WHY RESEARCH MATTERS
How one family transformed grief into action
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Three decades of advancing treatments and supporting families

Thirty years ago, David and Lynn Frohnmayer invited a group of Fanconi anemia researchers to a meeting in Portland, Ore. The 13 researchers who attended that meeting, along with the Frohnayers, developed the guiding principles that have driven the work we do here at the Fanconi Anemia Research Fund (FARF). These principles laid a foundation based on collaboration that continues to define the research we fund, the partnerships we form, and the way we engage with one another as a community. Throughout this newsletter, you will read about how your gifts empower our community to work together and the impact of 30 years of research and family support.

Philanthropy is often the first step toward new breakthroughs. Donors like you make it possible for the brightest minds to come together and push research and therapies forward. A couple of months ago, your gifts allowed us to hold the 2nd annual Joel Walker Meeting on Head and Neck Cancer. From this meeting, we established a plan to form a virtual tumor board so that individuals with FA have access to the right doctors when they’ve been diagnosed with cancer.

Your gifts enabled us to work with the National Organization of Rare Diseases (NORD) to develop a clinical registry, which launches this summer. The registry will track the natural history of disease in people with FA and provide valuable information to scientists and clinicians as they work to advance treatments.

Such treatments include gene therapy. Thanks to you, we have supported research into gene therapy for many years, and we are seeing progress from ongoing clinical trials in Spain and in the USA. In this newsletter, you’ll read about research in real life, as one family participating in a gene therapy trial shares their story, fears, and hopes for the future.

With your help, we are moving closer to a future where people diagnosed with FA live vibrant, happy, and long lives.

With gratitude,

Mark Quinlan
Executive Director
Fanconi Anemia Research Fund
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Thank You Notes
In 1983, Oregon parents Lynn and David Frohnmayer learned their two daughters, Kirsten and Katie, had Fanconi anemia (FA). They would later find out that their third daughter, Amy, also had the disease. At that time, the Frohnmayers were told that patients with FA rarely live to adulthood and that there is no cure for this illness.

In 1989, the Frohnmayers founded the Fanconi Anemia Research Fund (FARF). Thirty years later, all three Frohnmayer daughters have died from complications of FA. At the 30th Scientific Symposium in late 2018, Lynn Frohnmayer addressed the audience, speaking about her family’s story and the progress made in three decades of FA research. Her whole speech is available as a video at www.fanconi.org. What follows are highlights from her address.

The Beginning

In the early 1980s, things were going extremely well in our family. We had wonderful children who were smart, kind, and seemingly healthy. I remember going to the beach in Oregon, looking at my lovely family and thinking: ‘I have got to be about the luckiest person I know.’ Alas, that happy picture was not to last.

Over the course of the 1980s, we were to learn that of our five children, all three of our daughters had Fanconi anemia. We were told it was a fatal disease, that kids usually died in the first two decades of life, and very few ever lived to adulthood. Therapies then were practically nonexistent. I just do not have the words to tell you the extent of the anguish we felt.

One of the harsh realities of life is that we’re not always in control of the things that matter to us the very most of all. We all do the best we can with what we have been given, and sometimes we’re fortunate to see that progress, and even great good, can come from our own misfortune.

Gene Discovery

David and I founded the FA Research Fund in 1989. Our first priority was to discover the FA gene. We now know that mutations in any one of 23 different genes cause FA. Five of our 23 genes are breast cancer susceptibility genes (including BRCA1 and BRCA2), discoveries that put our rare genetic disease in the mainstream of cancer research. All of our FA genes function in the FA/BRCA pathway, and their main job is to protect and repair the genome. But the proteins encoded by these genes have functions independent of DNA repair. Some are involved in controlling oxidative stress, some in protecting against endogenous aldehydes and inflammation, and others in enhancing stem cell survival.

Bone Marrow Transplant

We’ve come very far in improving bone marrow transplant outcomes. In 1986, our daughter Katie needed a transplant, but she did not have a matched sibling donor and no center would perform the transplant. When daughter Kirsten developed leukemia in 1995, centers were willing to transplant her but gave her only a 20% chance of survival.

In 1999, Dr. John Wagner did a trial to see if one drug, fludarabine, could make a difference. Practically overnight, success rates went from 20% to 60%! Today in the United States at our three major FA transplant centers, success
rates for unrelated donor transplants are approximately 90%. As a result, we are seeing a huge improvement in survival.

