Why we're focused on

CANCER

and how you're helping transform what's possible
CONTENTS

FA Research is Cancer Research ................................................................. 4

FA: Then and Now .................................................................................. 6

FARF Co-Founder Lynn Frohnmayer Celebrates 80th Birthday ................. 8

Your Gifts Drive Research Forward........................................................ 9

RESEARCH PRIORITY: Develop Integrated Approach To Addressing FA Cancers ................................................................. 10

Impact in Real Life: Michelle’s Story ...................................................... 11

RESEARCH PRIORITY: Address and Improve Mental Health ................ 12

Impact in Real Life: The Lanas’ Story ..................................................... 12

RESEARCH PRIORITY: Make Bone Marrow Failure Treatments Safer .... 14

Impact in Real Life: Violet’s Story .......................................................... 14

RESEARCH PRIORITY: Develop Preclinical Models ............................ 15

RESEARCH PRIORITY: Understand and Treat Fanconi Anemia Neurological Syndrome ................................................................. 16

Impact in Real Life: The McQueen Story .............................................. 16

Honoring Family and Advancing Cancer Research: Meet Mira Frohnmayer.... 17

FA Legacy Society .................................................................................. 17

Thank You Notes ................................................................................... 18

Donor Honor Roll .................................................................................. 21

Your Gifts at Work .................................................................................. 23

EDITORS’ NOTE AND DISCLAIMER

Statements and opinions expressed in this newsletter are those of the authors and not necessarily those of the editors or the Fanconi Anemia Research Fund. Information provided in this newsletter about medications, treatments or products should not be construed as medical instruction or scientific endorsement. Always consult your physician before taking any action based on this information.
Over the last year, organizations like ours faced an important challenge: how do we move progress swiftly forward while understanding the future – and often present – is marked by uncertainty? I believe we face this challenge by leveraging our internal strengths to create and facilitate powerful external collaborations.

We make an impact by harnessing the power of many to address a problem. In the 12 months since I last wrote to readers of this newsletter, we have done this by building and strengthening collaborations that will better serve the FA community. I’d like to highlight two major research collaborations we worked on in the last year: the Joel Walker Cancer Ideas Lab, and the Fanconi Anemia Cancer Consortium.

The Joel Walker Cancer Series Ideas Lab was held this past November and for the first time, we directly asked attendees to come prepared with fundable project ideas. Researchers formed seven groups and competed for a $500,000 project award. Ideas were assessed based on innovation, significance, collaborative potential, and therapeutic value. In the end, the winning proposal seeks to better understand cancer in individuals with FA by using animal models and organoids created from FA patient cells. These models will allow the research team to develop a deeper understanding of the influences of external environmental factors and internal elements that contribute to the onset and progression of FA cancer.

The other major collaborative project we are excited to launch this year is the Fanconi Anemia Cancer Consortium (FACC), a first of its kind clinical care path to preventing, detecting, and treating cancer. FARF has invested $1.6 million into the consortium this year, thanks to donors like you. This is a collaborative partnership between the FA community and a network of expert FA clinicians and physician scientists who have expertise and experience in the diagnosis and management of FA cancers and FA cancer research. The FACC aims to streamline cancer care decision-making processes for patients with FA through evidence-based research. This coalition will be housed at the National Institutes of Health (NIH). While housed at the NIH, it will include international collaborators to establish a comprehensive patient care strategy for FA cancer.

The development of these projects is possible because of you, our donors. This statement is not an exaggeration. In 2021 thanks to your contributions, FARF raised $3,986,048, and for the fourth straight year, we increased our total assets and equity. This financial health allows us to strengthen existing programs and gives us the ability to develop new impactful efforts like the two mentioned on the left. Your contributions go far beyond a simple donation. Many of you had your gifts matched by employers, donated stocks from your investment portfolios, and worked with our fundraising team to establish planned gifts for the future. This generosity is a remarkable show of your commitment to helping us advance our mission.

And while the uncertain economic conditions and effects of the pandemic continue to impact our decision-making, we are thriving because of our ability to adapt. Focusing on what is essential and creating partnerships to address areas of importance is how we operate. You have shown us your commitment to our mission, and we don’t take this commitment lightly. We will continue to use your gifts to make progress and provide hope to the FA community.

Thank you for all you have done, and I look forward to advancing our mission in partnership with all of you!

Mark Quinlan
Executive Director
WHY WE ARE FOCUSED ON CANCER

When the Fanconi Anemia Research Fund (FARF) was founded in 1989, Fanconi anemia (FA) was thought to be a childhood blood disease that led to leukemia. Thanks to donors like you, we now know that faulty DNA repair is what causes FA and that individuals with the disease have an extremely high risk of developing cancer at a young age.

Research into gene discovery and bone marrow transplants led to pivotal advancements in treating one of the major issues in FA: bone marrow failure. Thanks in large part to that research, kids with FA now live longer and are reaching adulthood. Advanced age for these individuals has revealed more FA-related issues, however, with one major problem at the forefront: cancer.

Young adults – and even teenagers – with FA may develop aggressive cancers typically seen in 60 and 70-year-olds in the general population. Head and neck cancer and anogenital cancers are the most diagnosed solid tumors and cancer is the now the main cause of death in adulthood for patients with FA. Depending on the type of cancer, the incidence to FA cancers is 500- up to 3,000-fold higher than in the general population.

