

# Chapter 19: The Grieving Process and the Physician's Role: A Mother's Perspective

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## Introduction

When I first wrote reflections on the grieving process more than a decade ago, I described the classic “stages” of grief that were prevalent in the psychosocial literature. I no longer believe people travel through such predictable stages to some ultimate resolution. Furthermore, I failed to appreciate fully that families dealing with a genetic illness grieve a *series* of losses inherent in living with a child or children with a life-threatening illness. These unique challenges greatly complicate the grieving process. I try to address these issues in this updated chapter.

Obviously, no two people confront a profound loss in the very same way. Even within a family, each person experiences emotions with different intensities and at varying times. By necessity, this chapter leans heavily on my personal experience of grief and the stories of others whose lives have been forever altered by Fanconi anemia (FA). I hope that understanding the emotional challenges faced by FA families will enable physicians to better meet the needs of this unique population.

In the 1980s, my husband and I learned that of our five children, all three daughters were born with FA, a life-threatening genetic disorder. We lost our daughter Katie in 1991 at the age of 12, and Kirsten died in 1997 at the age of 24. Our Amy is now 27 and her health is stable, but knowledge of this disease makes us fearful for her future. Living with our unspeakably profound losses has inescapably deepened and altered my understanding of the grieving process. Knowing so many families who have struggled with this disease or have experienced the loss of a child or spouse with FA has magnified my own awareness of the special challenges faced by our grieving families.

### **The Onset of Grief**

The grieving process that affects families dealing with FA can begin during pregnancy or at the moment of a child's birth, when severe physical anomalies signal a serious underlying problem. Some children with FA appear normal at birth, but a significant number are born with abnormal or absent thumbs, absent or shortened radii, small size at birth, small head and eyes, and/or other serious physical problems. Some conditions require immediate or repeated surgical intervention. The loss of the "normal" child one expected and eagerly anticipated can be devastating. The realization that one does not share the unreserved joy that others experience upon the birth of a child can be wrenching.

Parents typically experience intense shock and a range of painful emotions as they realize that their child does not look like other children and may require a series of difficult medical interventions. Parents may learn soon after a child's birth that the cause of various anomalies is FA. With that diagnosis comes the realization that the child has an inherited disorder that results in bone marrow failure, sometimes leukemia and other cancers, and a shortened life expectancy. This knowledge raises the possibility that other children in the family might also have FA. The cumulative impact of this devastating information plunges parents into an immediate and extremely painful grieving process.

FA is highly variable in terms of physical presentation, onset of symptoms, and course of the disease. Many patients are not diagnosed at birth. During the first decade of life, loss of energy, repeated infections, or signs of abnormal bleeding may lead ultimately to the FA diagnosis. Some patients are diagnosed because of an affected sibling. FA also can escape detection for many years and even decades. Infertility, cancers that appear far earlier than one would expect, or other subtle physical findings may suggest FA. But whenever the diagnosis is made, parents will experience the acute loss of the expectation that their child would lead a full and normal life. Learning what might lie ahead, they ache for their precious child and, indeed, for their entire family.

FA often progresses slowly, and patients can live for years and sometimes decades after the diagnosis. As a result, families may endure chronic grief. With every acute crisis such as worsening bone marrow failure or the diagnosis of cancer, loved ones experience again the most painful phases of the grieving process.

## **Characteristics of the Grieving Process**

### ***Shock or denial***

The first expression of grieving is often characterized by numbness and an inability to accept the diagnosis. Parents may tell themselves that the diagnosis is inaccurate, that someone has made a dreadful mistake, or that there must be a magic pill that will make this go away. Some individuals appear calm and can seem to be functioning normally. They carry on with their daily routines, perform regular tasks, and ask appropriate questions. But in fact, they may be functioning on “automatic pilot.” Often they cannot hear, remember, or process information accurately. This phase can last from hours to months and is often intermingled with other characteristics of grief.

### ***Roller coaster of emotions***

Shock and denial give way to a roller coaster of emotionality. Family members commonly experience feelings of crippling sadness, anger, guilt, anxiety, despair, terror, and being out of control. Sudden outbursts of tearfulness or expressions of rage are common. With any loss, we frequently experience some level of guilt. When parents have unknowingly passed lethal genes on to their children, feelings of guilt can be quite intense, even though guilt is entirely unjustified. These intense, painful emotions can wax and wane for months, even years.

