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Reflections on Dealing with Adversity

By Dave and Lynn Frohnmayer, with introduction by Tom Elden

For what will we be remembered? If we are lucky, excellence in our chosen profession, compassion when dealing with others, or a general commitment towards the greater good. I suspect Dave Frohnmayer and his wife, Lynn, will be remembered most for how they responded to tragedy with charity, and to loss with new hope.

Dave Frohnmayer hardly needs an introduction. A Harvard graduate (magna cum laude) and Rhodes scholar, Dave was active in the Salem legal community from 1981 to 1991, having been elected Attorney General after serving three terms in the Oregon House of Representatives. Dave successfully argued before the United States Supreme Court, prevailing six of seven times, before embarking on a storied academic administrative career at the University of Oregon, first as the Dean of Law School, and later as President. Now living in Eugene, and "of counsel" with Harrang Long Gary Rudnick, P.C., Dave remains a good friend of the MCBA, and has returned to Salem several times to help with CLEs.

Lynn also led a distinguished career. After graduating from Stanford University, Lynn served in the Peace Corps in Ivory Coast from 1964 to 1966. She also spent several years working to improve the lives of children, including with a stint as the branch manager of the East Lane County Children's Services Division. From 1975 to 1985, she gave workshops in 25 states on methods for securing permanent homes for children in foster care. In recent years, Lynn has been a dedicated writer and organizer for the Fanconi Anemia Research Fund (the "***Fund***"), which will be discussed in greater detail later. Lynn attends all of the Fund's meetings, including symposia and science workshops. Lynn also serves on the Fund's grant review committee and board of directors, and is an editor of its various publications.

Sadly, no amount of accomplishments can immunize one from the frailty of human existence, the cruelty of disease, or the inevitability of loss. We cannot control tragedy, but we can control how we respond to it. Often, an individual's response to tragedy is a reflection of that individual's character.

Dave and Lynn Frohnmayer, with their daughter Amy and sons Jonathan (left) and Mark (right)

Dave and Lynn's tragedy came in the form of Fanconi anemia, a rare recessive genetic disease which stole from them two daughters: Katie at age 12, and Kirsten at age 24. A third daughter, Amy, continues to battle the disease.

Though Katie and Kristen are gone, their stories live on through their loved ones. Additionally, donations from DOJ employees and MCBA members funded memorial plaques for each girl, which can be found on Capitol grounds. When you exit the east end of the Capitol, walk towards the statue of the Circuit Rider, and make a quick turn towards State Street. The plaques are located by the Magnolia tree.

In the face of such great losses, the Frohnmayers put aside their personal grief, and harnessed their heartbreak, intelligence, courage, and faith. Their resolution: to fight Fanconi anemia, so that other families might be spared the same tragedy. Recently the Frohnmayers received the 2012 Outstanding Service Award from the American Society of Hematology, honoring their vision in founding the Fanconi Anemia Research Fund. This is their story.

A Devastating Diagnosis: How We Began

Our family's journey began in 1983 when our ten-year-old daughter, Kirsten, was diagnosed with Fanconi anemia (FA), a genetic disorder that leads to bone marrow failure, leukemia, and cancer. We later discovered that our two other daughters, Katie and Amy, had inherited the same disease; our two sons, Mark and Jonathan, had not. We learned that patients rarely lived to adulthood and that there was no known cure for this illness. We were utterly devastated by this shattering news.

We began to read the available literature on FA, and systematically called the authors of every article we could find. Scientists were uniformly generous with their time, while acknowledging that this was a fatal and poorly understood genetic disease.

Early Outreach to Families

In 1983, we knew of no other family in the world with Fanconi anemia. We were depressed, terrified, and lonely. A researcher at The Rockefeller University, New York, had developed a registry of all known cases of FA, and in 1985, she suggested that we start a support group. She agreed to mail our letter to families in her registry, inviting them to communicate with us. We readily agreed. Nineteen families responded, and our informal support group was launched. Back in 1985 there was no Internet – no helpful search engines. Our early communications were by telephone and letter. We began to write *The FA Family Newsletter* to share with families what little knowledge we gleaned from scientists.

