distance from St-Louis, so the travelling was no problem. Once again, Godfrey helped us move our luggage in, and Richard arranged for the hotel cleaners to shampoo the carpets. It Was imperative that the apartment be made as clean as humanly Possible. I allowed myself the thought that, at long last, things were looking up.

The bigger apartment was much nicer to live in than the others. Richard worked really hard at ensuring it was clean. He did every surface again and again. The place sparkled. We were now living in Chaligny, a very pleasant street near the Bastille. There were not so many shops, but there were restaurants everywhere - not that we could afford to use them. There was, however, a big market, which was open daily, a couple of blocks away. Richard had turned into a shrewd shopper.

20 April: *Kelly is excited about her 'great escape'. She has been preparing all her things, anxious to have them ready to go home with her. It's good to see her spirits back up again. Her white count is hovering between 1 and 2. I just hope it doesn't fall again.*

On the Tuesday, Madame Devergie, Professor Gluckman's assistant, saw Kelly in order to judge whether or not she could be released. The answer was yes! We were all totally delighted. Then there was a meeting with people from an organisation called Hôpitalisation à Domicile (HAD) to arrange for the administration of Kelly's IV in the apartment. Fortunately, once again, Isabelle was there to translate for us. The cost was 972FF per day, and this would include a nurse visiting twice a day, the cost of Kelly's drugs, and the ambulance to return her to St-Louis for her day visits and platelet transfusions. They asked me to write a letter for the trust in New Zealand so they could attach it to an advance account and fax it to New Zealand for payment. It was all fixed.

Kelly, however, was apprehensive. She wanted to hear the good news from the 'boss's mouth'. A few minutes after she announced this, Madame Devergie and her team filed into the room. Kelly was playing with some syringes and water. She said to them, 'If you don't let me out tomorrow I'll squirt you!' Everyone laughed, and Madame Devergie officially told her that they would 'kick her out tomorrow!' It was all wonderfully light-hearted and it was obvious that everyone was extremely happy that Kelly was well enough to leave. I guess a case like hers makes up for the ones that never get to go home. I don't think we realise just how the failed cases affect the doctors and nurses, and it must be so difficult because so much of what they do in Tréfle 3 is experimental.

For the rest of the day, we helped Kelly complete her packing as various staff members popped in to share her happiness. We were delighted to find that her white count was up to 3.8. Richard and I lugged, I lot of her things home on the *métro.* By the time we got the apartment sorted out, it was 12.30am. Tomorrow/today was going to be a big day for all of us!

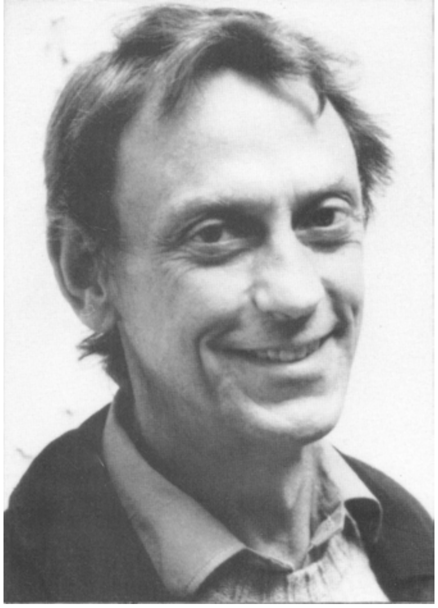
Jan and Kelly in the sterile tent, Tréfle 3, Paris, March 1992

The effects of high doses of steroids begin to show, July 1992.

SOME OF KELLY'S PARIS SUPPORTERS


Professor Eliane Gluckman, head of the transplant programme


Alain Silverston


Graeme Allright


nurse Evelyne from HAD

Kelly's dreams come true: playing with a dolphin at Napier Marineland, November 1995. *Courtesy Christine Pearson*

Back to 'normal': Kelly and her family, March 1996 *Courtesy Ross Herbert*

CHAPTER 27

Out of hospital at last

ON WEDNESDAY, 22 April 1992, Kelly left Hôpital St-Louis. She had spent 82 days there, 71 of them in the isolation tent. Jan and Richard were ecstatic - and apprehensive. Now Kelly's care was very much in their hands. The major fear was that of attempting to maintain a semi-sterile environment for her. Things that had become second nature in the hospital now took on a new significance. A tiny Parisian apartment was no sterile tent in Tréfle 3.

Richard: When I first saw Kelly on the morning of her release she was perkier than I had ever seen her. She was all set to go - now! After Jan had dressed her in a bright yellow tracksuit, she stood on the bed and I filmed her. All the staff were as excited as we were. After all the ups and downs, uncertainties and heartbreak of the past weeks, Kelly was finally coming out. This was a day that I had been living for. Jan and I had never given up hope during Kelly's time in the hospital, but things sometimes got on top of us both. Fortunately, we had each other. When one of us was down, the other managed to keep things on an even keel, often with a little or a lot of help from the friends we had made.

Then we arrived at the great day. I had spent hours getting the apartment spotless, steam-cleaning the carpet, scrubbing, wiping everything with strong disinfectant. 'Bugs': fearing them had become a way of life, and now Kelly was coming 'home'.

Jan: There was more good news when we went to get Kelly. The rate that had been quoted for Kelly's home treatment (972FF per day) was in fact for an adult. As a child, Kelly's rate was to be 478FF a day. That was wonderful news, as the funds in the trust account had really dwindled because of Kelly's long stay in hospital. Her first hospital appointment was scheduled for the following Monday. The home visits would start that evening. There was so much information to take in, my head was once again spinning.

Early in the afternoon Kelly got dressed in a tracksuit, and Dr Thomas came in to see her all dressed-up and ready to go. He was as happy as if Kelly were his own child, I could see real emotion in his eyes. I felt an unmeasurable amount of gratitude towards him. He'd had the difficulty of dealing with us every day, trying to answer our endless questions and, of course, examining a little girl who took all of her anger out on him. He somehow managed to handle all of that, and still emerged as such a wonderfully caring person and very professional doctor.

At 2.00pm, Kelly was given her gamma globulin IV, and when that was done she was allowed to leave the tent. This was the big moment. We put a mask on her - it just about covered her whole face - then we watched her take her first steps outside of isolation. She was very shaky as she tried to walk faster than her legs would carry her. She soon realised she had to slow down. As she walked out of her room, she was fascinated by all the things we had come to take for granted. She looked at everything. Of course she had seen it all before when she was admitted, but to a little girl that seemed like a century ago. She walked all around the unit with a big entourage of nurses, all sharing her excitement. Each time any of the other staff or parents saw her there was a great fuss. Most of them had never seen her out of her tent. The atmosphere was amazing.

One moment was very special. We had made friends with Joël, a 37-year-old who had had a marrow transplant. He had children Kelly and Daniel's age, and was anxious to speak to Kelly as we had talked so much about her. When we entered his room, Joël was sitting on his bed inside his tent. We introduced Kelly, and it was very emotional as Joël sat there with tears in his eyes speaking to Kelly in English. Here was a 37-year-old meeting a nine-year-old, each having received a marrow transplant, each hairless and swollen with the steroid treatment. It was a very touching moment. Joël's wife had given Kelly a toy hedgehog in a little basket, and Kelly was carrying it to show it to Joël.

Kelly continued her tour, and then there was panic. Dr Thomas rushed into the administration office where we were talking to the staff. He said Kelly had to go back to her room immediately. A donor child had arrived in the unit suffering from chickenpox. He had been isolated, but it wasn't safe for Kelly to leave her room until the child had gone. We got her back to the room and waited quietly for the ambulance to arrive. Finally, at 5.30, it turned up and we could go. Gilbert from EGMOS 3 came to help us with all of Kelly's luggage.

At 6.00pm we arrived at the apartment. I breathed a sigh of relief when Kelly was inside and the door was shut. She was able to take off her mask and walk around examining everything, before we unpacked in her new bedroom. We all enjoyed sitting down to our first meal out of the hospital environment. At 8.00pm, the nurse arrived. She spoke a little English and introduced herself as Elisabeth. There were many boxes of equipment that had been delivered to reception. We brought them to the apartment, and Elisabeth set up a drip stand and IV line and connected it to Kelly's catheter. It was strange seeing Kelly receiving these medical treatments out of the hospital. That night, we all went to bed exhausted. It had been an extremely hectic day.

Richard: I'll never forget the look on Kelly's face when she walked into the apartment, she was fascinated with not being 'caged in'. I was so glad that Jan was handling her drugs and daily care. It was great not having to rush over to the hospital every day, but it was still hard to adapt to another routine.

❖ Kelly's new routine soon established itself. The nurses called at 8.00 in the morning and again at 8.00 at night. Jan administered all of Kelly's oral medications. Richard went shopping for groceries, while Jan dressed Kelly and began the housework, which now had taken on an entirely new and different significance.

Jan: I felt paranoid about germs. Because Kelly had lived for so long in a sterile environment, I now felt personally responsible for protecting her from contracting any infections. Fortunately the apartment had a tiny dishwasher. Whenever I unloaded the clean items, I would wrap some in tin foil exclusively for Kelly's use.

Watching Kelly moving around the apartment, she was very sluggish and pale, and seemed quite spaced-out. It was no wonder really, with all the medication she was on and the complete change of routine. Her time in bed with no physical activity had wasted away a lot of muscle. Her legs looked so thin and delicate, and yet her face was swollen and she had a 'moon' look. I had so much looked forward to her release from hospital, but somehow it was different to what I had imagined. I had thought I would be bringing the old Kelly home, but that wasn't possible because of all the changes she had undergone in hospital. I suddenly found myself grieving for my old Kelly and all the wonderful naivety we had before. I felt torn inside, part of me knowing that the transplant had been necessary to save her life, and part of me wishing we had never put her through it. Although we had been told that all of Kelly's physical changes were only temporary, I was very impatient for things to be as they had been.

Therese: When I saw Kelly's birthday video I was shocked beyond belief. The steroid treatment had bloated her so much I didn't even recognise the poor little soul as Kelly. I felt sick every time the image flashed into my mind. What cruel drugs she was having to take. I thought how terrible it must be for Jan and Richard having to stand by and see this all taking place.

The news that Kelly was 'home' at last was wonderful for us all, Daniel in particular. Poor kid, he was having bouts of tonsillitis about once a month and was having trouble with a cap on his tooth. Despite his cheerful nature, I'm sure the stress of him being apart from the others affected him physically. It would have been so easy to minimise what was happening to Daniel when thinking about what Kelly was going through, so we all made a determined effort to avoid this. In fact I probably went overboard and babied him. I felt he needed more love and attention than ever. It's not fun being sick when you are a kid, and it's much worse when you are not with your mum and dad. I did for Daniel what I did for my own children when they were sick, and cooked anything they fancied and had lots of fruit and drinks. It gave me a good feeling when Daniel said, 'That's just what Mum does' or 'Mum cooks that just like you do.' I knew in my heart that he was in the best place. With all the trials and tribulations Jan and Richard were facing in Paris, he would have been so unhappy.

Daniel: When I first saw Kelly on the video I wasn't too shocked with her looking so different. Mum had told me that this would happen because of the drugs Kelly had to take. She also said that it wasn't forever. I always trusted what Mum told me, she never lied to me.

❖

It was going to be a long time before Jan got her wish that things would be as they had been before, with her old Kelly back. Despite the change of accommodation, the problems Kelly had faced in Tréfle 3 were far from over. Her temperature fluctuated wildly, her platelet count remained low, and she suffered constant headaches. The memory of how close she had come to a brain haemorrhage was never far from Jan and Richard.

On Kelly's first visit back to St-Louis, however, there was some heartening news. Her white-cell count was 5.8 although her platelet count was only 12. The CMV was now detected in her blood, whereas previously it had been detected only in her urine. Because the virus had manifested itself so extensively, it would be more difficult to control. Kelly would require the IV treatment a lot longer than had been originally expected. She would also need to remain on the GM-CSF treatment for the period she received the antiviral drug.

During the next visit to St-Louis, Jan and Richard were told that a new drug would be tried against the virus. Foscavir was a much stronger drug than the one she

was on, Cymevan, and was known to be toxic to major organs, necessitating its use with copious quantities of glucose solution. This process, known as hyperhydration, was designed to flush the drug through Kelly's system. It would be administered twice a day for two hours at a time.

The revised treatment regimen called for Kelly to return to St-Louis three times a week for platelets and every two weeks for red-cell transfusions. Her platelet count was often below 20 and at times below 10, and Jan declared herself a nervous wreck waiting for Kelly's transfusions.