Cancer

I wish we could declare victory and go home, but because of increased longevity, the next shoe to drop is cancer. Back when we founded FARF in 1989, one FA researcher estimated that 2% of the FA population would get cancer. Our 2014 Clinical Care Guidelines stated that from birth to age 40, about 14% of FA patients would develop oral squamous cell carcinoma. But when you consider only the adult FA population, the numbers become alarming. A German study of 142 individuals from ages 18 to 45 showed that 35% had developed cancer, with the likelihood increasing steadily with age.

What is FARF doing to get ahead of this huge challenge? We now have two full-time scientists on our staff working on this problem. We’re committed to holding small cancer workshops annually. We’ve developed an adult cancer registry. We’re giving grants to researchers who are working hard to identify ways to prevent and treat FA cancers.

A Request to Researchers and Doctors

I suspect that every single FA family member in this room has an overwhelming sense of urgency. Families depend on us to find answers, to identify drugs and better approaches to prevent and treat malignancies.

I make one request of all you scientists and treating physicians: that you share our families’ sense of urgency. It’s not enough to identify a hopeful compound or to write an article and get it published in a scientific journal. Those efforts won’t help patients until we put promising drugs into clinical trials. Not everything we do will be successful, but we must take reasonable chances and move very aggressively to tackle this problem. Our young adults desperately want and deserve a chance at a full lifespan, and depend on all of us to make that hope a reality.
WHY RESEARCH MATTERS
How our family channeled grief into hope

By Zachary and Rachel Gratz-Lazarus

Our Mighty Mouse

Well before her diagnosis of Fanconi anemia (FA), our daughter Norah was a model in resiliency for us. Born at just five pounds and three ounces, she had the strongest heartbeat on the hospital floor, surprising us and her doctors. It was a high-risk pregnancy because she wasn’t growing as much as she should have been. In the third trimester, we had to attend non-stress tests several times a week to make sure that Norah was not under any distress. Norah’s mom was scheduled for an induction, much to our chagrin.

Despite all of the doctor’s concerns, Norah was a rockstar. We ended up having an eight-day induction. Though Norah was not quite ready to join us, she showed no signs of ill health. The head OB/GYN even sent us home for 24 hours halfway through the induction.

When she was finally born, we called her Mighty Mouse. Small, but resolute. Our model of resilience. Our first born. Our Norah.

The Diagnosis

We received Norah’s diagnosis in stages. She was born with hearing loss that turned out to be progressive in at least one ear. Her doctor was concerned. Progressive hearing loss in children is rare. Progressive loss in one ear, even more so. The pediatrician sent us to get a blood draw (the first of many) and referred us to the genetics department. When the blood tests returned with decreased platelets, we knew something wasn’t right.

We first heard the words “Fanconi anemia” over the phone with our pediatric hematologist/oncologist. Getting the diagnosis sent us into a tailspin. We cried every day for weeks. Norah’s dad immediately regretted a decision he made in college to not take as many science classes. A DNA-repair disorder? We had our work cut out for us.

Bewildered, we started doing our homework. What’s the course of treatment? Who in our communities has expertise in FA? Most importantly, what can we do to take control over our circumstances and best care for Norah?

And so, with the FA diagnosis in hand, our family started putting the puzzle pieces together. We learned that hearing loss and small stature were related to Norah’s diagnosis, among other challenges. We reached out to the Fanconi Anemia Research Fund (FARF), read what we could stomach and watched videos on cell biology so we had a better sense of what the doctors were discussing. We turned to Norah, our dancer, singer, and bookworm, for help staying present.

Lucky is a challenging word to describe our change of circumstances, but despite our ignorance in cell biology, we felt lucky to have some of the tools we needed to face this challenge head on. Rachel works in public health doing policy work and has a background in early childhood education, race and health equity issues. Zach has worked in community organizing and as a social worker in community mental health settings. We started taking the bull by the horns: channeling our grief into hope, teaching our children to love themselves, and fighting for life.