## **Living with FA**

### ***Life after diagnosis***

Following the initial diagnosis, there can be long periods of stability when the individual with FA can experience low but stable blood counts and can function normally most of the time. A drug such as danazol can maintain and even improve blood counts for years. Following a successful bone marrow transplant, patients may experience decades of stability. Gradually the intense emotionality described above slows down. Waves of sadness, anger, anxiety, and other disabling emotions are far less intense. For many, there can be extended periods when life returns to almost normal: Families pursue work, school, and pleasurable activities, and FA is not the constant focus of one’s life. But FA parents sometimes characterize this stable period as “waiting for the other shoe to drop.” They frequently feel anxiety and dread about the future. With the appearance of new symptoms and the onset of feared or unexpected medical problems, they must deal, again, with the most painful phases of grief.

### ***The healthy sibling(s)***

Families affected by FA often include a child or children unaffected by this disorder. Parents worry about how this illness will affect the emotional stability and coping abilities of their healthy children. The medical and emotional demands of this illness can absorb much, and at times *all*, of the parents' time and attention, especially during times of medical crisis or extended intervention, such as transplant. Parents can feel guilty, fearing that their physical and emotional absence will negatively affect the entire family. Open and honest communication with all family members is crucial. The family needs to consider ways in which the unaffected siblings can obtain support during the most stressful times. Knowing that one is doing the best one possibly can under extremely difficult circumstances can lessen guilt.

*We have a son with FA and an unaffected daughter. I am always aware that I must not let our daughter feel left out, even inadvertently. She must never feel that our son gets all the attention because he is sick, or that he is loved more due to his illness. But I always wonder if I am doing justice to our daughter.*

—Mahazareen Dastur, FA parent

### ***Social isolation***

Feelings of isolation and loneliness are common, as family members realize that their friends deal with problems of a much different magnitude. Usually, parents know no other person in their community whose child has the same disorder. One feels alone, knowing that the hopes, dreams, and expectations that others have for their children may be drastically different from one's own.

Parents, unaffected children, and the child with FA may grieve the fact that the child's physical appearance sets him or her apart from peers. Short stature or missing thumbs can be the subject of other children's curiosity, and all too often, their cruelty. The ache family members feel for a child's unhappiness can be overwhelming.

### ***Chronic weariness***

Dealing with months and years of medical appointments, medical complications, insurance issues, financial concerns exacerbated by FA, and worry can lead to chronic weariness, including physical and emotional fatigue. Some parents describe feelings of low self-esteem and chronic depression. Most parents feel that part of their role is to protect their children from

dangerous, unhappy experiences. They feel helpless and out of control when confronted with the knowledge that they cannot shield their children from a life-threatening condition.

### ***Coping strategies***

*I must use my energy to do something good for others—to put purpose to the pain.*

— Diane Pearl, FA parent

The loss of control family members experience when dealing with a rare, life-threatening, often unpredictable illness contributes enormously to stress and unhappiness. Learning about this disease, treatment options, comprehensive FA treatment centers and future research directions can help family members regain a sense of hope and control. We advise families to attend FA Family Meetings whenever possible, and use that opportunity to ask questions of FA experts and other families. Use the FA Support Group for information and support. Read the *FA Family Newsletters* and pertinent sections from this *Guidelines* handbook. Many families have found that a focus on fundraising for research is an enormously therapeutic outlet, and one that might hasten life-saving results.

*Parents of children with a life-threatening illness also need to give themselves a break. We don't have to be brave and strong all the time, and it's okay not to think about FA or the future all of the time. That would drive me crazy! I call this "conscious denial." When I need to, I step up to the plate and deal with what is necessary.*

—Lisa Mingo, FA parent

Some families have identified positive aspects of dealing with this life-threatening illness. I have yet to hear a parent proclaim that the benefits outweigh the negatives, yet still, this illness has brought surprising insights and changes in life's focus to many. Families speak of having a greater compassion and empathy for the suffering of others. Realizing that a family member's life expectancy may well be limited can instill a deep appreciation of every minute that each one of us is given. Instead of living in the past or future, some families consciously focus on making the most of the present. Some report deeper and more satisfying relationships with family and friends, and an enhanced capacity to appreciate the things they have taken for granted. They

utilize Make A Wish Foundation, take family trips that otherwise would have been postponed, and pack as much enjoyment as possible into the stable times. They look for every opportunity to “seize the day.”