As the weeks passed, both Jan and Richard wondered when Kelly's marrow would begin producing the platelets she so desperately needed. Her white-cell count, however, settled into a range between 5.0 and 9.0 owing to the continued use of GM-CSF treatment.

The waiting game had entered a new phase, but at least now Kelly could go walking, and Jan and Richard made a point of taking her out of the apartment every day. This brought with it a new set of problems. The sight of the little girl in the mask produced some unwelcome attention, and Jan and Richard worked hard at making Kelly's difficult situation bearable, scared that Kelly would refuse to go out for a walk. However, she developed her own defence against the constant stares. She found that she could pull faces at people under the mask, and they wouldn't know - a hint of the old Kelly was truly beginning to emerge.

CHAPTER 28

It drags on and on

EARLY IN MAY 1992, there was a scare. Kelly woke up with a rash all over her body, which Jan feared was GVHD. Kelly was taken to St-Louis by taxi, where Jan's fears were confirmed. Kelly would have to spend two days in hospital. She was devastated, as she had only been out for a few weeks. The treatment was a course of IV steroids, and the two days turned into four.

Far from being a negative, however, the emergence of the GVHD was positive confirmation that the new marrow was working. The drug regimen was adjusted to compensate, the life-saving GM-CSF was stopped, and Kelly returned home to the apartment.

Homesickness began to strike at both Jan and Richard now with an increasing intensity.

Jan: I was missing my home, especially my garden and trees. When-ever I was stressed, I would walk there. I was missing nature, it was so hard to find it amongst the concrete and high-rise buildings of Paris. I was really beginning to feel claustrophobic. I was missing Daniel something terrible, and we just seemed to be drifting from one day to the next, there didn't seem to be an end to it. I just wished I could go to sleep for a long, long time, and wake up when it was all over. Richard too was feeling it. I had many tearful, late-night discussions with him, always though he kept me propped up. These conversations were almost always the same. 'When's it going to end?' I would say through my tears. 'Soon. Soon it will all be over.' Richard tried to sound so positive.

'God, I hope so. I don't know how much more of this I can take.' 'We've come so far, Jan. It's almost over.' I wondered so often if he really believed that. Was it almost over? I would always go to sleep wondering just what else late had in store for us.

Richard: It was tough on us all. The little things assumed so much more significance. Like- Jan, I missed being out in the open air, in the country. My escapes were in the simple things. I looked forward to doing the grocery shopping each day, so I could get out of the apartment. At times the walls seemed to close in on me. While Jan was busy seeing to Kelly's medication or correspondence school lessons, I did the shopping, cleaning and washing, all the time longing for the wide open spaces and the New Zealand bush I enjoyed hunting and tramping in. Sometimes I went to see Cesar at his apartment and the two of us would go for a walk together, which was always refreshing, but it wasn't home.

I took Kelly for walks as often as I could, and I encouraged her to walk up the stairs to our apartment as I knew she needed the exercise to build up her muscles. We made a game of it: I would pretend to race her, or we would count the stairs as we went. I learned to tell when her haemoglobin count was low, as she would become breathless and wouldn't be able to make it up the five flights; then we would take the lift. The worst thing of all, though, was missing Daniel. Like Jan, I hurt terribly when I thought of him all that distance away from us. We were both missing his growing up.

Jan: Because I was so watchful over Kelly's treatment, I 'rocked the boat' a bit on occasions. One of the major things I was con-cerned about was trying to get Kelly larger transfusions of platelets, because they began to expect her to go three days between transfusions and the three units she received only lasted two days. The platelets had a five-day life, but they were already days old when they were transfused. My first priority was to Kelly, and while she didn't like it, I pushed and pushed for the increases. The fear of her having a major brain haemorrhage never left me. She began coughing again. This was a result of the hyperhydration treatment. A physiotherapist came to our apartment three times a week. His therapy encouraged Kelly to bring up the secretions, which helped her a lot.

We received a letter from Yvonne's sister to say she had died on 2 May. We didn't tell Kelly, she was going through enough as it was. The same day we received that letter, I got a Mother's Day card from Daniel. We were so faraway from home and New Zealand culture that it came as a shock, and brought me to tears. This was the first Mother's Day we had spent apart. When Kelly saw the card, she disappeared into her room and told me not to come in. Later she came out with a card she had made, and there was a gift that Richard had obviously gone out and bought me. It was an emotional time - how lucky I was to have such a loving, caring family. I thought of Yvonne's three children and my heart just went out to them. I knew that what I was going through would soon pass. For them, it was forever.

Kelly's glucose level became high again because of the large dose of steroids. The staff at St-Louis were confident that her diabetes was only temporary, but they agreed that she had to have daily insulin injections. A sliding scale was worked out so that each day Jan could administer the correct amount of insulin depending on the level of the glucose reading.

Kelly's liver function tests also registered as very high, four times the normal level. Jan was informed that this was 'normal' for tests conducted after a transplant.

There still seemed to be so many things going on with Kelly's system, and I was determined to stay on top of it all. I had been running on instinct with Kelly all her life, I wasn't about to stop now. One Friday towards the end of May, we had a dreadful experience. Kelly had just had a transfusion of platelets, and I asked Dr Bancillon (who now called at the apartment) when Kelly would get some more red cells as her count was under 8.0. The doctor told me 'Next week'.

The following day Richard took Kelly for a walk, and she was so weak she could hardly walk up the stairs. We put it down to the low red count. Richard went over to Tréfle 3 to see the duty doctor, and it was arranged that Kelly would go over later for a transfusion. She would have her Foscavir IV treatment in Tréfle 3 as well, that meant a long transfusion time. We arrived at 5.30 and it took until 12.30 for the IV to be completed. It was then we had a disaster!

The nurse was a weekend relief who didn't understand English. When working with the catheter, she pulled it upwards from Kelly's skin. Richard and I both yelled in horror, as we knew there were no stitches to hold it. We were too late, and about 5cm of catheter was pulled out. The nurse looked a bit panicked and covered the catheter with sterile gauze and went to find a doctor. The duty doctor was busy, and would perhaps he an hour getting to us. Three nurses then came in and discussed what to do. One of them spoke English; he said the doctor would need an X-ray to see if the catheter was still in the correct place. Later, when the doctor arrived, she commented on the catheter having 'played up'. 'Played up?' I snapped. ‘Played up, nothing! The nurse pulled the damn thing out.' The poor doctor bore the full brunt of my anger and frustration. She knew what had happened. Eventually I calmed down. Losing my cool wasn't going to do Kelly any good whatsoever.

It took an hour of discussion between the doctor and nurses to decide what to do. At 2.00am they decided to stitch the catheter in place and send Kelly down for an X-ray. Poor kid. She hated needles, and had to be given two local anaesthetic jabs before the stitches, all because of the nurse's carelessness. It was 4.45am before Kelly had the X-ray.

It was 6.00am before the doctor could check the X-rays and verify that the catheter was still in the correct place. At 7.00am we caught a taxi home and put Kelly to bed. It had been a long day, and it wasn't over.

At 8.00am, Elisabeth arrived to give Kelly her Foscavir treatment, and we noticed that there was a lot of blood seeping through Kelly's dressing from where the stitches had been inserted. She was also having pain now that the local had worn off. Two hours later, another nurse came to unhook the IV line. Kelly's dressing was soaked in blood. The nurse changed it for a clean one. The blood was very fresh, and it had been seven hours since the stitches had been inserted. The nurse told me that if a lot of blood came through the new dressing we might have to take Kelly back to Tréfle 3 for a platelet transfusion.

At 2.00pm I noticed the dressing was again soaked. I phoned Tréfle 3 and they said to bring Kelly straight over. When we arrived there all the staff seemed to know of our ordeal the night before, and were very kind. The cause of the bleeding was basically the fact that Kelly had received so many red cells that her platelet count of 36 had been unable to cope. The only solution was to transfuse more platelets. They gave her five units, and we arrived home at 5.45pm just in time for Elisabeth to give Kelly her Foscavir treatment. When we crawled into bed that night we were like zombies. The past 24 hours had not been amongst our best.

The next morning we found out that the tests they had run on Kelly the day before showed a white count of only 0.5. She had to be started on GM-CSF again. Would it never end?

Madame Alby asked me to go to her office on our next hospital visit. She had heard about the catheter incident. She asked me to sit. 'Mrs Turner, you must trust our people. Not having trust in them makes it so much more difficult for them to treat Kelly.'

'Madame Alby, Kelly is my daughter and no one has the same emotional attachment to her as I do, so whether it be in France or in New Zealand I don't trust anyone looking after her until they have earned that trust; I said. That was it, pure and simple. My instincts had been right so many times. There was no way I could lock them away in a cupboard - that's the way I am. Madame nodded. She understood what I was saying. I spent a few minutes talking to her about my homesickness. It was always good for me to talk frankly to her. Richard bore the burden most of the time. Madame Alby gave me the chance to off-load many of my fears. Like Richard with Cesar or Dr Thomas, sometimes it helps to have someone of the same sex to talk things through with. I will always be grateful for Madame Alby for offering me a broad, female shoulder to cry on.

❖ Things now settled down into what seemed to Jan and Richard to be an endless routine. They were now into June, and were very concerned that the trust funds were getting terribly low because of their long stay in Paris. Alain Silverston had been following their progress, and wanted to help raise money. He advised Jan and Richard to obtain a letter from Professor Gluckman stating why Kelly's stay had been so long and advising that if further complications arose she would have to be re-admitted to Hôpital St-Louis. Professor Gluckman obliged.

By 10 June, the Turners had been in Paris for five months, and still there was no end in sight for them. Kelly was still receiving frequent transfusions of platelets and red cells, and insulin injections. She was still on a sugar - and salt-free diet. On 29 June, the staff at the New Zealand Embassy assisted Jan and Richard to obtain visa extensions. There was no talk of them being able to go home yet.

CHAPTER 29

Is an end in sight?

ON 12 JUNE 1992, Jan and Richard received the news that the CMV was at last gone from Kelly's blood, and the Foscavir treatment could be ceased. This was wonderful news. At last it seemed that there was going to be an end to Kelly's intensive medical treatment. It was on this day also that Kelly had some special tests done. This series of tests was carried out on all transplant patients three months after their transplant.

The first of the tests measured lung function: the result was normal. This was followed by an eye test, which was also normal. Lastly, Kelly was taken to the Institut de Puériculture de Paris for a heart scan. Once again, the results were normal. Kelly's white-cell count was gradually rising again with the aid of the GM-CSF. Now Jan and Richard dared to believe that she was finally over the worst.

Godfrey Payne, who had been such a tremendous help to the Turners, had finished his stint in Paris and had returned to New Zealand. Both Jan and Richard were sorry to see him and his family go. It was at this time that they were introduced to another of the people who has a very special place in Kelly's story.

Graeme Allwright was a Kiwi, a friend of Alain who had been born in New Zealand and had gone to France when he was 21. Now aged 66, Graeme had been a folk-singer in France for most of his life. Graeme told Jan and Richard that he would like to put on a concert in September, the proceeds to go to Kelly if she were still in Paris, or to the FA Association if she had returned to New Zealand. The thought of still being in France in September wasn't one that either Jan or Richard wanted to even think about, but they knew if they were still there that funds would be desperately low, and they gratefully accepted. They were also thrilled to find out that Graeme lived in an apartment only 500m away. He was the only person in the area that they knew.

In late June, Kelly once again developed signs of GVHD, but this time it was managed in the apartment. Professor Gluckman indicated that Kelly should be well enough to return home to New Zealand in September, but only if she were making her own platelets by then. The frustration of not knowing why the new marrow was taking so long to produce platelets and red cells continued to plague Jan and Richard.

Jan: I was getting desperate to know why this was dragging on and on. Professor Gluckman told me that it was because of the mixture of old marrow and new. She was confident that one day the new marrow would just 'take over'. She was so positive that I just knew it would be so - it was just that the waiting was wearing us all down. September! Still months away, months before we could even contemplate going home. It was as depressing as hell. There was another thought that got to me even more. With Daniel's birthday coming in October, he would have spent most of his twelfth year away from us. In a flash of selfishness, or self-pity, I realised that I would never have any memories of him growing up through this year which was so slowly crawling by us all. I suddenly had a terrible surge of resentment at Kelly's medical condition and these past months. This whole thing was robbing me as a mother of the chance of so much, and the kids of an important part of that lovely thing called a 'normal childhood'. I loved Kelly dearly, and if it had been Daniel instead of her I would have done the same for him -but at that moment I felt, as a mother, that I had had a raw deal.