The Norah Needs You Campaign

Part of the FA diagnosis is facing the reality that Norah may one day need a bone marrow transplant. When we learned that there were no perfect matches in the bone marrow registries, we reached out to Be the Match and Gift of Life (which specializes in working with Ashkenazi Jewish populations) to build bone marrow donor campaigns. We leaned into our community to host bone marrow drives, connect us with media, and to help publicize the search. Rachel used her incredible skills as an artist to build a website (www.norahneedsyou.com), while Zach reached out to an old friend in the California State Assembly. With the help of State Assemblyman Marc Berman, we passed legislation to encourage people to join the bone marrow donor registry. The work snowballed from there. As of July 2019, we have registered roughly 8,000 people as a part of our Norah Needs You campaign.

None of this, of course, would have been possible without the tremendous support
Norah with her parents (top), at the California State Assembly (bottom left), and with Dr. Agnieszka Czechowicz at Stanford University for the gene therapy trial (bottom right).
from our friends, family, co-workers and community at-large. And it has not come without hesitation: we are constantly concerned with the emotional well-being of both of our children (including our three-year-old son Ellis, who does not have FA). Being so public with FA feels scary. And, while being the parents of a child with FA is our story, actually having FA is not. We have robbed Norah, to some degree, of her anonymity in the hopes of finding her a bone marrow match and to help save as many lives as we can. We hope that, with time, this knowledge gives her pride and a sense of meaning.

**Gene Therapy**

While the bone marrow registry continues to grow thanks to the Norah Needs You campaign, Norah herself still does not have a perfect match for when she may need to have a transplant. This is the case of other kids and adults with FA, too. Decades of research have made transplants for people with FA much safer, yet researchers continue to ask, what if there’s another solution to bone marrow failure? Particularly, what if we could repair the gene itself, therefore fixing the bone marrow and potentially avoiding the need for a transplant? That’s where gene therapy comes in. Donor gifts to FARF have funded basic science studies into gene therapy for many years, and there are now two clinical trials open for people with Fanconi anemia.

Within months after Norah’s diagnosis, we learned about a gene therapy trial that had just opened 25 miles from our house. Our timing was serendipitous. After a series of referrals, we reached Stanford’s gene therapy team just a couple of months shy of the opening date of the trial. Despite the exploratory nature of clinical trials, the team had data from two prior studies that demonstrated both a lack of negative short-term effects and hope for the possibility of avoiding a transplant.

Blessed that the trial was opening, that Norah was eligible, and that there was a spot available, we did our best to make an informed decision. Within months of the diagnosis, we had to make a decision whether to enroll our daughter in this experimental trial. We needed to talk with the experts. We spoke with doctors at Fred Hutch in Seattle, Cincinnati Children’s Hospital, University of Minnesota, Children’s Hospital of Philadelphia, University of California San Francisco, Dana Farber Cancer Center, and others. Through FARF, we reached out to parents whose children had participated in previous gene therapy clinical trials.

The information we received was overwhelming and confusing: risks unknown, benefits questionable. But, at the end of the day, the level of monitoring was going to be similar whether we went forward with gene therapy or not. Either way, regular blood draws and biopsies were in our future. The question was: would we have hope for improvements? Or simply hope for stability and a slow, albeit expected descent. We voted for hope.

Now, as with everything else, time will tell. All we can do is be honest with our feelings, empowered in our actions, give Norah every tool we can think of, and take one step at a time.

We are so grateful for FARF, the FA families, and donors for all of the incredible work that’s happened over the last 30 years, giving us reasons to hope, ways to connect, and knowledge to share. Thank you.
Donor Newsletter 2019

That low number is not a result of Duncan being dramatic or pessimistic. He’s trying to be realistic given that he has Fanconi anemia (FA). This makes him 500-700 times more likely to get cancer than people in the general population.

This statistic is brutal. It’s heartbreaking!

It’s overwhelming!

Yes, I am yelling. I am crying. It is crushing to me and it’s not even my timeline. While I was barely beginning my adult life at 28, my son may be near the end of his, struggling with quality of life. For most parents it’s virtually a given that their children will outlive them. It’s a common expectation that our children live easier and more fulfilling lives than we do.

But those expectations are not a given for Duncan. Those expectations are not even a dream in Duncan’s case. They are more like a fantasy, because like all people with FA, he is extremely likely to experience bone marrow failure and cancer that could end his life prematurely. Writing that last sentence feels like a bit of a betrayal of hope and I hated writing it. As his mom, I wish I could give him more days. I’d give him mine if I could. But that’s not possible. I can only resolve to give some of my time to try to raise funds for research which could ultimately give him those days.