“The cornerstone treatment for FA patients with cancer is surgery,” explains Premal Patel, MD, PhD, FARF Scientific Advisory Board Chair. “However, outcomes are poor if the diagnosis is at an advanced stage. Patients with FA also have significant toxicity issues from chemotherapies used to treat cancer in the general population.”

With most children with FA reaching adulthood, it is even more urgent to find safer, better treatments as fast as possible.

WE’VE ALWAYS INVESTED IN CANCER, BUT THIS IS A NEW LEVEL

We have invested heavily in research on FA solid tumors since we were founded in 1989. To date, we have invested more than $9 million dollars to support over 40 research projects focused on FA cancer. These projects focused on early detection and screening, genomic sequencing of FA tumors, drug screening and testing studies, creation of FA cancer preclinical models and treatment studies focused on delivery of drugs and radiation therapy. Results from these studies revealed how FA cancer develops and have identified promising avenues for prevention and therapeutic strategies.

Grant programs offered by FARF since 1989 provided an opportunity for individual investigators to solicit their proposals. These grants have been instrumental in initiating the fight against FA cancers.

Now, FARF’s focus is to expand on this model and bring FA cancer research to the next level to increase our impact and save lives.

FARF has now shifted its focus to funding collaborative...
cancer research teams with interdisciplinary expertise to expedite resource sharing and cross-pollination of ideas. These multi-institution grants include funding for the Stand Up to Cancer Research Team and the Joel Walker Ideas Lab Research Team in 2021.

“FARF is now taking collaborative initiatives a step further by creating the infrastructure and grant programs needed to support a larger integrated global network of FA researchers and clinicians who will focus their effort on FA cancer research,” explains Isis Sroka, PhD, FARF Scientific Director. “This new approach led to the development of the global Fanconi Anemia Cancer Consortium (FACC).”

INTRODUCING THE FANCONI ANEMIA CANCER CONSORTIUM

A first of its kind clinical care path to preventing, detecting, and treating cancer

The Fanconi Anemia Cancer Consortium (FACC) is a collaborative partnership between the FA community and a network of clinicians and physician scientists who have expertise in the diagnosis and management of FA cancers and FA cancer research. The FACC aims to streamline cancer care decision-making processes for patients with FA through evidence-based research.

FACC programs and research projects that patients can choose to participate in will include:

- early detection cancer screening
- accurate diagnosis of pre-malignant and malignant tumors
- tumor profiling
- virtual tumor board review of clinical care plans
- cancer care
- access to psychosocial support programs specific for adults with FA who face a cancer diagnosis

Patients and their families will also have the opportunity to participate actively as patient advocates in FACC programs to support research and accelerate approvals for potential therapies.

The FACC is a global consortium with primary sites at the National Institutes of Health (the clinical coordinating center for the FACC), the University of Düsseldorf, The Rockefeller University, and British Columbia Cancer Research Institute. The current and future FACC sites have been chosen based on pre-existing partnerships and records of collaborative success, diverse expertise in relevant clinical and research-based specialties, and excellence in clinical and translational research involving FA patients.

Because FA is so rare, no single center has been able to acquire sufficient patient numbers to adequately assess the natural history of FA cancers to improve prevention and treatment strategies; therefore in the next few years, the FACC will expand to include FA Centers of Excellence where sizable numbers of FA patients are treated in North America.

Dr. Stella Davies, director of the FA program at Cincinnati Children’s Medical Center, comments on the value of the consortium: “The key to curing cancer is to study the disease and test treatments in an organized plan. To do that, we all need to get together and work as a team. This consortium brings all the members of the team together for the first time.”

The Fanconi Anemia Cancer Consortium is made possible thanks to donors of the Fanconi Anemia Research Fund and our partners at Fanconi Canada. Thank you, Fanconi Canada, for pledging your support for a portion of this important initiative.
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No Genes Identified</td>
<td>Few Dedicated Researchers or Physicians</td>
<td>No Clinical Care Guidelines</td>
<td>Considered a childhood blood disease</td>
<td>Poor Outcomes</td>
<td>Little Hope</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**WHAT DID WE DO ABOUT IT?**

- Funded basic research to understand the disease
- Cultivated dedicated researchers all over the world to work on FA
- Gave seed funding to investigators who leveraged it to secure large grants from major institutions
- Supported the development of FA Comprehensive Care Centers
- Built a thriving patient and family community
- Invested early in gene discovery, gene therapy, and gene editing
- Dedicated funding to the relationship between FA and cancer

**THEN**

Children rarely survived to adulthood
Little was known about Fanconi anemia

One family started by contacting a dozen investigators, asking them what they needed to advance research. This family then gathered these experts in a room to discuss problems and solutions. This tradition has carried on for 34 years and resulted in major advances in FA care.
Much of FARF-funded research is now focused on ways to prevent, detect, and treat cancer. To do this, we are funding collaborative research and clinical programs, including specialized focus-groups, a cancer clinical registry, a cancer early detection program, and consortium.

WHAT ARE WE DOING NOW?

- Developing a global FA Cancer Consortium to centralize data, research, and treatment approaches
- Supporting translational and clinical research to get to treatments faster
- Running a global FA Patient Registry to store and share data
- Convening a Virtual Tumor Board to give FA patients with cancer immediate help
- Continuing to fund basic research to understand how FA cancer develops
- Supporting ongoing efforts to make transplants even safer
- Funding further research into gene therapy and gene editing
In the Fanconi anemia (FA) community, the name “Frohnmayer” carries a legacy like no other. Lynn and David Frohnmayer founded the Fanconi Anemia Research Fund (FARF) in 1989 as a means to legally support the work of a handful of researchers. This is how ‘the FA research fund’ was created.