When I told Kelly she might have to stay in Paris until September, and longer if she wasn't making enough platelets, she got upset also. She was fretting for Daniel now. One night about this time I had a brainwave: why didn't we fly Daniel over here for his August school holidays?

When I said this, Richard looked at me as if I had gone stark, staring mad. He opened his mouth to tell me that, but I just ploughed on. 'Remember the air ticket that was donated by Air France during the fundraising in Auckland? Why don't we see if it's still available?' Suddenly Richard grinned, the idea wasn't so silly after all. 'Okay, let's give it a go!' he said, 'We'll ring the station and find out!'

We did that, and waited for a reply. I crossed my fingers, my eves, everything. This was one little dream that would help make it all bearable. Maybe, just maybe, we could be together as a family again, even if only for a few weeks.

By July the temperature in Paris had soared; the apartment was unbearably hot. Nerves were stretched, and Jan and Richard knew that funds were too. Richard mentioned his concerns to Alain, who immediately arranged a meeting with Charles Bichet, who was involved with the French FA Association. They decided to contact some of the Paris newspapers to do an article and hope-fully bring in some funds. The ever resourceful and influential Alain Silverston managed to obtain an even greater reduction in the apartment rent, which eased the funding crisis a little.

The heat of the Paris summer affected us all, Kelly in particular, as she had to wear her mask whenever we went out. The Silverston and Bichet families were wonderful to us, taking us all out when they could, and Graeme Allwright became *a* true friend. Cesar came by quite often or Richard called on him; they had become good friends. That contact really helped Richard, just having another man to talk with. Kelly was working hard at her studies, and it was at this time that she wrote her book about her transplant. It is a very touching story, and was a good emotional release for her to write about what she'd been through. I was very interested to read her perspective of it all.

Her hair was growing back now, but the colour was different – instead of being blond, it was quite dark. The cyclosporin A had caused an excess of hair growth all over her body, but this we were assured would go away when she stopped taking the drug. The GVHD was still coming and going.

On 16 July, we were delighted to have a visit at our apartment from Dr Thomas, who told us he was on his way back to Hungary. He hadn't wanted to leave Paris without saying goodbye. He was anxious to see Kelly. He examined her, and pronounced that he was delighted with her condition overall. I told him that we were honoured to have had him as Kelly's doctor, his face lit up with pride and he gave me a hug. It was an emotional farewell as we knew we would never meet again. He shook hands with Kelly (he still didn't know if she regarded him as friend or foe). Richard was out grocery shopping, and was sorry he missed seeing the doctor to thank him himself. We had often talked about how lucky we had been in having him as Kelly's doctor. I have no doubts that in Hungary now there are other parents expressing the same sentiment.

❖

There was more good news on the way. Professor Gluckman informed Jan and Richard that the latest chromosome test showed all of Kelly's white cells to be of donor origin. The professor had had the results double-checked. Now all they had to do was wait for Kelly's marrow to get stronger. The GVHD was now short rather than long term, and the professor said that she would rather see that than any rejection problem. It was decided that the GM-CSF would be stopped, to test the white-cell count. This time the count didn't plummet, but settled into a range between 1.5 and 2.0 for the remainder of July. Another milestone had been achieved.

Throughout August, the summer heat continued. Kelly began having terrible fits of depression, and became very uncooperative. At age nine, she rationalised so many things: Why couldn't Daniel be with her? Why couldn't she have lollies (the diabetes)? Why had she even had to have the transplant? The fact that, as yet, there was no end truly in sight didn't help.

This was a very frustrating time. Try as we might to maintain as pleasant an everyday life as we could, Kelly's mood swings made it very difficult. I had never seen her like that before. She would run into her room and slam the door whenever she got angry at something - or nothing.

Then, on 10 August, we received a fax from Richard's cousin at the radio station in New Zealand. It wasn't an easy fax for me to read at the time. It hadn't been possible to arrange for Daniel to fly over in the height of the holiday season - but there were other things in the fax that upset me as well. I was being questioned as to the wisdom of even contemplating bringing Daniel over, because of the possible disruption to his situation. There was even a suggestion that because Kelly was 'over the worst', Richard should perhaps fly home early. I was so angry that someone else was questioning something we had thought so much about. Someone who wasn't having to live through the whole thing with Kelly.

In hindsight, I know the comments were well-meant, but as stretched as we were emotionally and physically, I just grabbed a pen and blew up. I felt insulted, and really disappointed. We had consulted with Therese on the question of Daniel, and there was no way I could cope without Richard's support at this time. Richard's cousin had no idea of the situation.

When the other FA families in Paris heard that Daniel couldn't get to Paris, they rallied around and came up with the money for his airfare, which was wired to a Taupo travel agent who was a family friend. A ticket was arranged at a greatly reduced cost, and Daniel was scheduled to arrive in Paris on 8 September. The effect of this was a very positive one for Kelly. She perked up immediately, and threw herself back into the school-work she had been neglecting. She was being given a more rigorous set of exercises by the physiotherapist, and was becoming much stronger. She managed to go six days between platelet transfusions on two occasions during the month. The Turners were hanging on for the test results each time they were run.

At the beginning of September it was decided that Kelly no longer required physiotherapy: another milestone had been reached.

On 7 September, the first thing Kelly said to me when she woke up was, 'Daniel will be getting on the plane now.' All day she spoke about what Daniel would be doing at that time. It was now eight months since we had seen him, and through that time I had tried not to think about him too much because it had been so painful. Now I was thinking about him all the time, because we would see him tomorrow. Having the whole family together was so important to us. Only those who have gone through such a difficult separation can have any idea what it is like. In hours, we would all be together again.

Daniel: When I found out I could go to Paris I was rapt. I hadn’t seen Mum, Dad or Kelly for eight months, and at times I wondered if I would ever sec them again. I wanted to see them, see where they lived and some of the things they mentioned in their letters. It was exciting. Then suddenly I was on my way. I didn't mind travelling alone all the way to Paris. The air hostess was really nice to me, even on the stopovers she took me with her. I was happy when I saw Dad at the airport. Later, when we got to the apartment and I saw Mum and Kelly, I felt like I never wanted to leave them again. Even in the tiny apartment it felt like I was truly home with my family again.

CHAPTER 30

Our long-awaited family reunion

Richard: We were all awake early. Marie-Pierre Bichet came to drive me out to Charles de Gaulle to meet Daniel, while Jan and Kelly remained in the apartment. All the way out to the airport I talked non-stop to Marie-Pierre, I was so elated. When I saw Daniel walk through the gates, I had trouble holding back my tears. I rushed over to him and gave him a big hug. He had grown at least 10cm. I was surprised when an air hostess came over and asked for my passport, to prove I was Daniel's father. I panicked for a moment because I hadn't brought it with me, however Marie-Pierre vouched for me. At least I knew that they had looked after him very well on the way over, and were certainly very protective. Once we reached the apartment it was very emotional for us all, even Marie-Pierre had tears in her eyes.

Jan: When the doorbell finally rang, I let Kelly run to the door. She flung it open and threw her arms around Daniel. It was touching to watch the two children hug each other. When Kelly finally let go, I got my turn at a hug. It felt so good after so long. He had grown so much, the top of his head reached my chin, and his face looked thinner. He was anxious to look around the apartment, and Kelly had organised a treasure hunt with lolly prizes. I'm glad that we had sent a video home to New Zealand showing the temporary changes in Kelly's physical appearance. Daniel hadn't got a shock when he saw her, she was just his little sister. It was wonderful to see them playing a game straight away, just as if they had never been apart. Then it was time for Daniel to find all the goodies in his suitcase. It was like Christmas, things that we took for granted at home, like magazines in English. Kelly was talking non-stop, just like her old self. Daniel was exhausted, and by night time he just wilted. There was a spare bed in Kelly's room. When I tucked them both into bed I felt complete for the first time in a long while. I went to sleep knowing that our family was together again, even if it was just for a few weeks. I slept very soundly.

Over the next few days, Daniel was introduced to life in Paris. He was fascinated by the treatment Kelly was receiving, and by Hôpital St-Louis. In Tréfle 3 he met Dr Richard, who was eager to take a blood sample from him for his research. Daniel was honoured to be in demand. All the other FA families had heard much about him, and they all made a big fuss of him. He quickly had to get used to the French greeting of being kissed on both cheeks, and soon became very adept at returning the compliment.

Graeme Allwright's fundraising concert was scheduled for 19 September. To promote it, Alain and Graeme arranged for the press to interview the Turner family and take photographs. Jan had horrible visions of the New Zealand fundraising circus. The funds in the Trust were very low by now. The accommodation account had not been paid, and at the bank there was difficulty drawing living-expense money.

Richard and I began talking about him returning to New Zealand after Daniel and possibly needing to do more fundraising. It was a horrible thought, but waiting for Kelly's platelet count to hold was taking forever. Professor Gluckman told us that all of Kelly's problems to date had been caused by the CMV. I was shocked when she said the virus was still showing up in Kelly's urine. She would continue to be treated with an oral antiviral medication called Zovirax to keep the virus suppressed. The last chromosome test showed only donor cells. Really, the only reason for Kelly's continued stay in Paris was the wait for her blood count to raise and stabilise. God, I was sick of waiting, we all were.

Kelly couldn't go to Graeme's concert because of the risk of infection in being around so many people. The event was a great success, and Richard filmed it for Kelly. Graeme had to do many encores. By this time we had learned that he was actually a very famous singer in France, with many albums released. Certainly by the response of the crowd, you knew he was a favourite, and he sang beautifully. It was a very moving and impressive show. I felt so sorry that this very talented and generous man was virtually unknown in his own country. Kelly loved watching the video that Richard had taped for her. The proceeds from the concert were given to the French FA association who in turn paid our accommodation, which took some of the financial pressure off the trust. We were so grateful to Graeme and his efforts on our behalf.

❖ **During Daniel's time in Paris, the whole family had an opportunity to see the sights of the city, thanks to Graeme, Alain and Marie-Pierre who took them sightseeing in their cars. Kelly was unable to ride the *metro,* but Richard frequently took Daniel exploring. The family life they were enjoying made Jan even more determined that they should get home as soon as possible.**

In late September there was more good news. Kelly's white-cell count had risen dramatically, to settle between 3.0 and 4.0, and for Kelly the news had an even greater significance. She no longer had to wear a mask out of the apartment except among crowds. Jan was able to be a little less sterile with her food, and Kelly's drug doses were reduced. Life was becoming a little more normal.

One day I went to *a* salon to have my hair cut, and we decided that Kelly should have a new style. The hairdresser snipped off the wispy bits, and her hair looked thicker when he had shaped it. Kelly walked home with her head high and a huge grin on her face. That simple act had a tremendous effect on her morale.

❖ **Medically, things were looking much better for Kelly, but there was still a problem with her blood-glucose levels: ketones, an indicator of high glucose, were showing up in Kelly's urine. Because Kelly's diabetes was a temporary but direct response to the steroids she was on, she would not be free of it until the course of steroid treatment stopped.**

October arrived, and Daniel was due to fly home on the 3rd which was, coincidentally, Richard's birthday. It was agreed that Richard would fly hack to New Zealand in time for Daniel's birthday. The day before Daniel's departure, they celebrated Richard's birthday.

The morning of Daniel's departure was not an easy one. We were all feeling anxious about being separated again, but we didn't have much time to dwell on it. Alain arrived at 7.45am, and drove Richard and Daniel to the airport while Kelly and I had a good cry.

Daniel: I was enjoying being with everyone and I didn't want it to end. When it came time for me to go back to New Zealand, it was very difficult as I had settled in and didn't want to leave. Then Dad said he would be coming back soon after me so I didn't mind too much, but it was still very hard saying goodbye at the airport again. I don't like thinking about those times, it's too painful. I try to forget it now.

CHAPTER 31

What else can go wrong?

DECISIONS HAD BEEN made. Richard was booked to fly back to New Zealand on 16 October. Early in the month the Vitry Lions Club, through Alain, invited Richard to a meeting where they presented him with a 10,000FF donation to Kelly's fund. Once again, Jan and Richard were reminded of the generosity of complete strangers.