### ***Loss of a child or spouse***

*If you have ever lost someone very important to you, then you already know how it feels, and if you haven't, you cannot possibly imagine it.*

— Lemony Snicket, *The Bad Beginning*

Even when family members are well prepared for the possibility that a child or spouse might die, they often react with shock and disbelief to the loss of their loved one. The most painful emotions of the grieving process return. The rush of support from caring friends and family, the public or private events that follow the death, and the need to survive this intense period can carry one through the initial days of the grieving process. But the enormity of the loss usually leaves the bereaved with overwhelming sadness, despair, and an intense longing for the child who has died. This most painful period can be very extended.

### ***Marital issues***

Some couples report that struggling with a life-threatening illness and the death of a child brought them closer together. For others, their different coping strategies became a threat to their relationship.

Spouses often react in different ways to the death of their child. Some cry frequently and need to express their emotions constantly. Some are uncomfortable expressing their feelings and believe they must project “strength” to their family and friends. Differences in coping often lead to marital stress, as spouses can feel misunderstood, unappreciated, and resentful of one another. Each may feel that the other spouse is unable or unwilling to provide sufficient emotional support. Some couples report an unhappy disruption of their previously satisfying sex lives together. The grieving process can even threaten a formerly strong marriage. Communication between partners about fears, feelings, and needs is essential. Marriage counseling may be crucial to help couples learn to be more tolerant, understanding, and supportive of one another throughout this extremely painful time.

### ***Guilt***

One of the irrational and truly unfair aspects of grieving the loss of a precious child is the extent to which parents often feel intense guilt. Even those who have learned all they could about this disease, followed the advice of esteemed physicians, and tried their best to make the “right” decision at each step of the way can be riddled with guilt when a child ultimately dies. They may blame themselves for going too early or too late to transplant, for picking one transplant center instead of another, for being too aggressive in trying to influence a physician’s decisions – or not asserting their own beliefs strongly enough. They may remember those times they could not be “there” for their child, and dismiss all the hours they spent, in fact, being there. If they felt responsible for protecting their child, they conclude they have ultimately failed. Parents need to reassure themselves that they made the best decision they could at that particular time, that they can never know the outcome of an alternative decision, and that they must learn to be more compassionate towards themselves.

### ***Crisis in religious beliefs***

Parents with strong religious convictions often state that their faith has brought them peace and comfort, and has enabled them to cope with this illness and the death of a child. Many find solace in the belief that everything happens for a reason, their child is in a better place, and someday they will be reunited with the lost child. They state that their religious community has been a tremendous source of help and support.

For others, the suffering and death of a child have caused them to question their beliefs. Some experience a deeply painful crisis as they try to reconcile their firm convictions and the enormity of their suffering. Those who have always believed that “God does not give us more than we can bear” suspect that they have, in fact, been given more than they can bear. Parents who believe that “everything happens for a reason,” even when we cannot understand the reason, wonder what possible benefit could come from the suffering of an innocent child? Those who believe strongly in miracles question why a miracle did not rescue their precious child. A trusted minister, priest, rabbi, or other spiritual leader may be crucial in helping parents work through and come to peace with these most difficult issues.

### ***Other complications of the grieving process***

A grieving family member frequently experiences cognitive and physical changes. One can suffer forgetfulness, memory loss, slowed thinking, confusion, short attention span, and difficulty in making decisions or problem solving. Common physical symptoms include insomnia, headaches, respiratory problems, higher blood pressure, gastro-intestinal problems, and weight gain or loss. Those experiencing chronic grief are themselves at higher risk for serious health problems.

### ***Grieving multiple losses***

*Grief and trauma are cumulative. We can think of each of us as having a "grief bank" in which we make deposits (adding to our griefs/traumas/losses) and withdrawals (letting go of our griefs/traumas/losses). Every loss has a distinct weight and bundle of emotions, and as you move through life, you deposit each into your grief bank. With many losses, your bank becomes quite full, and as you grieve new losses, the contents mix and begin to spill over. Emotions are not just linked to a single loss, but reflect cumulative losses. You begin to grieve pieces of all of your losses at once.*

—Rev. Tom Harshman (summary of remarks)

Families can have more than one FA child, so families can and do experience multiple losses. It is an unimaginable and devastating tragedy to live for years or decades with multiple children with a complicated disorder; one that can pose a series of life-threatening challenges unique to each child, and that can end in the death of two or more children. Each loss reactivates a previous one as a parent relives the earlier emotions of loving and losing another child or children. The experience of grief is compounded and the work of integrating yet another loss is overwhelming. Families dealing with multiple losses need a tremendous amount of support and strong coping strategies to manage the grieving process.