Thirty-four years later, this living room operation has grown to a worldwide organization that has funded more than $32 million in research, supported thousands of people affected by FA, developed life-saving therapies, and uncovered major connections to a problem that affects us all: cancer.

“When our daughters were diagnosed with FA in the 1980s, we were told that patients with this illness would probably not live past the first decade of life, and certainly not past the second,” Lynn Frohnmayer recounts. “We were told the primary cause of death would be bone marrow failure because these patients simply couldn’t produce enough blood cells to sustain life. The only cure for that problem was a bone marrow transplant, but back then, the outcomes for transplant were terrible. So early on, we decided to focus a large part of our resources on improving protocols and outcomes for transplants. I’m happy to report that investment in research did in fact improve outcomes tremendously. Now, transplants are safer than they have ever been, with more than 90% success rates at FA centers.”

These incredible advances mean children with FA are becoming adults with FA. In fact, more than half of people with FA in FARF’s database are adults. Unfortunately, adulthood brings another major complication.

“We now have many individuals in their 20s, 30s, 40s and even older. Many have had a chance to go to college and pursue careers. Some have gotten married and even had children,” says Lynn. “But there is another shoe to drop. And that shoe is cancer. That has become our primary focus today.”

Lynn has now spent half of her life working to cure FA. She has lost all three daughters to this disease, and her husband David to cancer. In August, she turns 80 years old, and we want to mark this occasion with you. We want to celebrate Lynn by ensuring that her family’s legacy of advancing life-saving research and finding a cure will continue. We invite you to celebrate all that the Frohnmanners have made possible, and join us in taking FA research and treatment to the next level.

Wish Lynn a happy 80th birthday in the envelope attached to this newsletter. All messages and gifts are welcome. Whether it’s a few words of thanks, or a gift for the dedicated Frohnmayer cancer fund, help celebrate this incredible woman and her life’s work on FA.
YOUR GIFTS DRIVE RESEARCH FORWARD

In the last 12 months, you helped to fund our biggest year in research yet: $3,124,852 to new and ongoing initiatives

CANCER AND PRECLINICAL MODELS

Project: Cytology Based DNA Analysis to Investigate the Malignant Potential of Oral Lesions in Patients with Fanconi Anemia
Investigators: Martial Guillaud, PhD, and Denise Laronde, PhD
Institution: BC Cancer Research Institute
Amount Funded: $304,300

Project: Building Collaborative Partnerships to Understand Fanconi Anemia Tumor Pathogenesis, Prevention, and Treatment
Investigator: Agata Smogorzewska, MD, PhD
Institution: The Rockefeller University
Amount Funded: $193,475

Project: NIH Center Comprehensive Program for Natural History of Development of Squamous Cell Carcinoma in Fanconi Anemia
Investigators: Neelam Giri, MD, and Sharon Savage, MD
Institution: National Cancer Institute
Amount Funded: $1,107,464

Project: Development and Characterization of FA-HNSCC PDX Models
Investigators: Jennifer Grandis, MD, and Daniel Johnson, PhD
Institution: University of California, San Francisco
Amount Funded: $100,000

Project: Oral Mucosal Gene Therapy as a Prevention for FA-Associated Cancers
Investigators: Ray Monnat, MD, and Markus Grompe, MD
Institutions: University of Washington and Oregon Health and Science University
Amount Funded: $250,000

Project: Modeling Environmental Responses of Fanconi Anemia Epithelial Stem and Progenitor Cells to Prevent Squamous Cell Carcinoma
Investigators: Ken Weinberg, MD, Frank Ondrey, MD, and Hiro Nakagawa, MD, PhD
Institutions: Stanford University, University of Minnesota, and Columbia University
Amount Funded: $500,000

Project: Synthetic Lethal Approaches to Treatment of FA Gene Mutant Head and Neck Cancer
Investigators: Barbara Burtness, MD, and Gary Kupfer, MD
Institutions: Yale University, Georgetown University
Amount Funded: $250,000

MENTAL HEALTH

Project: Psychosocial Experiences of Adults with Fanconi Anemia: A Participatory Mixed-Methods Research Study
Investigators: Kathleen Bogart, PhD, and Megan Voss
Institutions: Oregon State University and University of Minnesota
Amount Funded: $98,495

FANCONI ANEMIA NEUROLOGICAL SYNDROME

Project: Fanconi Anemia Associated Neurological Syndrome — a Search for a Cause with Advanced Technologies
Investigators: Prashanth Ramachandran, MBBS, and Michael Wilson, MD
Institution: University of California, San Francisco
Amount Funded: $71,118

BONE MARROW FAILURE

Project: Understanding Clonal Hematopoiesis in Fanconi Anemia to Improve Patient Surveillance Strategies
Investigator: Grant Rowe, MD, PhD
Institution: Boston Children’s Hospital
Amount Funded: $250,000

FARF is committed to supporting research to further our mission of finding new treatments and a cure for Fanconi anemia.