Shortly before Richard was due to fly out, Kelly developed diarrhoea and fevers. A course of treatment was begun, but after a week it was clear that Kelly was getting worse. Faeces samples sent to the laboratory came back negative: it was yet another puzzle. On 13 October, Kelly awoke with a temperature of 40.1° C. Tréfle 3 were contacted and Kelly was rushed to St-Louis by ambulance. There were no available beds in Tréfle 3, so she was admitted to an adjacent children's ward.

Now there was a problem. Jan and Richard knew that the trust fund did not have enough money to pay the 8340FF per day to keep Kelly in the hospital. The solution came from Professor Gluckman. She had met a man at a dinner who told her that he had trust-fund money available to her if she ever wanted it. The professor met with the man that afternoon, and asked for 100,000FF.

Jan: I was amazed. Speechless! The professor was incredible. We knew she was a clever woman, and we had come to trust her completely. She had already saved Kelly's life and now we saw her in yet another light. This wasn't her problem, but she was coming to our aid. Once again we had cause to he both grateful and humble for her efforts on Kelly's behalf.

Kelly was to be moved into Tréfle 3 the next day. In the meantime, Jan found a fold away bed in Kelly's ward, and made the derision to stay with her because she wasn't familiar with the ward or the staff. This quite possibly saved Kelly's life.

In the evening a nurse came in, and injected a drug into Kelly's catheter. Kelly suddenly began yelling that the substance was burning. She fell back on the bed, her eyes rolled into her head and she became unconscious. The nurse, who was concentrating on the catheter line, didn't notice.

I yelled at the woman in terror, wanting to know what she was giving Kelly. 'Antibiotic, antibiotic!' she yelled back. Richard was shouting, 'Get a bloody doctor!' - he raced off looking for one. Then the nurse saw what was happening with Kelly and rushed for the emergency trolley in the corridor, shouting for assistance. I was beside myself. Kelly looked dead, she was so white and she wasn't moving. I was powerless to do anything. Richard came running in with a doctor in tow, and the other staff piled into the room. There was great panic as they quickly hooked Kelly up to a blood-pressure machine and a heart monitor.

Richard: Jan and I were pushed aside. My head was spinning with shock, Kelly was chalk-white and totally limp. It seemed to take forever until there was a sign of life and the blood pressure machine finally began to beep. I have never been so terrified in my life.

Jan: To us, the reason for Kelly's reaction was obvious. The nurse had injected the undiluted antibiotic too quickly into the catheter, and it had shocked her system. Until now, she had always received such medications in a glucose solution in a slow drip. Richard and I were so angry. The doctor didn't agree with our conclusion. He preferred to believe that there had been a microbe in the blood. No matter what had affected Kelly, neither Richard or I will ever forget what happened that day. Some people could, and have, accused us of being 'too protective' of Kelly. But, looking back at the last nine years, I am sure that without our protection she wouldn't have survived. I say to all parents, when you think something is wrong with your child - don't ever take 'No' for an answer.

❖ **Tests showed that Kelly's white cells were 2.5; however, her platelets were down to 8 and she was given five units. Jan slept beside her that night, always conscious of the sound of the monitors.**

The next day Kelly's blood pressure and temperature were normal. This crisis appeared to be over. She was moved to Tréfle 3.

Kelly became upset when we reached Tréfle 3. When I asked her why, she said that it was because I couldn't stay at night with her. Poor kid, she had had such a fright. I promised her, there and then, that I would sleep in a chair, and wouldn't leave her. They gave her another dose of the antibiotic, this time in a glucose solution. Through the day her temperature remained normal, but the diarrhoea continued. She was cross because she wasn't allowed to eat.

❖ **Richard now began to question whether or not he should return to New Zealand as planned. Jan insisted that he go. While Jan stayed with Kelly, he packed in preparation for his flight and spoke to Graeme, Alain and Cesar, establishing a support system to help Jan out once he had left. Because Graeme lived just around the corner, it was decided that he would help Jan with the shopping. Cesar would help at the hospital if needed, and Alain would continue to pay for the hospital, home service and accommodation with the money that had been raised.**

Kelly's white-cell count remained at 2.4 and her platelets at 50, but in only one day her red count dropped markedly as a result of the infection. Dr Alexis of Tréfle 3 and Jan discussed getting Kelly home to New Zealand. The doctor agreed that, because Kelly was not now receiving any special treatment, she could obtain what was needed in New Zealand. Jan decided to talk it through with Professor Gluckman when she next saw her.

Richard: On the morning of my departure, Graeme collected me at 6.00am. We loaded my bags into the car, and he drove me to the hospital. When we arrived, Jan and Kelly were still asleep, Jan was stretched out in a chair beside the bed. I felt so sorry for her sleeping in those conditions. She looked exhausted, and I felt miserable about having to leave her like that.

Kelly started crying because she didn't want me to go. I felt like hell, as if I were running, out on them. There was no easy way to say goodbye, so I gave them both hugs and told them I loved them. I saw some of the nurses on the way out, and they farewelled me. It wasn't how I had pictured it would be. I always thought we would be leaving together. All I could hope was that Jan and Kelly would be close behind me.

At the airport, Cesar, Graeme and I had some time together while I waited for my flight to be called. I was understandably pretty uptight. They tried to reassure me that Jan and Kelly would be all right. There was a hassle about my baggage being overweight, and it was going to cost too much to take it all, so Graeme said he would take it for Jan to bring later. After saying our farewells I got on the plane, my head full of doubts and fears. I felt so alone. It was a little easier from England on because I could understand the language.

Our friend Barry met me at Auckland airport. It was tremendous to see his smiling face, and so good to be back on New Zealand soil. I felt like bending down and kissing it. At the first opportunity, I had a feed of good old Kiwi fish and chips, something I had craved for months. They tasted fantastic. Then Barry and I headed for Hamilton and Therese's. I couldn't wait to see Daniel.

Daniel: It was neat when Dad came back. It really felt as if I was inviting him into my home, the home I'd had all the months we'd been apart. I wanted to show him everything, my school and where I played, and have him meet all my friends. It was my turn now to show him around. With Dad back, I felt really good and didn't miss Mum and Kelly so much because it really did seem now that they weren't far away.

Jan: In the afternoon after Richard's departure, Cesar came to see us in the hospital. He asked me to go down to the cafeteria with him for a break. By the way he spoke, I knew Richard had asked him to look after us. Cesar made it very clear that I was to call him any time I needed anything.

It was nice to know that there were good friends there for us if we needed them. Kelly was unhappy about the hospital food, so I went to a supermarket for groceries so I could cook her meals. The lady in Kelly's room was allowed home for the weekend, and the staff said I could sleep in her bed until she returned. I decided that I would make sure I got two good nights' sleep at least.

On Saturday, Kelly was looking much better and was free of the diarrhoea. The CMV was still showing up in her urine, but Dr Alexis did not feel it was causing any problems with the marrow. He believed that Kelly's haematological system was taking a long time to develop because she had received an unrelated transplant. He said it was not known why these sometimes took so long to function afterwards. It was just another of those mysteries. We know so much about how the body functions, but there is obviously much still to learn.

At 6.30pm, Kelly and I talked of Richard, knowing he would be arriving in New Zealand. I felt envious, and sorry for myself being left behind. I was also beginning to wonder if Kelly's new marrow would ever work normally. Sometimes I found it so hard to see an end to it all. Was there light at the end of the tunnel?

CHAPTER 32

Almost alone in Paris

With Richard gone home, Jan had the sole responsibility for Kelly's care on her shoulders. Tired, alone, and frustrated by the slow progress Kelly was making, it wasn't the big things that got to her. Those she could handle. Rather, it was the little niggly things that got through the chinks in her armour. Tréfle 3 was the last place she wanted to be. Kelly had been released in May and, after the apartment, being camped on a chair in Kelly's room was agony for Jan. A simple thing like preparing Kelly a meal in the kitchens became a major task because of the unfriendly kitchen staff.

Jan: All the parents had talked about the incredible difference in attitude between the nursing and the catering staff. Each came from opposite ends of the scale. The nursing staff were very caring, and, while we had our moments with them, they were very concerned professionals. The kitchen staff, in the main, were plain bloody-minded, some of them were quite belligerent, not just to us, to everyone it seemed. I often wondered how in hell they were chosen. One incident took place on the Sunday morning after Richard's departure.

18 October: *At 8.00am I went to cook Kelly an omelette for breakfast, and the kitchen lady wouldn't let me do it. She kept saying, 'Après, après' (meaning later), as she scowled at me and made as much racket as possible. The area I would have been using had no one in it. I was really annoyed, knowing they don't take the breakfast around until 9.30 and Kelly was hungry now. After her bout of diarrhoea, I was keen to get some solid food into her us soon us possible. I felt like crying with frustration, this silly little thing was the last straw. I wish just for once that I could swear in French because I would have let her have it. God! I can't wait to get out of this place.*
At 9.00 I went and sat outside the kitchen until I saw the breakfast trolley leave, then I went in and cooked the omelette. Kelly really enjoyed having a cooked breakfast, as the French breakfasts consist of hot chocolate, bread and sweet spreads, so different to what she is used to at home. She can't have Vegemite now because of the high salt content.

That Sunday was another of 'those days', but once again, our friends helped me get through it. Therese phoned, as did Richard, Graeme, Mum and Cesar. Richard was really happy to be home. He told me the first thing he did on arrival was get a feed of 'fish 'n' chips'. I couldn't wait for that myself. The calls helped pass the day, and then there was a bonus. When Kelly's room-mate came back to Tréfle 3, they put her into a sterile room that had become available. Thank you Lord, I have a bed for tonight!' I thought to myself.

On the Monday morning we were told that, after a chest scan, Kelly could go home to the apartment. Wonderful news. I went to see Professor Gluckman - more wonderful news! The man with the trust fund would pay the hospital account direct, which was a huge load off my mind. One worry less! Then I decided to ask the question I had been waiting to ask for so long. Heart in my mouth, I plucked up the courage. 'I think it is time I took Kelly back to New Zealand,' I said, watching the professor's face for a hint of what was to come. Suddenly she smiled and nodded. 'Yes, I think it is time!' she replied. I felt a great wave of relief rush through me. I was pleased and surprised, and it showed. The professor gave a little chuckle. There is no reason why not. All of Kelly's transfusions can be done in New Zealand. We will meet on the 29th to see if Kelly can go.' I did a quick mental calculation: 12 days! I left the professor's office happy, hoping that over these next 12 days Kelly's blood counts would stabilise even more. I didn't dare get my hopes too high. I had done that before, only to have everything conic crashing down - but, deep inside, I had a feeling that this was it!

Dr Alexis gave me a treatment order for Kelly to have a complete blood count (CBC) and biochemistry blood test each week. That day's showed white cells, at 2.9, red, at 10.0, and platelets of 68, so Kelly didn't require any transfusions. I also received a prescription for her daily medications. I asked Isabelle to ring the HAD to let them know about the new medications. It was a shock when she said that Kelly no longer required HAD. She would have to go to a laboratory near our apartment once a week, and we would phone the results in to Dr Bancillon. The laboratory couldn't take blood from Kelly's catheter, it would have to be out of her arm. I wasn't happy with the new arrangement and I put up a good case for continuing the HAD, but after Isabelle telephoned them, she confirmed that they didn't want Kelly's case. Reluctantly, I had to accept the decision.

We went back to the apartment by taxi. There was a lovely note from Richard waiting, and the place was very nice and clean. It was great to be 'home', but I felt uneasy. Losing the HAD and Richard left me feeling very vulnerable. Suddenly I felt as if we had been abandoned. I rang Richard, and told him about Kelly's possible return. When he heard about the HAD hassle, he suggested we ring the Silverston and Bichet families to see if they could do anything about it. I did this: they were shocked to hear of the HAD decision, and couldn't understand how it had come about. That night, I put Kelly down in her own bed, that felt good but I wondered how I was going to cope without HAD help.

In the morning, Graeme rang to see what vegetables he could get me from the market. I was pleased with his offer, as I was used to Richard doing all the shopping and I hadn't had time to establish a new routine. I also received a call from Isabelle saying that a nurse from HAD would be coming on Thursday to take blood for a CBC. After all the hassle the day before, I was most surprised and confused. Isabelle couldn't tell me any more. Why had HAD changed their mind; they had seemed so adamant in their decision? My question was soon answered when I had a call from Marie-Pierre Bichet. Apparently, Charles had been contacted by the social worker at St-Louis about Kelly not being able to have the HAD services. Charles had stressed that she 'must' have it - there wasn't any choice in the matter. It must have been his influence that helped change their minds. Needless to say, I was really pleased, it was a weight off my mind. Yet again a friend had come to our aid, and I was so grateful.