We all know someone who has battled cancer and maybe even lost their battle eventually. You may have even fought that battle yourself, and maybe you are still in the trenches. Wouldn’t you love to help prevent other loved ones from having to fight that fight? Some people afflicted with FA have had over 100 cancers, so you can see why FA is a model disease for cancer research.

Donating to the Fanconi Anemia Research Fund (FARF) can give you a sense of taking a bit of control over cancer. Because FARF funds prevention studies, it’s also logical to donate. Think about how much you spend on your health every year. How much of that is for paying for insurance or for medicine for a condition you already have? How much of what you pay goes to medication to treat the side effects of other medications? And then compare that with how much you put toward maintaining your health and preventing illness. Let’s say we pay 80% for treatment and 20% for prevention. It seems to me if we evened out or flipped this distribution – if we resolve to spend more proactively on potential health issues by funding research into prevention and cures – we would definitely spend less overall in the long run for our health.

Dreams can come true

It happens. Not every day, but sometimes they do. Dreams come true because someone takes action, not because of divine intervention or magic or good luck. Dreams are less likely to come to fruition if we don’t believe in them. They can come true if we persistently work at them. We must befriend them, feed them, and fund them.

I dream that all cancers will be 100% curable, and that precancerous cells can easily be detected and treated prior to Stage 1. And of course, I dream that Duncan’s FA will be cured and he can have a normal life timeline.

Duncan graduated from college last year with a degree in Cell and Molecular Biology. He has been working with a team at the University of Rhode Island on, you guessed it, FA research. His goal is to have his doctorate degree and have a career researching FA. He recently started a new job at Novartis Institutes for BioMedical Research in Boston. His resolve is to make an impact for the world, for his friends, and for himself.

Writing this article is painful, maddening, and slap-in-the-face real. Yet, I had to write it in the hope that you would read it. Because if you read it, then maybe you will feel at least a little of Duncan’s angst. And if you feel his angst and his resolve, then maybe you will resolve to do something to help ease it. FA is not contagious, but I hope the inspiration and resolve to CURE it is.

With deepest gratitude,

Nancy Nunes
Strides in Research

Applying cancer-fighting strategies from the general population to the FA population

To fast-track therapies for people with Fanconi anemia (FA), it’s often best to start by examining progress that’s already been made in the general population. Large-scale studies such as The Cancer Genome Atlas (TCGA) have made it possible to detect abnormal chromosomes and mutations that lead to cancer in people without FA.

According to Dr. Carter Van Waes, the clinical director and chief of head and neck surgery at the National Institute on Deafness and Other Communication Disorders, data from the TCGA study of 1,400 squamous cancers can provide clues for FA researchers as to which abnormalities in FA tumor cells can be exploited for treatment purposes. TCGA results showed that all squamous cell carcinoma (SCC) tumor cells – despite their site of origin – share common characteristics, exhibit DNA mutations, and have changes in the number of chromosomes that can lead to cancer. This finding could make them more sensitive to certain therapies where DNA damage helps kill cancer cells.

How do we apply this in FA? FARF-funded researchers and others are currently studying whether the characteristics observed in SCC cells in the TCGA study also occur in FA squamous cell carcinoma. If similarities exist, the goal would be to test targeted therapies that work in the general population on FA patients with cancer.

One such researcher, Dr. Ruud Brakenhoff of the Cancer Center of Amsterdam, is working on noninvasive diagnosis and targeted treatment of oral precancers. Detecting precancer before it becomes cancerous gives us the opportunity to stop it before it requires aggressive treatments that could be detrimental for people with FA. Dr. Brakenhoff’s study typically showed that FA tumors have many DNA mutations, making them similar to the SCC tumors in the general population analyzed in the TCGA trial.