TOTAL AMOUNT OF RESEARCH DOLLARS AWARDED IS $32,965,950

263 GRANTS
202 INVESTIGATORS
86 INSTITUTIONS WORLDWIDE

Read about each project in the following pages
DEVELOPING AN INTEGRATED APPROACH TO ADDRESSING FA CANCERS

PROJECT: CYTOLOGY BASED DNA ANALYSIS TO INVESTIGATE THE MALIGNANT POTENTIAL OF ORAL LESIONS IN PATIENTS WITH FANCONI ANEMIA
Martial Guillaud, PhD, and Denise Laronde, PhD
BC Cancer Research Institute
Researchers will run samples collected by brushing lesions through an automated system to detect abnormal DNA content and malignant changes. By identifying high-risk lesions, closer follow-up and early intervention can be used to prevent malignancies. The goal is to establish a centralized lab at BC Cancer to process samples to identify the risk of malignant transformation for FA patients.

PROJECT: BUILDING COLLABORATIVE PARTNERSHIPS TO UNDERSTAND FANCONI ANEMIA TUMOR PATHOGENESIS, PREVENTION, AND TREATMENT
Agata Smogorzewska, MD, PhD
The Rockefeller University
This team will facilitate collaborations between all current and future participants of the Fanconi Anemia Cancer Consortium (FACC). The goal is to gather information and samples from past, present, and future patients to fully understand how tumors develop in FA patients and facilitate new prevention and treatment strategies. This team envisions a world where every tumor from every FA patient is studied and collectively contributes to eradicating cancer.

PROJECT: NIH CENTER COMPREHENSIVE PROGRAM FOR NATURAL HISTORY OF DEVELOPMENT OF SQUAMOUS CELL CARCINOMA IN FANCONI ANEMIA
Neelam Giri, MD, and Sharon Savage, MD
National Cancer Institute
People with Fanconi anemia have an extremely high risk of developing squamous cell cancers of the oral cavity, vulva, anal area, and esophagus. The risk of these cancers starts around teen years and increases throughout life with the highest risk for oral cavity cancers in ages 20s to 30s. Oral cavity cancers arise in areas of changes visible as white or red spots. We plan to screen teens and adults with FA for cancers at regular intervals and study the visible spots in mouth scientifically to identify early changes before progression to cancer. This will help in designing treatments to prevent the development or progression to cancer. People with concerning changes or cancer will be discussed at the tumor board in coordination with FARF and referred for treatment at NIH or elsewhere. Regular screenings and early treatment will offer better chances of cure, will have fewer side effects and result in better quality of life.
Hi, my name is Michelle and I’m from a small town outside of Pittsburgh, Penn. Like a lot of teenagers, I had big dreams and goals for what I was going to do with my life. I knew early on that I wanted a career, to get married, and have two children. I grew up with the assumption that I would grow old with my husband and have grandchildren. I also assumed that any major medical issues that we might have would develop when we were much older. Cancer is very prevalent in my family, but all my relatives developed their cancers in their seventies and eighties.

I never imagined I would get cancer in my thirties. In the fall of 2010, I felt a lump on my right breast. After speaking with my physician, I had a mammogram and an ultrasound, and then a biopsy. Two days before Christmas, I received the news that I had triple negative breast cancer. In that moment, my life turned upside down. I remember wondering how this could be possible when I was only 32 years old with a five-year-old son just starting kindergarten. Little did I know this was only the beginning of the fight for my life.

The day before starting chemotherapy, my oncologist held a tumor board meeting to consult other doctors on my case. During this meeting, a keen genetic counselor recognized potential signs of Fanconi anemia (FA). Thankfully, she suggested that they wait to start the treatment and have me tested for FA right away. Hours before my chemotherapy was set to begin, vials of my blood and a skin biopsy were sent off to the lab instead. While waiting for the results, the doctors decided to switch to surgery first. That genetic counselor saved my life.

The day before starting chemotherapy, my oncologist held a tumor board meeting to consult other doctors on my case. During this meeting, a keen genetic counselor recognized potential signs of Fanconi anemia (FA). Thankfully, she suggested that they wait to start the treatment and have me tested for FA right away. Hours before my chemotherapy was set to begin, vials of my blood and a skin biopsy were sent off to the lab instead. While waiting for the results, the doctors decided to switch to surgery first. That genetic counselor saved my life.

Two years later, in 2013, I was diagnosed with vulvar cancer. Once again, I started another battle to fight this cancer and underwent surgery to remove it. During a routine mammogram and breast MRI in 2016, I was diagnosed with breast cancer again, but in the other breast this time. It was difficult to receive this news, especially knowing that I would need to start treatments again. The cancer was removed with surgery and radiation treatment.

I was hopeful the worst was behind me, but in 2020, I was once again diagnosed with a new cancer. This time, it was thyroid cancer. My thyroid was removed, and I was put on a medication for the rest of my life.

Most recently, in 2021, I was diagnosed for the third time with breast cancer. My nightmare came true as I realized it was time to put an end to my breast cancer once and for all. After consultations with doctors, some soul searching and many prayers, I decided to get a double mastectomy with reconstruction. I knew this would be the biggest battle of them all and the most invasive surgery yet, but I also knew that with FA, this needed to be done. I’m a fighter. I’m a survivor. And I will never back down from these battles.