Many FA families have formed a close supportive network. In addition to giving and receiving advice and emotional support, families are also deeply affected by the ups and downs of others in the support network. They grieve the deaths of children and young adults they have met through the support group and at the FA Family Meetings. Ironically, the many medical challenges and ultimate loss of others in this close network can be threatening to other families and can add to the cumulative losses experienced by this unique group.

### ***What helps, and what doesn't***

*Grief is not a disorder, a disease, or a sign of weakness. It is an emotional, physical, and spiritual necessity, the price you pay for love. The only cure for grief is to grieve.*

—Earl Grollman

What helps one survive the most painful aspects of the grieving process varies greatly from one person to the next. In my experience, anti-depressants and even therapy did not help (although both can help many). I finally concluded that I owned this grief, and if life could ever become more bearable, I had to walk right through the middle of the most painful feelings imaginable. I had to cry (incessantly, my husband would say), and I had to express my deepest feelings if a special friend would listen. I needed to live with my immense sadness and the longing for what I had lost. I had to grieve. I also had to find those caring family members, friends, and physical activities that would bring positive energy to my life. I had to walk, immerse myself in the beauty of nature, ski down a mountain, and listen to the classical music that brought peace and joy into my life.

Some find comfort in creative and artistic pursuits, in journaling, in prayer, and in meditation or mindfulness. Immersion in any special passion can be a great source of support. Reaching out to people in need or devoting energy to a cause that serves others can be therapeutic. Many parents affirm that their religious beliefs have been crucial to their emotional survival. And yet some get “stuck” in the grieving process and find it extremely difficult to function over an extended period of time. In these situations, professional help may be essential to move through the most painful phases of grieving.

### ***Recovery: Is this possible?***

*The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same nor would you want to.*

— Elizabeth Kubler-Ross and John Kessler

Parents frequently believe that they will never experience happiness again and that the depression and deep sadness they feel will be with them forever. This

is very rarely the case. Over a period of months and even years, the pain one initially experiences will lessen. Parents find increased energy to engage with other people, to work with energy and purpose, and to follow new pursuits. There is a time when one can laugh again and experience true joy. But I believe that when a parent loses a child, the parent never really “gets over” the loss. Rather, one integrates the loss—it becomes a part of the parent’s being. A persistent, sometimes gentle ache ties you forever to the person you have lost. Many grieving parents believe that this is as it should be. The special relationship you cherished, the precious time you shared, and the essence of the one you lost is forever a part of you. And in spite of your suffering, you might well admit that you were truly fortunate to be the parent of this wonderful human being. Many acknowledge that, in spite of what they and their child have been through, they would forever choose the time they had, than never to have known this child at all.

*At some point, the pain lessens. The hole in my heart shall always remain, but there is healing around that hole, and I carry my daughter in my heart, always.*

—Beth Janock, FA parent

## The Physician’s Role: What Helps and What Hurts

This section refers to the role of the physician, but often, especially during a prolonged hospitalization, an entire team is involved in caring for the patient, including nurses, social workers, physical therapists, and a wide range of professionals. The comments below apply to all health care providers.

### ***How physicians can help***

A patient’s physician is not expected to “treat” the emotional distress of the grieving parents or spouse, although it may be appropriate for the physician to refer the parents or spouse to a support group, grief counselor, or other professional in one’s local community. The patient’s physician, however, has enormous power to affect the emotional state of the family caregivers. The physician can play a crucial role in helping the family move from the depths of despair, anger, and self-blame into understanding the disease, making and participating in a treatment plan, and maintaining hope.

### ***Physician characteristics that help***

Almost all pediatricians or family doctors and even many hematologists have had no prior experience in treating FA patients. The treating physician needs to be willing to learn, eager to explore current literature and to seek out information from experts. The doctor must be willing to invest the time to learn new therapeutic approaches. FA families can help by providing physicians with this updated *Guidelines* book and with pertinent information from scientific symposia and family meetings.