The Dutch group is now investigating the potential toxicity of drugs targeting certain proteins in FA patients. Once the safety profile is determined, the intent is to develop clinical trials in people with FA. This therapeutic method would: 1) screen for precancers, 2) treat precancerous lesions once they’re detected, and 3) monitor for progression to cancer.
Donors enable 2nd Joel Walker Meeting on Head and Neck Cancer

One of the most effective ways to make progress on the issue of cancer in Fanconi anemia is by forming a dedicated focus group of experts to work on the issue. This spring, we held the 2nd Joel Walker Meeting on Head and Neck Cancer. More than 20 specialists attended, including surgeons, oncologists, radiation-oncologists, oral medicine specialists, pathologists, epidemiologists and basic science researchers. The main takeaway from the meeting was that the FA community needs a Virtual Tumor Board (VTB) to help with developing clinical care plans.

A Virtual Tumor Board is a group of medical care specialists and other health care providers who, when required, meet to discuss cancer cases and share knowledge through a virtual platform. The board’s goal is to determine the best possible cancer treatment and care plan for an individual patient. This would be a tremendous help for individuals with FA who are diagnosed with a tumor and in need of an individualized treatment plan. As it stands now, most physicians do not know how to treat a tumor in a person with FA, leaving that person with very few options. FARF is now working with clinicians from the Joel Walker meeting to develop this Virtual Tumor Board.

Making bone marrow transplants safer

Thanks to many of your gifts, we have seen vast improvements in bone marrow transplants for people with FA. However, there is still more to be done to make transplants safer. Current transplants require use of irradiation and/or chemotherapy, which can be extremely harmful, especially to people with FA, whose cells cannot fix DNA damage caused by these agents.

One of FARF’s goals is to help develop a way to eliminate toxic treatments used for bone marrow transplant. Your contributions allowed us to fund a study at Stanford University focusing on just that. Researchers, led by Dr. Agnieszka Czechowicz, of the Center for Definitive and Curative Medicine, are investigating an antibody that targets a receptor on the surface of stem cells. This antibody eliminates stem cells with a non-functional FA pathway in bone marrow prior to transplant with donor cells. Using this antibody could reduce the need to use toxic radiation and chemotherapy, which could reduce later cancer risk. This basic science study was funded thanks to donors like you and will soon be translated to a clinical trial developed at Stanford.

Ten young investigators jumped into the FARF Tank...two came out!

The FA scientific community is growing each year. One of our core principles is mentorship and supporting the next generation of FA researchers. That’s why we developed FARF Tank, to allow up and coming researchers an opportunity to pitch their innovative ideas to the scientific community and win a $10,000 grant. The first ever FARF Tank took place at the 30th Scientific Symposium in 2018. Ten contestants had five minutes each to describe their ideas to nearly 400 audience members and our panel of judges. At the end, the audience voted for the project with the most potential to shift the clinical care paradigm for people with FA. The judges also chose a winner. The two winners will return to this year’s Symposium to present on outcomes from their research.

*People’s Choice Winner: Allison Bartlett (Cincinnati Children’s Hospital Medical Center) for “Serotonin – A Novel Target in FA”*

*Judges’ Choice Winner: Lianne Vriend (Amsterdam University Medical Center) for “Addition of mild hyperthermia to improve treatment of FA/BRCA pathway deficient head and neck cancer in Fanconi anemia patients”*
Investigating a different approach in gene therapy

What about the ultimate goal of ‘curing’ FA (at least in bone marrow)? Donor gifts have provided support to past basic science gene therapy studies and, excitingly, there are now two current clinical trials for people with mutations in the most common FA gene, FANCA. These trials require that stem cells are removed from patients, transduced with correct genes, and then transferred back to patients. This ex vivo (or out of body treatment) can be difficult because FA stem cells are so fragile.

In an effort to improve outcomes, FARF is funding preclinical studies at Fred Hutchinson Cancer Center where the focus is to perform gene therapy in vivo (directly inside the body), so that stem cells would not require removal prior to gene correction. We thank all of our donors for your support, which continually expands the possibilities of gene therapy for people with Fanconi anemia.

Understanding cancer in FA at a basic level

How we can better understand why people with FA get cancer and how can we treat the disease when they do? Those two questions, along with the issues of detection and prevention, are at the forefront of our research priorities. Thanks to our donors, we are now funding two research projects at The Rockefeller University and the University of Washington that are focused on killing cancer cells in people with FA without harming normal cells.