Knowing I have the love and support of family and friends, and most importantly, knowing God is with me, has helped keep me strong. Many times, I’ve been asked how I got through it all, and I respond that this is my journey. Life is what you make of it and sometimes there will be difficult times, but it is how you choose to get through those times that matters. I cannot change the fact that I have Fanconi anemia and that I’m prone to cancers. Instead, I can fight, and I can share my story with doctors and researchers to help them find a cure someday. Most importantly, I hope my story inspires others to keep fighting and inspires family members and caregivers to never give up hope.
RESEARCH PRIORITY

ADDRESSING AND IMPROVING MENTAL HEALTH

PROJECT: PSYCHOSOCIAL EXPERIENCES OF ADULTS WITH FANCONI ANEMIA: A PARTICIPATORY MIXED-METHODS RESEARCH STUDY

Kathleen Bogart, PhD, and Megan Voss
Oregon State University and University of Minnesota

Investigators are partnering with members of the FA community to design a first-of-its-kind quality of life study, considering the physical, mental, emotional, and spiritual aspects of living with FA, as well as issues of diversity, equity, and inclusivity. Results of this study will help FARF and clinicians around the world develop ways to improve the mental health of those living with FA.

IMPACT IN REAL LIFE: THE LANAS' STORY

NAVIGATING DEPRESSION AND FA

By Mary Ann Lana

My son Eli was diagnosed with Fanconi anemia (FA) in 2011 when he was found to be in bone marrow failure. Despite having several physical characteristics of the disease present at birth, hand and arm abnormalities being among the most obvious, the disease went undiagnosed until Eli was six. Thankfully, Eli’s bone marrow transplant was (for the most part) uncomplicated. Even so, he spent the next two years recovering, isolating, and finally adjusting to normal life again. Normal for an individual with FA, that is. He missed half of his kindergarten year and all but the last couple of weeks of first grade, when he attended a few hours each week for socialization.

Once Eli had regained his health, we wanted to plan a substantial fundraiser for the Fanconi Anemia Research Fund, the organization that had funded much of the research that made his transplant successful. We had taken part in letter writing campaigns and collected online donations up until this time, but we wanted to do something even more impactful. We decided on a 5K run/walk with a raffle auction. Our first 5K for FA event was in 2015, and for five years straight we held it on the first Saturday of May through 2019. In 2020, the Covid pandemic put an end to public gatherings and officially ended our event.

In all, the 5K for FA raised over $140,000 for FARF and we were thrilled with what we had accomplished. But the truth is, we were tired. And more than that—something about Eli, who was 14 by then, had changed.

Noticing the changes

During those final two years of hosting the 5K for FA when Eli was 13-14 years old, our family had also suffered several losses, one after another, and we could not catch our collective breath. Eli suffered especially. In 2019 after our last event, he was wrapping up 8th grade and preparing to start high school. He had become sullen, was engaging in risky behaviors, and withdrawing from those he loved. We sought treatment for him, and admittedly we were discouraged to find that the
progress was slow. We wanted so badly to help him. By the second semester of his freshman year of high school, we were in Covid lockdown. The combination of remote learning and isolation from friends kept Eli from the human connection and day-to-day interaction he so desperately needed. He sank lower.

When adolescence had arrived, it had done so as predicted with all the normal hormonal, social, and emotional challenges teens are faced with. But for Eli it also magnified his body self-consciousness and awareness of being different. Plus, while the 5K for FA drew positive attention and raised significant dollars for FARF, by 2019 Eli no longer enjoyed being the center of attention or the kid on morning talk shows talking about his disease, promoting his 5K. He wanted to be invisible. He understood increasingly about the lifelong challenges FA posed and asked tough questions for which he deserved answers: How does FA cause cancer? What exactly is cancer? What happens if I get cancer? Will I ever be able to have kids? Will I live past 30? Why did this happen to me? Why was I even born? Questions typical teenagers don’t often think about. We could see FA taking an emotional toll.

Seeking professional support
Over time, with behavioral counseling and support from our family and close friends, things improved. We learned how to talk about depression and to explore how it affects our lives, and we are still learning. We found a pediatric psychologist who specializes in chronic diseases who provided stability and support for Eli and guided my husband and me to say things the right way, and understand this was not a mood or a behavior Eli was choosing. It was and is an illness. There are days when we still struggle to know how to help Eli, and we worry what will happen if we make a mistake. We always consider the extra weight he carries when helping him to make decisions for the future, whether that future is tomorrow or next year. On days he feels his worst we do what we can to lighten his load. He’s an exceptional young man who just wants to be ordinary. So, we must remember that ordinary people cannot carry all that weight. He is a junior now and having his best year in a long time, but it’s not easy. We still hold our breath a lot.

I am realizing now that parenting Eli is parenting a young man with two diagnoses that can be life-threatening. There is the Fanconi anemia that looms on the horizon and threatens cancer, and there is the depression that tricks him into thinking he has nothing to live for. I will admit, I was not prepared for that second one, but I am learning.
MAKING BONE MARROW FAILURE TREATMENTS SAFER

PROJECT: UNDERSTANDING CLONAL HEMATOPOIESIS IN FANCONI ANEMIA TO IMPROVE PATIENT SURVEILLANCE STRATEGIES

Grant Rowe, MD, PhD
Boston Children's Hospital

A major problem in the care of patients with FA is managing the known risk of leukemia. Thanks to recent technology, researchers can find very rare DNA mutations in the bone marrow that suggest the possible development of leukemia. Finding such mutations often leads to the decision to recommend that FA patients undergo bone marrow transplantation, resulting in exposure to side effects of transplant. This proposal aims to understand the consequences of mutations found in FA patient blood stem cells with the goal of informing the decision to undergo transplant.