It is extremely helpful if the physician is a caring, warm individual, concerned about the welfare of the patient and aware of the stress the family is experiencing. Treating physicians must be good at both explaining and listening. They must communicate in a language the family will understand. Physicians need to listen to fears and concerns, and answer questions in understandable terms. It is crucial that they give families the *time* they need to ask questions, and listen to their concerns and feelings. Physicians may be helpful in encouraging the family to ask difficult questions that fear may cause family members to avoid. It is all right for doctors to admit they don't know all the answers and to assure families that they will try to find out.

*After suspecting FA, our wonderful hematologist, Dr. Richard Sills, sat down with us very late one night explaining, reviewing, and answering every single one of our questions and fears. He was amazing, intelligent, and compassionate.*

—Beth Janock, FA parent

### ***Maintaining hope***

The treating physician must be honest, straightforward, and frank in discussing the diagnosis of FA. The family needs to know that this is a very serious, life-threatening disorder. False reassurances do not help, nor does withholding information. At the same time, doctors should encourage families to be hopeful. The literature on FA and its gloomy statistics reflect past treatment approaches. Statistics do not include the high probability that bone marrow transplant outcomes will continue to improve, that new methods of gene therapy could change life expectancies, and that future discoveries will improve overall survival rates. Families need to know that scientific discoveries concerning this rare disorder have progressed at a very rapid pace over more than a decade and that many laboratories are actively pursuing new and hopeful approaches.

When appropriate, they need to know that new discoveries could greatly improve the prognosis for their child or spouse.

Depressed parents (and FA parents have reason to be depressed) must work harder than most to be great parents. They can unwittingly create an atmosphere of sadness and worry which permeates every day and which children immediately sense. As a result, the time that is shared between parent and child may not be “quality time” at all. By emphasizing progress and helping to instill hope, physicians can greatly assist in improving the family's quality of life.

### ***Entering into a partnership with families***

Family members should be encouraged to play an active role in the treatment plan. Making families part of the decision-making process enables them to cope with the anxiety, depression, and loss of control they are experiencing. The relationship between physician and family should be one of mutual respect, shared information, and joint decision-making. Caretakers know the patient well and are aware of subtle or abrupt changes in the patient's condition. They can be an invaluable source of information.

The doctor should encourage family members to voice their concerns or disagreements with the treatment plan. Parents and patients are often intimidated by medical authority, or fear appearing foolish by asking inappropriate questions. But they must live with the results of any medical intervention, so they must understand and agree with decisions. Often, decisions are not clear-cut. Outcomes are unknown and risks are enormous. Family members must believe that the most appropriate decisions were made, given what was known at the time. When they are ill-informed and have never voiced their questions or concerns, they may forever feel guilty if the outcome is not good.

### ***Being responsive to patient needs***

A doctor's responsiveness and empathy with the patient helps foster a good relationship with other family members. When the physician is warm, caring, and concerned about the patient, parents feel positively towards that provider. Whether the patient's immediate concerns are about pain, nausea, fear, or side effects of treatment, these concerns need to be addressed in a caring manner.

Parents are terrified that their child will experience unmanageable pain. I believe that a great deal of pain can be eliminated when pain management is

a priority. Bone marrow aspirations and biopsies can be performed under very short-term, general anesthesia, leaving the patient with a less painful experience. Bone marrow transplant centers have done this routinely for years. But outpatient clinics, aware of the importance of this issue, may be able to offer the same service.

Even though total anesthesia is more costly and the assistance of an anesthesiologist is mandatory, the children and adults who must experience these procedures on a regular basis should not have to endure unnecessary pain. On very rare occasions, a patient's clinical status makes total anesthesia unusually risky. However, in many cases in which patients are not provided with total anesthesia, it is simply because it is not suggested or offered by the physician or care facility, not because it is unavailable.

### ***Communicating diagnostic results promptly***

Family members experience much agonizing distress while waiting for the results of clinical tests. From a simple CBC to a full-body CAT scan or MRI, parents or spouses wait with excruciating anxiety for results which may tell them if their loved one is doomed to die soon or has dodged a terrible diagnosis. For many, the waiting process is more painful than dealing with the results. Once one knows the extent of the problem, he or she can begin to deal with it. The treating physician should make sure that family members get crucial information as soon as possible. If the news is catastrophic, it is important that the patient's primary doctor deliver the bad news if at all feasible.