We know people with FA are predisposed to early-onset and aggressive head, neck, and anogenital squamous cell carcinoma (SCC). Treating these SCCs is challenging due to a high recurrence rate and the sensitivity people with FA have to chemotherapy. The team at The Rockefeller is tackling this problem by identifying ways to kill cancer cells but spare the normal cells in people with FA. They are building cell lines that mimic patient cancers and using them to identify their vulnerabilities, with the intent to then develop better therapeutics.

The team at the University of Washington aims to identify features of cancers that provide new insight into their origins and better ways to treat these cancers in the context of FA patients. They are developing and characterizing FA and non-FA cancer cell lines which can be used to test new cancer therapies for people with FA. Both of these studies will enable us to have a better understanding of cancers on a basic level, which is vital in order to identify treatments.

International partners gather for Fanconi Anemia Summit

You probably already know that FARF is an international organization, but did you know that there are several partner FA organizations around the world? Some are run by FA families, some by doctors and some by FA researchers.

In late 2018, more than 40 researchers, clinicians, FA family members, and representatives from 17 countries got together to build a more intentional global FA network. Participants addressed organizational and fundraising capacity, family services, and access to doctors and medicine. Together, the group determined needs, priorities, and action steps in each of these areas. The second summit will take place at the 2019 Symposium in Chicago to continue progress in each area. We are excited to work with our international partners to develop a more cohesive network of FA research and support services.
Before she was born, Aria Gatzlaff’s parents, Kevin and Rachael, were told she would likely not survive outside the womb. Yet, in January 2011, Aria came into the world, determined to defy the odds. She had multiple disabilities, experienced 21 surgeries and lived most of her life in the hospital, but despite this, Aria experienced the world vibrantly. She was enthralled by bright lights and fascinated with Disney princesses. She smiled often and enthusiastically. At only four years old, Aria died in September 2015. Aria touched many people’s lives and her family wanted to continue her legacy. They started Aria’s Army to raise funds for FA research and family services. Aria’s parents are strongly motivated to support other families living with the challenges of Fanconi anemia.

In Kevin’s words: “I know the value of community. It’s extremely isolating to have a child with a rare disease. It’s also an isolating experience to lose a child, and as a result, I’ve had to deal with most of the emotional baggage of that experience alone. And I can’t explain in words how much that hurts. I don’t want anybody else to have to suffer alone. The value of meeting someone else who understands your situation simply can’t be overstated. It’s life-changing, maybe even life-saving. That’s why the family support FARF provides is critically important.”

Thank you to everyone who carries Aria’s legacy forward by giving through Aria’s Army. Your gifts enable families to connect in meaningful ways that change lives.

Team BrAvery does not shy away from a challenge. In fact, they charge full force toward it. Founded in 2010 after the Marx family learned of their daughter’s Avery’s FA diagnosis, the team is comprised of Avery’s dad, Orion Marx, uncle Zar Toolan, and grandfather Charlie Scott. They take on crazy challenges that push them to their limits and require great strength and perseverance, all to raise funds for FA research. Team BrAvery has biked across seven states, ran 100 miles through the Florida Keys, and pushed a semi-truck around a track. Their motto is “do something epic”. This past May, they again raised the bar by running 109 miles on the Mickelson Trail near Mount Rushmore in South Dakota. They finished off the weekend by running the Mickelson Trail Marathon. In truly epic fashion, the team exceeded their goal and raised more than $113,000 for FA research. To the Team BrAvery members and generous supporters, we give immense thanks for pushing the limits and reaching new heights. You are epic!
Since 6-year-old Eli Borden was diagnosed with Fanconi anemia two years ago, his parents Sarah and David immediately immersed themselves in learning everything they could about how to care for their son. Part of caring and advocating for Eli means raising funds for research. The Bordens found support in their community and began organizing small events to raise funds. Last year, colleagues at Sarah’s company, eFaucets, donated money to see executives get a pie in the face. This year, they continued in that tradition with a Dunk-the-Leader benefit and ice cream social. Together, they raised more than $5,000. Thank you to eFaucets, the Borden family, and everyone who donated to make a difference!

On April 12, two Virginia families, the McQueens and the Vandermeys, held their annual Band, Brew & BBQ in downtown Richmond. The event featured live music, dancing, great food, silent and live auctions, and special appearances by four other Fanconi anemia families. Each year, the local Richmond community, along with friends from all corners of the country, shows its commitment to this cause.