❖ **With Kelly's release coming closer to being a reality, preparations were being made for her homecoming. Dr May in New Zealand had requested an update on Kelly's recent treatment, so that he could ensure that any medication she needed was on hand. Professor Gluckman had been sending him regular bulletins up until her**

release from hospital. Jan arranged to send this via fax to Therese in the delivery unit at the hospital in Hamilton, to be passed on to him.

It was agreed that Richard would approach Air New Zealand to see if their tickets could be upgraded to first class, to minimise Kelly's exposure to infection in the cramped economy section.

Kelly appeared to be over her infection, and Jan was praying that there would be no more unexpected hospitalisations. There were no funds available, and she dreaded the thought of having to go on the fundraising trail again.

The realisation of how little money we had left came when Alain phoned and asked if I wanted him to pay the past month's HAD account out of the funds he was administering for us. I told him yes, and he said he would also pay the accommodation up to date and then all the money would have been spent. I would pay the HAD's future account through my credit card. Fortunately, HAD would only be needed a few days a week. Evelyne came that first time, it was great to see her because she had become a familiar friend. Kelly's white count was 5.1, her platelets 24 and her red count 9.5. The white count had never been so high without the GM-CSF. Finally, I was beginning to have a reason to trust the marrow. I tried to put the low platelet count out of my mind.

Richard faxed to say that our travel agent friend in Taupo was trying to arrange the upgrade, plus special treatment for customs and the transfer at London. The main aim was to keep Kelly away from crowds as much as possible. All weekend I kept a close eye on her because of her low platelet count. It was hard trying to put that out of mind, because she had been dependent on transfusions for so long.

❖ **On the Monday the results of the CBC arrived by fax at 4.00pm, and Jan couldn't believe her eyes. The white-cell count was 5.4, the red 9.9 and, in four days, Kelly's platelet count had only dropped from 24 to 16. She was obviously making some of her own platelets. Jan couldn't put the fax down. It was a wonderful sign. The light at the end of the tunnel was starting to shine.**

***26* October:** *Things arc at last looking better, I'm trying not to get my hopes up too high. I don't think I'd cope by myself if it all comes crashing down. I'm not sure I have the strength left to go through it all over again.*

Graeme came around or phoned every day, and Kelly and I loved his company. One day I bought a leg of export New Zealand lamb and invited him for dinner. I cooked a typical New Zealand roast lamb dinner, which he thoroughly enjoyed. I was missing Richard's company and fluent adult conversation, so it was marvellous to have Graeme to talk to. The flavours of the meal brought back so many memories for him, and there was real nostalgia in his eyes. No doubt about it, he was still a Kiwi at heart despite all his years of travel and his life in France.

The next day Kelly received her platelet transfusion, and I found out from Dr Bancillon that she would have to have a good count for her flight back to New Zealand. The pressure of taking off and landing would be potentially dangerous with low platelets, so we would need to top Kelly up before we left. Richard rang to say that in order to upgrade our tickets I had to book a departure date and send him the reference number, which he would hand on to Koru Care for processing. I rang Air New Zealand and explained our story. They gave us a booking on Sunday, 8 November, to leave Paris on Dan Air to London, and from there out on an Air New Zealand flight departing London at 3.15pm, arriving in Auckland on Tuesday, 10 November.

We had our dates! Now all we needed were no problems with Kelly - and Professor Gluckman's approval. Kelly was so excited. I made sure she knew that the professor had the final say, and then I crossed everything I had for the hundredth time, and prayed.

CHAPTER 33

Time to go home

DECISION MADE, JAN felt confident that Kelly would be ready to travel. She was hoping that Professor Gluckman agreed.

Jan: After all that the professor had done for Kelly, I would never have gone against her judgement and put Kelly at risk, but I so badly wanted us home. I don't know what I would have done if she had said no. I rang Alain to tell him of our plans, and because we were leaving on a Sunday, he said he was able to take us to the airport in his van. I spoke to Graeme, who offered to help Alain with all our luggage and see us off. The next morning, Kelly and I were up early for her hospital visit and the consultation with Professor Gluckman. I must admit my heart was in my mouth.

They ran all the tests on Kelly, and she received a gamma globulin infusion. While this was running, the Silverston family came to see us, as Benjamin was also having a consultation with the professor. He was getting over a bout of GVHD which had appeared two years after his transplant. It seemed GVHD had no time limits. Alain told us it was Graeme's birthday on 7 November, the day before we were due to fly. They were going to have a party for him, and it was an ideal chance for them to farewell us. It sounded like a great idea. Sylvette said she would come and take us shopping for a present for Graeme on the 6th. It all seemed to be coming together. All we needed now was Professor Gluckman's blessing.

We got to see the professor at 2.30pm, and waited anxiously for the magic words while she examined Kelly. All signs of the GVHD appeared to have gone, and the professor announced that she was very happy with Kelly's condition. When I mentioned what her white count had been lately, she smiled and nodded, 'See, I told you the marrow would take off at some stage.' She gave a little chuckle. She had been so right - again. The professor then proceeded to make out a new prescription for Kelly. Although there were still a lot of drugs on it, she had dropped many of them.

'We've booked to go home on the 8th!' I said, my heart once again in my mouth. The professor just nodded. 'I'm pleased. I think the time is right.' What a relief I felt. Suddenly, after all those months, it was set. But still, there was so much I needed to know, and we began a long question-and-answer session. Kelly wanted to know if she would be allowed to keep Tigger her cat. Unfortunately, the answer was an emphatic 'No!' The professor explained that cats carry toxoplasmosis, and the risk of infection was just too great. 'Perhaps you can get a fish, Kelly. They are much cleaner!' she added. I could tell by the expression on Kelly's face that she wasn't so keen on the idea. I could almost hear her saying to herself, 'Fish can't be hugged!' I thought, 'Oh well, in for a penny, in for a pound,' and I told the professor about our Labrador dog, explaining that it lived outside. Reluctantly, she agreed it was okay, but stressed again that we had to be very careful. 'You can start Kelly back at her school in the New Year.' Kelly beamed, she had been without playmates and kiddie company for such a long time. She just wanted to be back with Daniel and her friends again.

The list of instructions seemed endless. Kelly would be scheduled for three more gamma globulin treatments on her return home: one a month until January. She would be able to receive all her vaccinations, such as tetanus, back in New Zealand, but the professor stressed she must always receive dead vaccines, never the live ones. She wrote out an order explaining all of this. It was a long session, and I tried to pay very close attention. I didn't want to miss anything. At the end, I asked the professor if she wanted to see Kelly at any stage in the future. She said, 'No, I think it is too far to come. I would like a holiday sometime in New Zealand, and I can see her then. Maybe in 1994.' She had a glint in her eye. It would be wonderful to be able to return some of the kindness she had shown us if she did come.

Finally, Professor Gluckman stressed that I must be very careful with Kelly until she got back to New Zealand, as there was no more money available for her to be hospitalised again in Paris. In New Zealand we wouldn't have that problem. We arranged to see her again before we left. She would have, a letter waiting for the doctors in New Zealand. We walked out of St Louis feeling like we were walking on clouds. My head was spinning from information overload, but it didn't matter. We were finally going home!

The following day, Richard rang to say the upgrade had been done but I had to ring Dan Air to check it was on their computers. Time from then on was a blur. Kelly shopped for gifts. She got a brooch for the professor, earrings for Evelyne and a scarf for Dr Bancillon. My insecurities surfaced again, and I became quite nervous through the weekend. We were leaving Paris, and the security of being near Professor Gluckman. It would have been so much easier if Kelly's post-transplant time had gone better and the roller-coaster ride had been a lot less violent. I never dreamed that we would end up taking Kelly back to New Zealand still needing blood transfusions. In my naivety, I had thought simply of the transplant working or not - I hadn't thought about difficulties occurring if it did work. I'd learned a lot of things in the last month and, no doubt, I was returning home a much wiser person.

❖ **Over the next few days, Jan anxiously watched Kelly's test results for any sign that her system was faltering. Far from it: the results showed that her red-cell count was rising rather than falling. The new marrow was working well. She wondered if Kelly's new positive state of mind had something to do with it.**

The only cloud was a call from Richard telling them that Air New Zealand couldn't upgrade them from Los Angeles to Auckland. However, preparations were being made for their return. The oncology ward at Waikato Hospital had a room ready for Kelly for a couple of days, so that Dr May could become familiar with her treatment before she went home. Richard also informed Jan that he had the house 'spotless' for their return.

Richard: The house had been so cold and empty when I first arrived home. It had reinforced the distance between us, with Jan and Kelly being so far away and Daniel still at Therese's. However, I settled in and Daniel came home for the last part of the school year, once we had firm dates for Jan and Kelly's return.

I wanted the house as clean as humanly possible because we needed to be so careful for as long as we could. We didn't want to overload Kelly's system too early in the piece. With the help of some friends and a commercial cleaner, I set to and did the whole place from top to bottom. We did all the hard surfaces, carpets, drapes, cupboards, everything, including the ceilings. When we were finished I was confident that no germs of any quantity were surviving. Now it was just more waiting.

❖ **On the Thursday before they were due to fly, Jan and Kelly returned to Tréfle 3 to collect Kelly's blood card and the information Professor Gluckman had prepared for Dr May. Kelly had biscuits and a tin full of lollies, to thank all the staff with. When they met with the professor, Kelly presented her with the brooch she had bought and some brochures on New Zealand. Professor Gluckman was keen on visiting the unspoilt outdoors.**

Jan: 'You know, Kelly, you should become a doctor,' the professor said, with that by now familiar look in her eye. Kelly gave her a smile, and I agreed but said, 'I want to teach her to be a child again first.' The professor laughed, and agreed. Then Kelly asked if she could eat McDonald's now. Professor Gluckman hesitated and said, 'Not until March.' Because Kelly's birthday was on the 22nd, we agreed that it would be a birthday treat. The professor said that if I had any questions when we were back in New Zealand I was to fax her right away. I felt a real sense of relief. It was a great comfort to know I could do that. As I shook hands with the professor I was lost for words. I felt so much gratitude to this amazing woman. Words could never express it. I left her office with damp eyes, a combination of emotions welling inside me. We owed her so much.

❖ **On the Friday, Evelyne came for the last time to change Kelly's catheter dressing. She gave Jan the information on the last CBC test. It showed without a doubt that Kelly's marrow was working very hard producing red cells. Dr Bancillon arrived to give Kelly her final four units of platelets for her trip, and closed off the catheter that she had been wearing since early February.**

The farewells started on Saturday with Marie-Pierre and Charles Bichet, who were unable to make Graeme's party.

It was sad saying goodbye. They and so many others had become such kind, good friends. We packed up all the food we had in the apartment, and Alain and Graeme came to pick us up at 3.00pm to take us to Alain's home. Kelly was so excited about the party, and Graeme had no idea that it was also a birthday party for him. At the Silverston's home people arrived throughout the evening, and all had little farewell gifts for Kelly. We were already having trouble fitting everything into our suitcases, we were going to need an extra bag just for the gifts.

It was *a* lovely party. When everyone had arrived, Sylvette brought out *a* birthday cake made in the shape of a guitar. It was exquisite, and the expression on Graeme's face was *a* real treat. We gave him a beautiful book on the Himalayas. He loved it, telling us that when he had been travelling there he hadn't had *a* camera.

With a certain amount of translating, we managed to talk to everybody. They had all been so kind to us over the last ten months. They had not only assisted us with funds, they had also extended the hand of friendship and helped us through some very difficult times. We would never forget them.

Finally we said our farewells, and Alain drove us back to the apartment. At reception I paid the last of our accommodation and the telephone bills, and the receptionist gave Alain a cheque. It was the one he had given at the first apartment as a guarantee: it seemed so long ago. Alain had been wonderful to us, he had worked so hard, even before we had arrived in Paris. He is a very special friend - a wonderful, caring person. He left saying he would see us at 9.00am in the morning. That night, as I finished our packing and reminisced over the year, I found myself wondering what it was going to be like stepping back onto New Zealand soil.

CHAPTER 34

Welcome home, Kelly!

THE BIG DAY had arrived. Ahead of Jan and Kelly were 30 hours of continuous travel.