### ***Encourage normalcy***

When appropriate and within prudent medical guidelines, physicians should encourage patients to live as normally as possible. Sometimes it is necessary to curtail physical activity, but simple measures such as a protective helmet or other modifications might make normal activities possible. When platelets are so low that participating in any contact sport is not wise, there may still be a role for a child in assisting the coach, thereby maintaining involvement with the team. Consideration should always be given to maximizing the quality of a patient's life.

### ***Being "there" for a family when a patient's condition worsens***

When a patient's condition worsens suddenly or when he or she approaches death, a physician should not suddenly withdraw from the family. Many families report that this occurs. They suspect that doctors need to protect

themselves from the family's emotional response and the physician's own feelings of grief. But families desperately need support at this time, and are deeply grateful when physicians are able to empathize with them during the hardest times. When appropriate, physicians should connect families with the palliative care staff if this service is available. Some parents struggle over how or if they should approach the subject of death with a child. The physician, a spiritual counselor, or a palliative care specialist may be able to help parents with this extremely difficult discussion.

***Attitudes and behaviors that do not help***

Family members have openly discussed physicians' behaviors that are not helpful. The doctor who knows little or nothing about FA and has no time to become informed is not helpful. Doctors who appear cold, distant, and unsympathetic do not gain the family's confidence. Physicians who speak only in complicated medical terms, have little time to answer questions, or are rushed or impatient are not helpful. Doctors who deal with families in a condescending way, or do not consider the family's input, contribute to emotional stress. And physicians who have no time or ability to empathize or listen to a family member's distress are perceived as aloof and uncaring.

*Our adult daughter is pretty much housebound now. She grieves that she hasn't been able to pursue her dreams of a career and family. When doctors ask her what she does for work or fun she is upset and embarrassed, and grieves the life she is unable to live. Doctors need first to listen to her, ask what she is able to do, and acknowledge how hard it is to live with FA.*

—Lynn Sablosky, FA parent

One of the most difficult decisions families may face is which medical center to choose for a bone marrow transplant. Families appreciate physicians who help them review their options with unbiased objectivity, focusing only on the needs and best possible outcome for this particular patient.

*I find it extremely upsetting when doctors get defensive when you ask if your child should be transplanted at another medical facility (i.e., one with expertise in transplanting FA patients). The doctor should recommend what's best for the patient. It can be very confusing for a parent trying to make the best decision possible, and a doctor's defensive attitude can add a lot of stress to one's daily life.*

—Lisa Mingo, FA parent

Many parents tell stories of doctors who informed them that their child would probably die within a specific period of time or before reaching a certain age. These comments have devastated parents and have frequently proven to be untrue. Too much is unknown about how any one FA individual will progress. The positive impact of future therapies is obviously unknown and cannot be addressed in the medical literature available today. Doctors who are noticeably missing when bad diagnostic news is delivered or who never come to see a dying patient bring additional pain to a grieving family.

The physician with endless time to research an orphan disease and provide ideal patient care may be difficult to find in these times of work overload, managed care, and pressures from other patients equally in need of quality care. But having dealt with this illness for over thirty years, this writer has observed enormous variance from one physician to another in terms of his or her ability to work with families burdened with a life-threatening, chronic illness. Families should try to identify physicians who can best meet the patient's physical and emotional needs. Physicians should become more aware of and responsive to the needs of this unique group of families.

## **Postscript**

No one should have to endure the devastating, life-long heartache that follows the loss of a beloved child or young adult. In an effort to spare other families what we have experienced, we and others have worked tirelessly to raise funds to advance scientific and medical discovery. In the last 25 years, our combined efforts have greatly extended the lives of individuals with FA. Bone marrow transplant outcomes have improved dramatically since our own children desperately needed healthy marrow. The discovery of FA genes sheds light on the basic science underlying our disorder, and researchers are developing new drugs to prevent and treat the cancers that plague individuals with FA. The discovery that aldehydes are uniquely toxic to the DNA of individuals with FA suggests new therapeutic strategies. We will continue to devote our lives to this cause. We have growing faith in the accelerating pace of scientific progress, justifying our fervent hope that, in the future, families will no longer experience the painful grieving process described in this chapter.