IMPACT IN REAL LIFE: VIOLET’S STORY

VIOLET’S STORY

By Paige Halverson

My name is Paige, and my three-year-old daughter Violet was diagnosed with Fanconi anemia (FA) in 2020. After nine months of testing and waiting, I received a phone call to set up a video visit. We were both excited and terrified, as I was sure this meant a diagnosis. I will forever remember September 18th, 2020. I sat alone while waiting for the doctor to come on the video, and when he did, I could see in his face that this wasn’t going to be good news. He said the words ‘Fanconi anemia with the complementation group D1’. I had never heard of this, and I tried to listen as he explained, while I trying to hold back my tears.

With the need to learn more about FA, I reached out to the Fanconi Anemia Research Fund (FARF) and quickly got connected to a family support group. From there, we were directed to a comprehensive FA center. We met with a specialist at The University of Minnesota, where we were almost overwhelmed with information.

We were told Violet needed a bone marrow transplant. With this came a huge flood of emotions, one of which was hope. Violet was seemingly healthy, so others did not understand the urgency and need for a transplant. I remember telling the FA team, “this gives us hope, and this will hopefully help eliminate the risk of certain deadly cancers”.

Violet went to transplant in January of 2021. Unfortunately by March of 2021, we were given news that Violet’s transplant had failed. This news was something we never expected. When our doctors told us she would need some time before trying again, we knew we could trust them. The plan was to do a second transplant in August 2021.

We are now nine months post Violet’s second transplant, and she is doing amazingly well! We feel so much hope for her and our FA family. We are extremely grateful for this community. I hope and pray that others can find the same kind of comfort that we have found. I know that Violet’s journey will continue, and she will continue to be a rockstar in everything she does. Since diagnosis, the biggest lesson I have learned is to just keep going, don’t give up, and have faith in everything you do.
DEVELOPING PRECLINICAL MODELS

PROJECT: DEVELOPMENT AND CHARACTERIZATION OF FA-HNSCC PDX MODELS
Jennifer Grandis, MD, and Daniel Johnson, PhD
University of California, San Francisco

Investigators helped pioneer the creation of patient-derived xenografts (PDXs – tumors from patients that are grown in mice) from head and neck cancers. They have now developed the first PDX from a head and neck cancer in an FA patient. Researchers will work to develop a collection of PDXs from head and neck cancers in FA patients to guide cancer treatment.

PROJECT: ORAL MUCOSAL GENE THERAPY AS A PREVENTION FOR FA-ASSOCIATED CANCERS
Ray Monnat, MD, and Markus Grompe, MD
University of Washington and Oregon Health and Science University

The goal of this project is to determine the potential of oral mucosal (lining) gene therapy to lessen the risk for oral cancer in individuals with FA.

PROJECT: MODELING ENVIRONMENTAL RESPONSES OF FANCONI ANEMIA EPITHELIAL STEM AND PROGENITOR CELLS TO PREVENT SQUAMOUS CELL CARCINOMA
Ken Weinberg, MD, Frank Ondrey, MD, and Hiro Nakagawa, MD, PhD
Stanford University, University of Minnesota, and Columbia University

This grant will develop models to better understand cancer in individuals with FA using animal models and organoids (small 3D tissue mass made from stem cells) created from FA patient cancer cells. Developing these models will help researchers better understand the pathways that result in cancer and determine the best prevention and therapeutic strategies to eliminate FA cancers.

PROJECT: *EXTENDED FUNDING* SYNTHETIC LETHAL APPROACHES TO TREATMENT OF FA GENE MUTANT HEAD AND NECK CANCER
Barbara Burtness, MD, and Gary Kupfer, MD
Yale University, Georgetown University

Typical treatments for cancer involve conditioning that damages DNA and can therefore be harmful for people with FA, who cannot repair DNA. Researchers are testing drugs using patient-derived xenografts (tumors from patients that are grown in mice) to find a way to kill FA cells without harming normal cells.
UNDERSTANDING AND TREATING FANCONI ANEMIA NEUROLOGICAL SYNDROME

PROJECT: FANCONI ANEMIA ASSOCIATED NEUROLOGICAL SYNDROME - A SEARCH FOR A CAUSE WITH ADVANCED TECHNOLOGIES

Prashanth Ramachandran, MBBS, and Michael Wilson, MD
University of California, San Francisco

A new and rare condition affecting some FA patients leads to brain lesions, which can cause weakness, seizures, and cognitive issues. The cause of this condition is currently unknown. Investigators plan to closely examine the immune profile in these patients to try and find the underlying cause and an appropriate therapy.

IMPACT IN REAL LIFE: THE McQUEEN'S STORY

SEAN STRONG

By Kelsey McQueen

My brother Sean loves sports. Growing up, he would quite literally throw himself around catching footballs, play basketball for hours at a time in the driveway, and was the best child golfer the South side of the James. The last few years have been hard for a lot of reasons, but one of the hardest has been watching Sean slowly lose so much mobility.

Over the last several months, his already limited mobility has been taken away from him. Sean lost the ability to use a fork, walk to the bathroom, or even squeeze someone’s hand while they put in an IV. Sean has said multiple times how surprised he is by how difficult ordinary things have become. All of this has really made us realize that moving your body is such a privilege.

We are so grateful for everything that Sean is still able to do, and we are reminded of how movement and health are not always guaranteed.