Jan: I got out of bed while Kelly was still sleeping. I wanted a nice hot bath to relax before we began our trip; it would be a long time before I could enjoy this luxury again. As I lay in the tub, I looked around the bathroom knowing it would be the last time. 'If the walls could talk; I thought to myself, as I remembered the times I'd climbed into the bath and just lain here crying with frustration - the times I had meditated, and even those when I was overjoyed. This had been the only place I could come alone. So, this morning was a time of reflection for me and it felt good: it had been a long time coming. Ten months in Paris - nearly a year.

Then my mind moved on and I thought about home, and the butterflies started. I felt nervous leaving the protection that Professor Gluckman offered us. Doubts crept in. 'What if. . .?' All the possible things that could go wrong came to me. Somehow I managed to push them away, and concentrated on the soothing warmth of the water. Later, looking around the apartment, I felt kind of sentimental. We had always complained about the lack of space, but this had been our home away from home. Then it was time to say goodbye, and pack away my memories until another day.

Kelly got up looking extremely bright-eyed and bushy-tailed. She was really excited about the trip. She told me she couldn't wait to get home. I had to remind her that we had 30 hours in the air ahead of us. She told me she knew that, but I didn't think she could really comprehend the time factor, and wouldn't until she experienced it.

When we had come over, we had taken a four-day break in Los Angeles. This time, we were doing the long-haul. Kelly had. I bath, we ate breakfast and I gave her her medications, putting all those I would need on the trip into a carrybag already full of 'in case of medical things, plus some individually packed milks, juices and rice cakes for Kelly if she needed them.

Richard rang to see if we were all set. I think we were calmer than he was. We were ready when Graeme arrived at 9.00am, but he was a welcome sight as Kelly and I were indulging in *a* battle to close the suitcases. The poor man had to lie on them to close them in the end. Alain arrived shortly afterwards, and between them they carried everything to the van. What a mountain of gear: we had three army bags, two suitcases and a large roll-bag. I was really worried about the excess baggage. Kelly and I had a carrybag each, plus my handbag. The bag with the medical supplies was very heavy, but I didn't dare be without it.

Then it was time to go! I took a last look around our temporary home. We handed in our keys, and thanked the reception staff who had always been very nice to us. The weather was dismal with heavy showers, it was a good day for leaving. At the terminal our baggage took up two trolleys, which Graeme and Alain handled. I had put a mask on Kelly because of the crowds, and she had to endure the stares once again. The benefits of our upgrade were immediate. There was only one other person at the Elite desk, while economy had a long queue. I was going to ask the girl on the check-in if we had any excess, but Graeme hushed me up. She didn't say anything, so maybe we were okay for weight. The luggage was checked right through to New Zealand, so we could leave it in their safe hands - what a relief! A huge weight had literally been lifted from my shoulders.

We all went into the Club lounge to get away from the crowd. It was a true haven, so few people. There was an hour to boarding, so we all had a drink and a snack, and enjoyed our last chance of a conversation. I told Graeme and Alain how grateful we were for all they had done for us, but as usual they were very modest. Kelly sat there very perky, with her mask off, enjoying little snacks that she hadn't been allowed to eat for so long, particularly things with salt on them.

Finally they announced the flight.

It was time to mask Kelly again. At the gate, as they screened our hand baggage, I was nervous about the medical bag. It contained everything from catheter tubes to syringes. However, they said nothing. We quickly farewelled Alain and Graeme, there was no time for more sentimentality as people were waiting to get through. We waved as we moved along the escalator, and then they were gone from sight and we were alone. It felt a little scary, but there was no time to be sad. At the desk in the departure lounge, I told the woman that Kelly needed to be boarded as soon as possible. She was great, and marched us straight onto the plane. There was no red tape at all, which surprised me. I put Kelly by the window, and we settled ourselves in. The seats and rows were very close together, so I told Kelly to keep her mask on. As everyone else boarded I felt very nervous, paranoid even, as they brushed past. It was better when they were seated, and we were in the air.

We had lunch and I gave Kelly her medications, using the drug chart I had prepared for the trip home. I was worried about ensuring I gave her the correct dosage when allowing for the time changes. I wanted to make sure I didn't upset the balance that was working so well for her. At Gatwick Airport, the hostess came and told us that someone was waiting for us at the plane exit. It was a girl in a British Airways uniform. I almost said, 'Bonjour' - suddenly I felt quite disorientated, but I finally got out a 'hello' in response to her greeting. I was to do that quite a few times in the next few hours. She took us to a van outside, and we were driven to the terminal where Air New Zealand was located. We were asked so many questions about our time in Paris. I didn't need any encouragement to talk, it was marvellous to be speaking English again.

At the Air New Zealand check-in, we were three hours before flight time. They issued us with boarding passes for first class, but still couldn't tell us if we were upgraded from Los Angeles to Auckland. I dreaded the thought of Kelly having to travel in economy for that length of time, but I had no control over it. We were shown to the Club lounge and made comfortable - they looked after us very well. There were even some of the potato chips Kelly had been craving. A man carrying a walkie-talkie came over to us and introduced himself. He was one of the ground staff who had been told of our arrival. He also asked about our time in Paris, and told us that they had everything arranged for us. They weren't sure what Kelly was able to eat, so they had prepared a selection of foods for her to choose from. He was so nice, and all my fears about the trip dissolved. It felt like New Zealand already with everyone speaking English. Kelly was laughing and it was wonderful to see. As I looked at her new hair and her swollen face, I thought of everything she'd been through - that we'd been through, together. It brought tears to my eyes. Sometimes in Paris I had thought we would never ever get to this stage. Now, here we were. A girl from Air New Zealand came and gave Kelly a children's play-pack, and she was delighted. 'I'm sure getting the VIP treatment, aren't I?' she said to me, and I had to agree, it was marvellous. I sat and read the English newspapers, and caught up on the world news.

When it was 45 minutes to flight time, a steward came to collect us and help with the hand luggage as he led us to the boarding area and showed us to a seat right by the gate. As usual, people were staring at Kelly in her mask. Five minutes later, two stewardesses came up to us. One was carrying a huge toy mouse dressed in a pretty dress with a big velvet bow. They knelt down beside us, and presented Kelly with the mouse, telling her that everyone 'upstairs' wanted her to have it. We talked for a few minutes; the stewardesses were lovely. I told them that Kelly was smiling under her mask. 'I can see that; one of them said. They wished us all the best, and left us. Kelly sat hugging her huge mouse tightly. It was really cute, and almost as big as she was. Then it was time for us to board.

Another stewardess appeared from the aircraft and escorted us on, to be greeted by the entire on-board staff. They made a big fuss of Kelly and her new friend. We were seated in first class, and I immediately noticed just how spacious it was. I could see that the upgrade really had been the best thing we could have done for Kelly. I told her to take her mask off, but that if anyone was coughing or sneezing she would have to put it on again. One of the hostesses came over and talked to us, she was very interested in Kelly's story. Then a steward came and did the same. They were all so friendly. The steward was very familiar with Taupo, so we chatted about 'home' for a few minutes. The first class section was only half-full when we took off, and I felt even more safe for Kelly's sake. Now we were truly on our way home. If it was a dream, I hoped no one would wake me up.

Just before dinner, the hostess came up to Kelly with a cake on a plate. On it were the words G*ood Luck, Holly,* and it had a card with it that said B*est wishes from Steels Aviation Service Catering* LGW, inside it had a picture with a happy face and the words *Keep smiling.* Kelly was once again delighted. The hostess apologised for the wrong name, but it didn't matter as it was the thought that really counted. I said to Kelly that she had found a name for her mouse: Holly. And Holly it was! The hostess took the cake away until after dinner.

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The flight to Los Angeles settled into its routine, and Jan and Kelly adjusted to it. Jan had kept Kelly's watch on Paris time as a reference for the drug regimen. Kelly slept easily, but Jan dozed on-and-off until she lost track of time.

They landed at Los Angeles at 6.30am local time. Because they weren't guaranteed first-class seats for the next leg, Jan and Kelly had to take their hand luggage off the aircraft with them. Unfortunately, they had to stay in the transit lounge, which was crowded, and that meant that Kelly had to wear her mask. This time there was no assistance given, as had happened at Gatwick. Luck was with them, however; when they re-boarded the aircraft they were shown back into first class, which was full but didn't seem crowded. Kelly was pleased to be able to take her mask off again. The last leg seemed the longest. It was 6.00am as they flew into Auckland.

We couldn't see very well because it was still dark, but I could make out Manukau Harbour and a few other familiar sights. My heart was racing with the anticipation of arriving. I wondered who would be at the airport. There was the chance of the media being there if they had found out about our arrival. I felt pretty worn out, and hoped they hadn't.

As we left the plane, an Air New Zealand girl came to help us, and took us to the luggage collection area. Kelly had her mask on again. I expected our luggage to come out early because of the first-class ticketing, but it turned out to be amongst the last. I was so impatient to see the family, I guess.

Half an hour later, we had the six pieces of luggage stacked on two trolleys; I was really grateful for the girl's help. We were quickly through MAF and customs, and as soon as we were through into the public area I spotted Richard, Daniel and Therese.

We were finally, truly home.

The hugs were long and tight. I was crying again, but this time these were tears of joy.

Richard: At the airport, I waited anxiously for Jan and Kelly to appear. It seemed to take forever before we saw their faces. Jan was smiling, and Kelly had her mask on. They had two trolleys piled high with bags. I felt tears in my eyes. This was the moment I had been living for, all my family back on New Zealand soil. I felt like shouting it to the world. All I could do was hug them. What more could a man ask for? We had lived through sheer hell, been separated by half a world. But now it felt like it was all over.

Therese: We anxiously waited for Jan and Kelly to appear through the airport doors. The moment had finally come. I was so happy when I saw them, but also shocked at the weight that Jan had lost. She was very tired, but I could feel the happiness and relief radiating from her. Dear little Kelly looked really healthy, much more so than when she left New Zealand. The effect of the steroids made her look much bigger than before, but she also appeared to be taller. What a wonderful reunion, and such a happy ending. All of those gruelling months of worry and pain were finally over.

Daniel: When Kelly and Mum arrived at the airport I was feeling sick because I had a sore throat, but it was great to see them. I had gotten used to seeing Kelly wearing a mask, and this time I had one on as well. I knew how she felt having to put up with them. Even though Kelly looked different, she was still the same person. She still talked the same and sounded the same.

CHAPTER 35

A normal life for Kelly at last

KELLY WAS TAKEN directly from the airport to Waikato Hospital, where a room with two beds and an attached bathroom had been prepared for them.

Jan: I remembered the last time I had been there, just before we went overseas. Then, I hadn't felt at all comfortable in the ward. Now, it was heaven. A bed for me, our own bathroom complete with shower. I was happy, and Kelly was very perky. However, poor Daniel wasn't feeling great. He had been having trouble with his tonsils and his glands. Also, the fact that Kelly was now back had had him thinking they would be going straight home. It wasn't to be. We couldn't let them be too close together, and we had to keep them wearing masks in turn. There had been an initial fear that Daniel had glandular fever. Fortunately, that wasn't the case.

At the hospital, the staff in the ward were very friendly. We unpacked what we needed. Therese left because she had to work, and the staff did the usual weighing, temperature and blood-pressure routines. Because I had been checking all of Kelly's vital signs, they showed me how to fill out the forms for their records. I had got used to the French system and now had to re-learn the New Zealand one - I didn't mind in the least! Dr May wanted to do a CBC immediately, so I asked the nurse for the laboratory tubes. I did the procedure myself. The nurse was happy to watch as she hadn't seen a catheter like Kelly's before, and the process using just gauze and gloves rather than sterile packs was quite different.

We had a steady stream of medical staff checking on us. Daniel started coughing, so Richard took him home to Therese's to rest. I was anxious for the CBC results and to find out how long Dr May wanted Kelly to remain in the hospital. Richard was very keen to get us all home to Taupo, and I certainly wanted us all to be together in our own place as soon as possible. But, I knew inside that this time spent in the hospital would help me adjust to the New Zealand medical system again and gain some confidence in looking alter Kelly here. When the CBC results came back they were okay. White cells were 3.9, red 9.2 and platelets 70.