Not only do donors support 20-year-old Sean McQueen, 16-year-old Alex Vandermeys and 12-year-old Jacqueline Vandermeys, they support all those affected with FA by giving for research. Thank you to everyone who made this year’s Band, Brew, and BBQ a success! Together, you gave over $120,000! Your generosity will help propel new projects forward and provide support to FA families.
Carol Ceresa is the second daughter in a family of four girls. She’s also the only sister who was not born with Fanconi anemia. The Ceresa family first learned of FA in the 1950s, and over the span of several decades, Carol witnessed both the joys and the sorrows that her sisters, Myra, Gail, and Paula, endured living with FA. Eventually, Carol lost all three sisters. To honor their lives and keep their memory strong, Carol has been a longtime supporter of FA research and family support programs at FARF. She has also chosen another meaningful way to make an impact. As Carol explains it, her plan is to “put love in action” by giving through her family trust. As an FA family member and an FA carrier myself, I feel a tribal connection with all FA individuals and families.

There is some degree of trust that we all care deeply for one another and would do anything to share the burden of living with FA and finding a cure. If my monetary gift, in the form of a planned giving, helps any individual with FA and/or family, I am happy and will feel that I have served one of my purposes on earth.”

Legacy Society
Thank you, Carol, for your commitment to give in this meaningful way. We are grateful to all donors who have included FARF in their wills and trusts. That’s why we want to honor those who have chosen to donate through planned giving by welcoming them into the Legacy Society. If FARF is in your estate plans, or you’re interested in learning more, please contact McKenna Knapp, Philanthropy Director, at mckenna@fanconi.org or 541.687.4658.

Monthly donors make immediate impact
Each year, dozens of individuals with FA register with FARF, seeking support, resources, and community. New grant proposals come to us and thanks to our fantastic donors, we are able to fund the best ones. We are grateful to our Monthly Donors, whose dependable gifts add up, allowing us to provide education and services to families and to fund promising research projects. Thank you, Monthly Donors, for providing steady support to all of our FA families and researchers. To become a Monthly Donor, visit www.fanconi.org/donate and choose “monthly”.

Donor puts ‘love into action’ with planned gift
The Fund is committed to supporting research to further our mission of finding new treatments and a cure for Fanconi anemia. Over our 30-year history, we have funded 239 research grants, two clinical trials, and one service grant to 155 investigators worldwide. The total amount of research dollars awarded is nearly $25 million!
We envision a future in which we can prevent and/or eliminate the primary causes of death and disability in people with FA, enabling them to live full and productive lives. The best way to do this is by funding research. That’s why most of our budget is committed to research. We also support families by providing them with education and other services, like our annual family camp and our meeting for adults with FA. Thank you for making our research and support programs possible!
You make this possible.

Advancing research and clinical care:

Fostering connections among the scientific community by bringing FA researchers and doctors together for focused conferences.

Funding grants to address the detection, prevention, and treatment of cancers in FA.

Funding basic science projects to further our understanding of the FA pathway and the functions of FA proteins.

Supporting the development of FA centers of excellence that can address care for adults and cancer-related issues.

Cultivating the next generation of dedicated FA researchers through special grants and mentorship opportunities.

Providing updated Clinical Care Guidelines for physicians worldwide.

Growing the FA Clinical Registry so that researchers understand the natural history of the disease.

Supporting individuals with FA and their families:

Creating a virtual FA cancer tumor board so individuals with FA who develop tumors have access to experts.

Developing two new handbooks for living with FA: one for adults, and one for families caring for a child or children with FA.

Developing a more intentional international FA support network by partnering with FA organizations abroad.

Strengthening support for the adult population living with FA by providing networking opportunities, holding an annual meeting dedicated to adult issues, and developing an FA Adult Council to inform and advise the FARF board of directors and staff.

Nourishing connections among FA families and between experts and families at the annual FA Family meeting in the summer.

Thank you.
We would not be able to make strides in research or provide family support services without you, our wonderful donors. Below is a list of donors who contributed $250 or more to the Fanconi Anemia Research Fund between July 1, 2018 and June 30, 2019. Although space prevents us from printing all the names of our generous supporters, please know that we appreciate every single dollar raised—gifts of $10, $20, and $50 all add up and together give us the power to make a difference through FA research and support. Thank you!

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