Starting a Non-Profit Organization – Our Naïve Beginning!

In 1988, a scientist from The Rockefeller University, New York, asked us to raise $50,000 for research. We promptly wrote to all our friends, family members and acquaintances, asking that they make a contribution to The Rockefeller University. In 1989, *three* institutions asked that we raise research dollars for their investigations. We again wrote to all our contacts, this time asking that they write checks to the "Fanconi Anemia Research Fund" (which did not yet exist) and send them to our home address. We then stacked these checks in three equal bundles and sent them to the three requesting institutions. How naïve we were! Two of the three research centers sent the checks back, since they could not cash them as written. We hurriedly decided to form a 501(c)(3) charitable corporation, named it the Fanconi Anemia Research Fund (the "Fund"), formed a Board of Directors, established Articles of Incorporation,

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and secured non-profit status from the Internal Revenue Service. Our new organization then prepared three checks to the appropriate requesting institutions and we were launched!

Convening Our FA Researchers

One of our earliest steps after our incorporation in 1989 was to bring researchers together for a brainstorming session. We invited almost every scientist whose name appeared as the primary author of a publication on FA, and others suggested by those scientists. We needed their strong guidance as we began to plot our strategy. Eighteen researchers, whom we asked only to "bring your brains," sat around an oval table in a Portland office bank building. Together, we drafted what would become our guiding principles, and developed a five-year plan to better understand this baffling disorder. These guiding principles have continued to define our work over the past 25 years and are summarized as follows:

1. Scientific collaboration would be crucial. FA is a rare disease, mandating a strong need for sharing insights and data, as opposed to scientists operating in isolation in competitive, secretive, warring camps. We would give special consideration to research grants that emphasized this principle.
2. We would adopt a multi-disciplinary approach. It was crucial to have the insights of basic researchers, transplant experts, other treating physicians and even FA families. Holding the interest and attention of these disparate groups continues to be one of our strongest challenges.
3. We needed to convene regular, face-to-face scientific meetings. Every single year, we would host a Scientific Symposium, where scientists would present their recent, often-unpublished findings, and submit their conclusions to the questions and scrutiny of the entire group. We could not pay salaries but would assume travel expenses. These intensive, productive gatherings have proved crucial to the advancement of FA science.
4. We would always seek out the best science possible. All grant proposals would undergo peer review by experts in the field. Grants would be scored using guidelines developed by the National Institute of Health (the "*NIH*"). We would create a Scientific Advisory Board. That group would meet with our Board of Directors every year, advise the Fund, and provide input into research direction.
5. We would give relatively small, start-up grants, enabling promising researchers to obtain much larger grants from their institutions or a government entity like the NIH.
6. We would immediately initiate a five-year "Gene Identification Project." Scientists attending our first scientific gathering did not know if one, two or even more genes, when mutated, caused this disorder. We needed to discover the exact number of these genes and then identify or "clone" them. Finding the gene or genes, then understanding the function of the proteins encoded by FA genes would be crucial to devising a rationale strategy to treat this disorder.

Family Engagement as a Central Strategy

Early in our effort, an FA mother suggested to David and me that we should convene a family meeting. David and I were skeptical, doubting that family members, already overwhelmed by this difficult disease, would ever come to such a gathering. We encouraged this mother to organize such a meeting, but cautioned her that such an effort was likely to be disappointing. How wrong we were! One hundred people came to that first meeting! It was the first time most of them had ever met anyone else with FA, the first time they had shared their fears, hopes and experiences with another FA parent.

Since that first event, we have held FA Family Meetings every year. We bring scientists and clinicians to five-day gatherings to present the latest research and treatment discoveries. We include support groups for parents and patients, recreational activities for the children, and give family members an opportunity to participate in various research projects. Scientific progress has benefited enormously by the availability of biological material (mouth swabs, saliva, even blood) from a large group of FA patients. This annual event has cemented many supportive friendships and given parents and patients valuable information on treating this disorder. We have added an annual FA Adult Meeting in an effort to meet the special needs of our growing adult population.