When Dr May came in, it was wonderful to see his face after so long. He had played such a big part in getting us to this point. We had a pleasant chat and discussed Kelly's results, which he considered to be very good considering the trip. There was, however, one thing that concerned him, and that was Kelly's blood glucose which was at 17. I hadn't understood the reading because the system I had used in Paris registered grammes per litre and here they used millimoles per litre. The conversion gave 3.06 under the French system, where anything over 2.00 was too high. Dr May decided to work out a care plan for the diabetic problem and get the hospital pharmacist to go over the medications with me, as some of the drug names were different here. In the meantime, Kelly was given insulin. In answer to my question, Dr May anticipated that she could go home at the end of the week. There were chest X-rays, eye examinations, blood counts, and many other tests he wanted to run. He also wanted us both to rest up after our long trip, although he conceded that we looked very good 'under the circumstances'. So for the moment it was going to be something of a 'holiday in hospital' for Kelly and I.

❖ **Richard decided to take Daniel back to Taupo and return when Jan and Kelly could leave the hospital. The staff were all interested in the Parisian experience, and Jan was pleased to talk, revelling in the chance to speak English. And, although she feared people would get sick of her 'raving on', they were genuinely interested. She also enjoyed being able to catch up with Therese, who because of her medical experience could understand a lot of the details about Kelly's problem and its treatment. Many people would simply find these baffling without having had their child go through a transplant.**

All the tests on Kelly had good results except for those on her eyes: these showed that she had cataracts. Professor Gluckman had told Jan that this was a possible side-effect from the steroids. The eye specialist said they hadn't started affecting Kelly's sight, and a new method of removing them was proving most successful. He suggested an appointment in a year to correct the problem. His words to Jan were, 'It's a small price to pay to have your life saved.' She had to agree with that.

The new drug regimen was organised, and Jan was given a new glucometer and educated on the management of Kelly's temporary diabetes. It was anticipated that when the effects of the steroids wore off and Kelly's body settled, it would vanish. The Friday CBC showed white cells at 5.9, red at 8.7 and platelets at 40. Kelly was free to go home.

Jan: Life felt so good as we travelled down to Taupo. As we turned the corner into our street, the first thing Kelly noticed was the brightly coloured playground equipment in the park over the road from our house. Then she and I saw our home, and it was a sight for sore eyes. I couldn't believe how all the trees and shrubs had grown. 'We're home at last, Kelly,' I said, and she just nodded, a huge grin on her face. I don't think either of us could really believe it. We couldn't wait to get inside. Our house isn't big, but it felt like a mansion. It seemed so spacious. After the apartment, it was like comparing a doll's house with a normal home. The scale was totally different. Even the dishwasher seemed enormous after the tiny one in our apartment in Paris. Kelly ran into her bedroom, which for once was tidy. In fact, the whole house was immaculate.

I grabbed Richard when the kids had taken off. 'We've done it. We've done it!' I was repeating myself, but it didn't matter. The sound of Kelly and Daniel's voices laughing and teasing each other was such a welcome background. The family was together. Richard gave me a grin. 'Yes, we've done it!' We just stood there holding each other, smiling, the sun streaming in the windows on a beautiful Taupo day. Paris was a whole world - a whole lifetime - away.

❖ **However, the world Jan had departed almost a year previously still held painful reminders that some things never change.**

Over the weekend we settled back into our home gradually, and established a routine for Kelly's medical care. It was during this time that a friend gave me a scrapbook of all the newspaper cuttings on Kelly that she had collected while we were away.

I was shocked to see the first article in our local paper was done shortly after we had left. Dated 14 January 1991, it was headed: 'Kelly Turner Operation - Paris v Christchurch.' It began: ‘Questions are being asked about why Kelly Turner of Taupo was referred overseas for a bone marrow transplant and not to the new specialist unit in Christchurch.’ It went on to mention an article in a Christchurch newspaper, in which Dr MacFarlane of Waikato Hospital explained why Kelly had gone to Paris. The head of the Bone Marrow Unit in Christchurch had acknowledged that 'there is no doubt that Professor Gluckman has done more transplants of that type than anyone else'. But he was also quoted as saying, 'However, if patients are always transferred overseas, New Zealand clinicians will never develop the expertise.'

My blood boiled when I read this. There were two reasons for my reaction. Firstly I didn't like Kelly's specialists being challenged for not referring her to Christchurch. They had discovered the FA: without them she wouldn't have even had a chance. Secondly, the Christchurch doctor didn't give us credit where it was due. As Kelly's parents, we had searched overseas for all the information that was available on treatments for FA patients, and we had based our decisions on that information. I was also annoyed that the article had appeared while the Lions were still trying to raise money for Kelly. Something like that could really damage an appeal, putting doubts into people's minds.

Once and for all, I know Kelly would have been dead if she hadn't gone to Paris. The experts admitted that the expertise and experience in FA transplants was not in this country at the time Kelly was at her lowest ebb. Fanconi's anaemia is *not* leukaemia, which at the time New Zealand doctors were treating very successfully with marrow transplants. As it was, we barely made it in time. My daughter for a guinea-pig: NO THANKS!

❖ **When the media came to interview Jan, Kelly and Richard on the Monday, Jan brought up the article to the paper concerned, and forcefully made her point, explaining about drugs such as GM-CSF, the one that more than any of the others was responsible for saving Kelly's life. She pointed out that it wasn't available in New Zealand as tar as she knew. She recommended that any doctor wanting to learn about FA transplants went to Paris. She finished by saying that no parent wanted their child treated as a 'guinea-pig' in an area that is largely experimental even for the experts, let alone beginners. She had made her point. Now it was time to get on with life.**

Jan set to and sent out thank-you letters to all who had given ongoing help in raising money and keeping the public informed of Kelly's progress in France. Although the Turners were struggling financially, they immediately stopped using Kelly's trust for living expenses.

On 18 November, Kelly had a platelet transfusion, but even then her count had only got down to 26. She has never required another transfusion of red cells or platelets since.

Kelly acquired a fish tank, and wrote to Professor Gluckman thanking her and naming all the fish. She returned to school in February 1993. Her catheter was finally removed in May 1993.

Jan began work part-time at the Waiariki Polytechnic, back with her old friends. Having something to concentrate on other than Kelly's medical condition helped integrate her back into the community.

In December 1993, a CBC result showed that Kelly's platelet count and her other blood counts had all climbed back into the normal range. Now 'normal' had a new significance for them all.

Although Kelly has had a successful bone marrow transplant, her chromosomes remain abnormally fragile. She still has Fanconi's anaemia, but she is alive and living her life with the fullness of any other youngster. She is a happy, healthy child approaching her teen years. In November 1995, she swam with her dolphins in Napier's Marineland. She seems to have changed her mind about becoming a doctor like Professor Gluckman, and now talks about becoming a marine biologist.

It has been wonderful watching Kelly change back to her old self, seeing her hair grow back and her lose the 'moon face' look from the steroids. Apart from a nasty attack of shingles in late 1994 and the occasional problems with diabetes, she has remained very well. The only ongoing problem relates to her small stature, and the effect the constant comments have on her self-esteem.

Jan: In December 1993, Kelly had a chronological age of ten years and nine months, but X rays showed she had the bone development of a seven-year-old. The issue of growth hormones was raised, but rejected as potentially dangerous. I persevered, because Professor Gluckman had mentioned that at a time in the future Kelly would 'probably need' a course of them, and she certainly wouldn't have mentioned this if she deemed it unsafe.

Early in 1995, I began a search of overseas FA treatments involving growth hormones. Dale Keegan had mentioned a Professor Shahidi at the University of Wisconsin-Madison Medical School. She had a high regard for him. I wrote to the professor asking his opinion (after all, I already knew Professor Gluckman's) on hormone treatment. In February, I received a reply.

Dear Mrs Turner,

Thank you for your letter of January 25, 1995 regarding your daughter Kelly. I am glad that Kelly had a successful bone marrow transplant, particularly since it was an unrelated match. I don't see any reason why she should not be given the benefit of growth hormone therapy since her hemopoietic progenitors are no longer her own. There is, however, the possibility that Kelly may have a chimeric hemopoietic system. This is easily ascertained by DNA analysis. Should the DNA analysis indicate that Kelly's hemopoietic cells are all of donor origin, then the risk of developing leukemia following growth hormone treatment is not greater than in the general population.

Please let me know if you have any further questions.

Sincerely yours,
Nasrollah T. Shahidi,
M.D. Professor Pediatric Hematology/Oncology

I was delighted to receive this letter, as it gave new hope for Kelly. The test was arranged, and showed that Kelly's bone marrow was now all of donor origin. This was wonderful news. The case was put to the Growth Hormone Panel in Auckland. This panel decides who should receive this treatment, as growth hormone product is very expensive and, under the New Zealand health system, only a limited number of cases can be treated.

On compassionate grounds, Kelly was granted 16 units of the hormone per week for a year's trial. I had mixed emotions regarding the approval because I could sense that Kelly's specialists really didn't want her to have this treatment. FA is still such an unknown quantity, perhaps they felt that having got Kelly to this point, introducing the growth hormone was simply tempting fate - inviting something to go wrong. I explained it all to Kelly, the risks, everything. She didn't see any problem. She felt fine, that was all she was concerned about. It reminded me of the problems during the fundraising, and how children view life. All she wanted to do was reach the stove top without having to stand on a step, and play netball without the other kids standing on her. She had a hundred reasons why she wanted to be bigger - not the least being that finally people would stop commenting on her size. The bottom line was that if it didn't harm her and helped raise both her height and her self-esteem, we would go ahead. The doubts plagued us, and in the end we decided to contact the one person whose judgement we valued above all others: Professor Gluckman. Our paediatrician faxed her a letter. For Richard and I, everything hung on her reply. Here it is:

/ thank you very much for the news you are giving me concerning Kelly Turner. Concerning the use of growth hormone, we have used it in several of our patients and we do not think that there is any problem with the new product. Therefore, I recommend the use of growth hormone in this patient because it can improve her.

This sealed our decision: we had Professor Gluckman's blessing. We had to fill out a consent form that covered every possibility. Seeing all the possible negatives down in black and white was frightening. No one could accuse us of not being informed as to all the risks.

Preliminary tests showed that Kelly had an enlarged liver and a simple cyst on one kidney. The liver abnormality was put down as being a result of all the drugs she had been subjected to; however, as in Paris, the function tests were normal. The cyst, we were assured, was quite common and not a problem. Kelly was started on the treatment.

❖ **Ten days into the growth hormone treatment, Kelly began drinking an excessive amount of water. Jan checked her blood-glucose level and found it high. Diabetes was once again diagnosed, and the growth treatment stopped immediately. The effect was devastating.**

Poor Kelly. All we wanted was for her to have *a* normal life. She had just begun to live life again, all she wanted was to grow, but now she has diabetes. Before, it had been caused by the steroids, now the growth hormone appeared to be having the same effect. Kelly was so depressed, and I slipped into a big black hole that I just couldn't seem to pull myself out of no matter how hard I tried. People were continually pointing out that diabetes wasn't the great problem it had once been, and many people lived full lives in spite of it. That did nothing for me. All I could think of was all the things that had happened to Kelly: why couldn't she just get on with life like any other kid?

I blamed myself for not having checked Kelly's glucose levels before she started the growth hormone. Then, I could have at least discovered there was a problem earlier. I mentioned this to a friend recently, and his reply was, 'You can't blame yourself for not thinking of everything, especially when you did a superhuman job all those years. If you'd stayed at the level you were at through that period they would be scraping you off the ceiling!' I guess that makes sense, even if it doesn't make it any easier. Over the last

12 years I've functioned more 'on guard' than not, so it feels more 'normal' (that word again!), and the blows are certainly more cushioned.

Eventually I emerged from the fog and began looking for answers. Then the paediatrician announced that Kelly didn't actually have diabetes - yet. Instead, she had a glucose impairment that can lead to diabetes later on. It was a partial relief. But it meant that the growth treatment couldn't be continued. As Kelly is making some growth hormone in the low-normal range and her bone age is delayed, it is hoped that she may continue to grow for a longer time than most kids, and gain some catch-up growth.

Kelly seems to have come to terms with her glucose impairment. It may never worsen, or medical research may find some answers to the mysteries associated with FA. She has been working with a counsellor who is helping her learn to cope with the many problems she encounters because of her small size. Life goes on. The whole experience of these last years has been difficult, but most of the time I do not feel a victim to it. I feel so much wiser from having lived through those times, as I've seen a side of life that not every parent has to see. Life itself has a different meaning for me now. It is to be treasured: I know just how priceless it is. No amount of money could save some of the children we knew of. I have no doubts that knowledge is the real power, in the knowledge of the genetic make-up of all human beings lies the answer. Quite often I look at my kids doing kid things, and I feel a wonderful warmth inside. I can't imagine never being able to watch Daniel shooting hoops with his basketball, or Kelly skipping up the road with her friends. These kids give me immense joy, and I never take that for granted.