Recently, my dad and I called a good family friend and one of the amazing founders of the Fanconi Anemia Research Fund (FARF), Lynn Frohnmayer. We thanked her so much for creating such a wonderful organization that has allowed Sean to be where he is today. Because of FARF, we were connected with some of the country’s top neurological experts to come up with a treatment plan for Sean. Now, FARF is funding a research project looking into FA Neurological Syndrome. It is because of such kind donations that we, and other families like us, have hope for advances. Thank you.
LIFE AND LEGACY: MEET MIRA FROHNMAYER

She’s the sister of FARF’s co-founder David Frohnmayer and has been a FARF donor since 1994
She recently included FARF in her estate plans, to honor her nieces Katie, Kirsten, and Amy Frohnmayer
She is a talented musician who specializes in voice, piano, and viola
She is a passionate educator who spent over 46 years teaching music at the college level, including leading the music program at Pacific Lutheran University
She is an avid traveler who has spent time across the United States, Germany, and France

Mira’s pledge will support the Frohnmayer Fund, which advances cancer research for the next generation of individuals living with FA. Gifts like Mira’s allow FARF to plan for the future. If FARF is included in your will, trust, or estate plans, please let us know so that we can celebrate your intention and honor your legacy.

FA LEGACY SOCIETY

As a supporter and friend of the Fanconi Anemia Research Fund, you have played a huge role in growing this family-driven, grassroots organization into the worldwide organization that it is today. Your gifts — past, present, and future — are vital in advancing our mission.

At FARF, we envision a future in which we can prevent and/or eliminate the primary cause of disability and death in people with FA, enabling our community to live full and productive lives. The best way to do this is by funding research. As long as FARF exists, we will be working toward this vision.

By making a legacy gift to FARF through your estate, you’re ensuring that this vital work continues. Your gift, whether through a will, living trust, life insurance, retirement plan, or real estate, entitles you to become a member of the FARF Legacy Society.

Legacy Planning Tips:
• Your legacy gift may entitle you to lifetime income tax savings;
• Make sure that your estate gift reaches FARF by sharing the legal name Fanconi Anemia Research Fund with your attorney or wealth advisor;
• Did you know that you can direct your legacy gift to support a specific FARF program?

Contact McKenna Knapp, Philanthropy Director, at mckenna@fanconi.org or 541.687.4658 to learn more.
THANK YOU NOTES

RACHEL ALTMANN HONORS HER DAUGHTER’S MEMORY BY GIVING BACK

We are fortunate to have several dedicated volunteers working on FA. One of these dedicated volunteers is Rachel Altmann, whose daughter Nina passed away from complications of FA in 2006. She has gone above and beyond, writing for the FAmily newsletter, serving on the Board of Directors, fundraising, donating, and supporting other family’s efforts. With each new way Rachel gives back, her community follows along in support, and we can feel the inspiration she ignites. This past FA Month, Rachel participated in the May challenge by drawing every single day and completing a strength exercise. On her fundraising page each day, she posted her drawing and exercise recap along with a message to her community. Her community followed her posts for 31 days and together, they raised $3,200 for FARF! Thank you for the numerous ways you give back to FARF, Rachel. No one says it better than her: “When I donate to FARF, I know my money will be used well. When I fundraise for FARF, I know your money will be used well. Thank you for your support — past, present, and future!”

“When I donate to FARF, I know my money will be used well. When I fundraise for FARF, I know your money will be used well. Thank you for your support — past, present, and future!”

THE McQUEEN FAMILY AND COMMUNITY DON’T SHY AWAY FROM A CHALLENGE

The McQueen family and community have been a part of the FA community since their son Sean was diagnosed in 2000 at a year old. Year over year, they have hosted galas, concerts, bike rides, and other incredible fundraising events. And their community of friends and family have supported them every step of the way. Now 23 years old, Sean is facing a complex set of issues known as Fanconi Anemia Neurological Syndrome (read more on page 16). As he and his family navigate the changes this has brought, the McQueen community continues to rally around them. Despite their hardships, the McQueens continued to advance the cause. At the beginning of May, Sean announced to the community that his family would match the first $10,000 gifts made for FA Month. The match was met in the first 24 hours! The McQueen friends and family are endlessly invested in Sean and his family’s future, and you can count on the McQueens to pay it forward. Thank you, McQueen family and each one of you who continues to show up in support of Sean and others living with FA!
JENNIFER AGGABAO RUNS WITH A PURPOSE

One of the ways people show up for the FA cause is by challenging themselves to run a race. A self-proclaimed non-runner, Jennifer Aggabao stepped up to this challenge when she signed up to run the OC Half Marathon again. She runs to raise awareness and funds in honor of her two children, Katrina and Jared. Before her run, Jennifer shared “I have run a few marathons before, but not because I have the love for running. I run because I am a mother on earth and a mother in heaven. I run to honor Katrina’s memory, and I run to fundraise in hopes that I am contributing to finding a cure for Jared. I run for a cause. I run to transform my grief into a legacy of love.” Her drive for the cause once again pushed her community to come to her side in support. Together, they raised nearly $2,500! Thank you for supporting the Aggabao family and all others affected by FA!

“I run to honor Katrina’s memory, and I run to fundraise in hopes that I am contributing to finding a cure for Jared. I run for a cause. I run to transform my grief into a legacy of love.”