We now have 885 families (including 623 FA patients— 295 of whom are adults) who have registered with our family support group. We serve a large group of unregistered families as well. Over 100 affected families raise the funds that power our program. Their efforts now raise approximately two million dollars on an annual basis. Fundraisers include cookie sales, garage sales, 5K walks and runs, fund raising letters, benefit dinners, concerts, golf tournaments, cow plops, raffles and a variety of other creative events. Families raise funds in the fervent hope that scientific discovery will make a difference in the lives of their children— and all patients struggling with this disorder.

We are an international support group. Families from Europe, Canada, South America, Israel and elsewhere attend our annual family and adult meetings. Eleven other countries have established family support groups. Several of these groups raise funds to support FA researchers in their own countries.

What Have We Accomplished Over the Past 25 Years?

We have now funded 190 scientific grants from 55 research centers, for a total cost of $16,183,280. These grants plus our regular scientific symposia have produced impressive results:

1. In 1989, no FA gene had been discovered. Researchers have now discovered 16 different genes that cause this disorder. Four of the FA genes are also breast cancer susceptibility genes (including BRCA2), discoveries that brought a new host of cancer scientists to our scientific meetings and placed our orphan disease in the middle of cancer research in general.

2. Gene discovery enables researchers to study the function of proteins encoded by genes. Scientists have established that our gene network is intimately involved in DNA repair and prevents cancer when FA genes are functioning normally.

3. The first manifestation of FA is usually bone marrow failure or leukemia. A bone marrow transplant is the only current cure for this devastating complication. FA bone marrow transplants have improved dramatically over these years. When our daughter, Katie, desperately needed a bone marrow transplant in 1986, no center in this country would do the transplant because she had no matched sibling donor. The National Donor Program was just formed in 1986 – an unrelated donor transplant was not yet an option for her. When daughter Kirsten developed leukemia in 1995, several centers were willing to do an unrelated donor transplant, but her chances of survival were 20%. In 1999, our research fund gave the University of Minnesota a grant to determine if one drug, fludarabine, could improve transplant outcomes. This proved a "game changer." Almost immediately, success rates reached 60%. Today, at any one of our three FA Comprehensive Treatment Centers, 85%-90% of patients survive their transplant. At least half of the patients attending our FA Family Meetings are transplant survivors, now back to school or work, living a productive life. We never saw this at earlier family gatherings!

4. We have turned our focus from basic science to developing better treatments for patients. Scientists are exploring a large number of compounds or drugs that might protect the cells of patients from damage. One of these is now in a clinical trial. We are optimistic that two more compounds will be in clinical trials during the next two years.

5. In addition to our large Scientific Symposia that attract over 200 researchers every year, we also hold small workshops on areas of specific interest, such as bone marrow transplantation, squamous cell carcinoma, identification of new drugs to treat patients, and gene therapy. Much of our progress has resulted from these dynamic meetings.

6. We produce two comprehensive newsletters a year (we just completed the 54th edition of the FA Family Newsletter) to keep families abreast of progress. We have published three editions of ***Guidelines for Diagnosis and Management,*** a comprehensive treatment guide for physicians and families. We will publish a 4th edition in 2014. This book is available in Spanish and in German, and is widely disseminated at national and international hematology and genetics meetings.

7. We now focus on prevention and early detection of oral cancers, a huge concern in this population. We support the work of a German team that routinely examines the oral cavities of FA patients worldwide, looking for lesions that suggest early signs of evolution to cancer. The hope is that very early detection will greatly improve survival outcomes. We fund scientists working on methods to eliminate precancerous cells.

8. FA patients are living longer and better. We estimate that life expectancy has increased by at least a decade since the inception of our Fund. The majority of patients now survive bone marrow transplant, which can give them extra decades of life. The fervent hope is that new treatments will continue to improve quality of life and greatly expand the life span of our patient population.

We still race the clock, hoping to foster breakthrough discoveries and therapies for beloved patients that might follow from them. While the challenge was uninvited and unwelcome, it has long been a central mission of our lives.

To learn more about the fight against FA, the cancers that afflict this population, and the heartwarming progress made over these years, see www.fanconi.org.