Our family's story has a happy ending, and I hope that all the people who donated money towards Kelly's appeal can share in our joy. We live for the day that medical researchers find the answers to the many genetic mysteries, and conditions such as Fanconi's anaemia will be curable - then other families will not have to follow the nightmarish path that we did for their children to have a chance for life.

Appendix

Extracted from *Fanconi Anaemia: A Handbook For Families & their Physicians.*
Please note that FA is referred to variously as: Fanconi anemia/anaemia or Fanconi's anemia/anaemia, due to language interpretations.

What is Fanconi anaemia?
Fanconi anaemia (FA) is named for a swill paediatrician, Guido Fanconi. In 1927, Dr Fanconi published his clinical observations on brothers who has inherited various abnormal physical conditions, and who also experienced bone marrow failure. These children suffered severe, life-threatening aplastic anaemia. Their blood systems could not successfully combat infection, fatigue or spontaneous haemorrhage or bleeding.

Recent research shows these discoveries:

- ❖ FA is one of several, deadly, inherited anaemias.
- ❖ Both parents must be carriers of a recessive FA gene for their child to be born with this disorder. If both parents carry the recessive gene, the changes are one in four that any of their children will inherit the disease. Scientists call this pattern of inheritance 'autosomal recessive'.
- ❖ FA patients may have a variety of noticeable birth defects, ranging from minor to serious. These defects may affect every major system of the body. Other FA patients are free from any visible disorder – other than ultimate bone marrow failure.
- ❖ FA patients experience a high incidence of leukaemia (10% -15%).
- ❖ The Chromosomes in the cells of FA patients, when studied in the laboratory, break and rearrange easily. Scientists do not yet understand this basic defect in FA but can use it as a diagnostic test for the disease.

Copies of handbooks are available from:

Fanconi Anemia Research Fund, Inc.
1902 Jefferson Street
Suite 2
Eugene, OR 97405,
USA
Phone: 001-503-687-4658
Fax: 001 503 687 0548
e-mail: fafund@rio.com

Other FA family organisations throughout the world are:

Canada
Peter & Tami Dunstan-Adams
330 Van Horne Street
Penticton, B.C., Canada V2A 4K5
Phone: 001-604-493-2910 (home)
001-604-492-2721 (Peter's work)
001-604-492-4000 (Tami's work)

England
David & Christine Westmoreland
4 Pateley Road, Woodthorpe,
Nottingham NC3 5QF, England
Phone: 0044-1-115-602-269634

France
Sylvette & Alain Silverston
Association Français de la Maladie de Fanconi
10, rue Emile Zola,
94400 Vitry sur Seine, France
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Boeckenweg 4
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Siersteenlaan 31
9743 EH Groningen, Holland
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0031-50-128858 (work)
Fax: 0031-50-182620

An international registry of FA patients and families is maintained at the Rockefeller University in New York, USA, in conjunction with the laboratory or Arleen D. Auerbach, PhD. The registry includes statistical information and clinical data concerning hundreds of FA patients.

All families are treating physicians are encouraged to report diagnosed cases to this registry.

Other associations
For families of children born with tracheo-oesophageal fistula (TOF) and associated conditions:

TOFS
St George Centre
91 Victoria Road
Netherfield
Nottingham NG4 2NN
England
Phone: 0044-1-115-940-0694

For families of children born with an immune deficiency:

KIDS Foundation
90 Park Road, PO Box 60-280
Titirangi, Auckland
New Zealand
Phone: 09-817-2612
Fax: 09-817-5380

Glossary

acyclovir: antiviral agent used in the treatment of herpes virus.

amniocentesis: prenatal test usually performed in the 15th to 17th weeks of pregnancy. A needle is inserted into the uterus and amniotic fluid is extracted. Cells are studied for the detection of chromosome abnormalities.

anaemia: decrease in the oxygen- carrying capacity of the blood; indicated by a low red-blood-cell count, low *haemoglobin*, low *haematocrit*.

analgestic: substance that relieves pain.

androgen drugs: artificial male hormones that may stimulate production of one or more types of blood cells for extended periods of time in FA patients.

antibody: a complex molecule produced by certain blood cells (see *lymphocyte*) in response to stimulation by *antigens; antibodies* bind to the antigens, causing the cells bearing the antigens to clump. These clumps are then destroyed by other blood cells.

anti-emetic: a drug that prevents or overcomes nausea and vomiting.

antigens: proteins present on the surface of all cells and bacteria and viruses. Our bodies are used to their own antigens and usually don't attack them. However, the body considers foreign antigens (such as bacteria, viruses, or grains of pollen) dangerous and will attack them.
Bone marrow transplant specialists look for 'matching' HLA antigens on the white cells. These antigens can help predict the likely success of a marrow transplant.

antithymocyte globulin (ATG): a serum produced from animals, used to decrease the number of circulating *T cells*. It is used to prevent and inhabit transplant rejection.

aplasia: lack of development of an organ or tissue, or of the cellular products from an organ or tissue. In the case of Fanconi's anaemia, this term refers to lack of adequate blood-cells production from the bone marrow. It also refers to the lack of thumb and *radius* in some FA patients.

autosome (autosomal, adj.): any non-sex-determining *chromosome*; in humans there are 22 pairs of autosomes.

basophil: type of white blood cells; type of *granulocyte*, involved in allergic reactions.

B cell: *lymphocyte* responsible for humoral (fluid-based) immunity and *antibody* production.

blast cell: an immature cell.

bone marrow: soft tissue within the bones where blood cells are manufactured.

bone marrow aspiration: a test in which a sample of bone marrow cells is removed with a needle and examined under a microscope.
Aspirates are used to examine more specifically the types of cell in the bone marrow and the *chromosome* pattern.

bone marrow biopsy: a procedure in which a special type of needle is inserted into the bone and a piece of bone (a plug) with marrow is removed. This test is very helpful in assessing the number of cells in the bone marrow.

cataract: clouding or opacity of the normally transparent crystalline lens in the eye.
CBC (complete blood count): number and/or percentage of certain blood cells, primarily white cells, red cells and platelets.

chemotherapy: the specific treatment of a disease by the administration of chemical compounds.

chorionic villus sampling (CVS): an early prenatal diagnostic test. In the 10th to 12th weeks of pregnancy, an instrument is inserted through the vigina or the abdomen into the uterus. Villus cells, which later form part of the placenta, are removed. These cells are then studied for early detection of chromosome abnormalities.

chromosomes: structure in the cell nucleus which contains the genes responsible for heredity. Normal human cells contain 23 pairs of chromosomes. One of each pair is inherited from a person's father and the other from the mother.

cyclosporin A: a drug used to prevent rejection of transplanted organs by degreasing the number of T cells.

cytomegalovirus (CMV): a virus of the herpes virus groups.

diepoxybutane (DEB): chemical agent that damages DNA in cell culture, and is used in a diagnosic test for FA, either before or after birth.

DNA: this abbreviation stands for deoxyribonucleic acid. DNA is the component of the chromosomes that carries the genetic code.

ECG (electrocardiogram): a tracing made of the various phases of the heart's action by means of an electrocardiograph.

endocrinologist: a specialist in conditions involving the endocrine glands, which secrete hormones.

eosinophil, eos: type of *white blood cell;* type of *granulocyte.*

erythrocyte: mature red blood cell; red blood cells go through various stages, starting out as *erythroblasts,* changing to *reticulocytes,* and finally becoming erythrocytes.

fistula: an abnormal passage connecting the cavity of one organ with another.

gamma guard, gamma globulin: plasma proteins produced by cells of the spleen, bone marrow and liver concerned with *antibody* formation.

gastrostomy tube: a tube inserted through the abdominal wall into the stomach to be used for artificial feeding.

gene: hereditary unit. Each gene carries the genetic code, or blueprint, for a specific protein. Each human cell has about 10,000 genes, but most of these are not active in a given type of cell.

GM-CSF: the abbreviation for *granulocyte-macrophage* colony stimulating factor, a substance used to stimulate the production of *white blood cells.*

Graft-versus-host disease (GVHD): a complication of bone marrow transplantation which occurs as a result of donor *T cells* reacting to host or patient cells. GVHD is more likely to occur when there is *HLA* mismatching.

granulocyte: type of white blood cells; includes the *basophil, eosinophil,* and the *neutrophil* (or poly), which is the main infection-fighting cell.

haematocrit: ratio of red blood cells to plasma in the blood; portion of the blood's total volume that is made up of red blood cells.

haematologist: a specialist in blood diseases.

haematopoiesis: formation and development of blood cells.

haemoglobin, hemoglobin: the oxygen-carrying pigment of the red blood cells; combines with oxygen from the lungs and carries it to the body's cells.

haemorrhage: excessive bleeding.

HLA (human leucocyte antigen) tissue typing: the tissue-type test done on white blood cells to determine if a bone marrow donor and recipient are compatible.

immunosuppression: decreases in the ability of the body's normal *immune response* to fight the invasion of foreign material; required to prevent graft rejection or GVHD.

intravenous (IV): injection directly into the vein.

leucocytes: white blood cells.

leucopenia: low white cell count.

lymphocyte: type of white blood cell that fights infection by producing antibodies and other protective substances; occurs in two forms: B *cells* that recognise specific antigens and produce antibodies against them, and *T cells* that are agents of the immune system. They are produced in the lymph system, not in the bone marrow.

macrocyte (macrocytic, adj.): an abnormally large *erythrocyte.*

macrophage: type of white blood cell that assists in the body's fight against bacteria and infection by engulfing and destroying invading organisms.

megakaryocyte: large cell in the bone marrow from which pieces break off to form platelets.

mitomycin C (MMC): a chemical which, in sufficient doses, causes the destruction and rearrangement of the *chromosomes* in cells. Because Fanconi's anaemia cells are used to diagnose this condition.

mixed lymphocyte culture (MLC): a special tissue-typing test that determines if *lymphoctes* from one person are *HLA-* compabile with lymphocytes from another; has been used to identify mached bone marrow donors. Recently, the MLC test is being replaced by more precise DNA typing methods.

neutropenia: low *neutrophill* (poly) count.

neutrophill: type of white blood cells; also called a poly; a granulocyte; the body's primary defence against harmful bacteria.

oesophageal atresia: a congenital abnormality where the oesophagus pharynx and the stomach, preventing anything from passing through to the stomach.

oral glucose tolerance test: a patient has to fast for 12 hours, and is then given a measured amount of glucose to drink. Blood tests are taken over a period of hours, and the blood glucose levels assessed.

paediatrician: specialist in the diseases of children.

pancytopenia: abnormally low number of red and white cells and platelets.

petechiae: tiny red dots on the skin due to bleeding under the skin caused by low platelet counts.

Platelets (thrombocyte): blood-cell fragment containing clotting factors which prevent bleeding and bruising.

prednisone: a synthetic cortisone-like drug used post-transplant to impair *lymphocyte* function.

radiation: the emanation of energy in the form of electromagnetic waves, including gamma rays, X-rays, infra-red and ultra-violet rays, and visible light rays.

radius: the smaller bone of the forearm.

recessive: a genetic mutation is said to be recessive if an individual must inherit two copies of the mutant gene, one from each parent, to show one mutant trait. Individuals with one mutant and one normal gene appear normal. They are called 'carriers'.

red blood cell (erythrocyte), red cell: oxygen-carrying cell in the blood which contains the pigment *haemoglobin;* produced in the bone marrow.

reticulocyte: immature red blood cell.

serum sickness: allergic reaction, usually 8 to 10 days after a serum injection.

shingles: acute infection caused by a virus called *herpes zoster.* It affects the peripheral nervous system, and is frequently a relapse of the same case of chickenpox first acquired during childhood.

stem cell: original cell from which *megakaryocytes, red blood cells* and *white blood cells* develop in the bone marrow.

T cells: *lymphocyte* responsible for 'cell-mediated' immune resistence to viruses, fungi, parasites and certain bacteria; important cells in transplant (graft rejection and GVHD) reactions.

thrombocyte (platelet): cell fragment which releases clotting factors into the blood.

thrombocytopenia: low *platelet* count.

thymocyte: *T cell.*

tracheo-oesophageal fistula (TOF): a congenital malformation where a *fistula* connects the trachea and oesophagus, causing food or acid stomach juices to enter the lungs and air to enter the stomach.

white blood cells, white cells: blood cells which fight infection.