JOEL WALKER’S LEGACY INSPIRES $500,000 RESEARCH PROJECT

A few years ago, Nigel and Ann Walker partnered with FARF to develop a way to further cancer research and honor their son Joel, who died of complications from FA cancer in 2016. Joel left FARF a generous bequest to advance FA research. In November 2021, 31 scientists came together for the Joel Walker Cancer Ideas Lab, where they brainstormed ideas to shift the paradigm for treating FA cancer. During these workshops, scientists formed interdisciplinary research teams and pitched their ideas regarding FA cancer research for the opportunity to win $500,000 in grant funding from FARF (see page 15). Thanks to Joel and the continued support of the Walker family and community, innovative research efforts like the Ideas Lab continue. The power of legacy gifts is incredible!

TEAM BRAVERY RUNS BACK-TO-BACK MARATHONS AND VISITS FARF HEADQUARTERS

Team Bravery is known for their epic physical challenges and major impact in raising funds for FA research. The team is led by Orion Marx, president of FARF’s Board of Directors, and father to a young adult living with FA. This spring, Orion and his father-in-law took on back-to-back marathons to kick off FA Month. First, they ran the Tacoma City Marathon in Tacoma, WA, followed by The Eugene Marathon the next morning, where they were cheered on by the FARF team and co-founder Lynn Frohnmayer. Team Bravery’s goal for 2022 is to raise $200,000. So far, they have raised over $46,000 thanks to their generous community! Your support means everything to Team Bravery and all of the other families impacted by FA. Thank you!
LONGTIME DONORS BECOME FUNDRAISERS IN HONOR OF FA MONTH

Laura Scott’s friendship with Kirsten Frohnmayer began in the 1970s when the Frohnmares moved into Laura’s neighborhood. Both were young girls and soon became fast friends. Laura and her husband Brian have been long-time supporters of the FA Research Fund. This year, they took their support and generosity to a new level. Representing themselves as Team Silly Socks, they spent the month of May getting into shape and preparing for a 10K fun run. Together with their community, they raised $1,633 during FA Month. Thank you, Laura, Brian, and friends!

DONATE WHILE YOU SHOP ON AMAZON

Visit smile.amazon.com, select Fanconi Anemia Research Fund as your charity, and start shopping. That’s it!
The photos throughout the donor honor roll give us a big reason to celebrate: these are kids, teens, and adults with FA graduating earlier this summer. We love to see and share these milestones!

Sustaining Life Donors
- Philip and Penny Knight

Legacy Society
- Carol Ceresa
- Mira Frohnmayer & Sandy Sweet
- Clint Johnson
- Nigel & Ann Walker
- Pamela Wharton
- Anonymous

$1,000,000
- Philip and Penny Knight

$125,000+
- Kendall & Taylor Atkinson Foundation with the Nash Family

$45,000 – 50,999
- Norman and Linda Brenden
- Pat and Stephanie Kilkenny

$15,000 – 27,999
- John and Martina Hartmann
- Orion and Lisa Man
- Kevin and Lorraine McQueen
- Elizabeth Rohlfing
- Sanders Family Foundation

$10,000 – 14,999
- Lisa Dalton
- Lynn Frohnmayer
- Mira Frohnmayer and Sandra Sweet
- Betty Massoni
- Patricia Peterson
- Nigel and Ann Walker

$5,000 – 9,999
- Rachael Alaniz and Kevin Gatzlaff
- Jeanne Altman
- John and Kate Armentrout
- Atlas Insurance
- Mary Beale, MD
- Chris and Sharon Brezski
- Mauro and Kerrie Cazzari
- Joseph and Nancy Chou

$1,000 – 4,999
- Bob and Diane Abrams
- Jack and Julie Adkins
- Michael and Jennifer Aggabao
- AmazonSmile Foundation
- Jon and Terri Anderson
- Jeffrey and Tamara Armentrout
- TB Automotive
- John and Anne Baldwin
- Dr. Roger and Dana Band
- Gene Barry
- Aydin and Oliver Bassett
- Charitable Account
- Baylaur Construction
- Anne and Philip Becker
- Phyllis and Andy Berwick Jr.
- Blackbaud Giving Fund
- Don and Mary Blair
- Jason Bramock
- Ryan and Rebecca Brinkmann
- Eugene and Joan Burke
- Charities Aid Foundation of America
- David and Barbara Chew
- Niki Christopoulos
- Mary Ellen Cleary and Gleaves Whitney
- Comcast Corporation
- CHC Community Health
- Greg and Tammy Cook
- John and Marcella Crewe

Penny graduates from college
- $500 – 999
- Bob and Diane Adams
- Jack and Julie Adkins
- Michael and Jennifer Aggabao
- AmazonSmile Foundation
- Jon and Terri Anderson
- Jeffrey and Tamara Armentrout
- TB Automotive
- John and Anne Baldwin
- Dr. Roger and Dana Band
- Gene Barry
- Aydin and Oliver Bassett
- Charitable Account
- Baylaur Construction
- Anne and Philip Becker
- Phyllis and Andy Berwick Jr.
- Blackbaud Giving Fund
- Don and Mary Blair
- Jason Bramock
- Ryan and Rebecca Brinkmann
- Eugene and Joan Burke
- Charities Aid Foundation of America
- David and Barbara Chew
- Niki Christopoulos
- Mary Ellen Cleary and Gleaves Whitney
- Comcast Corporation
- CHC Community Health
- Greg and Tammy Cook
- John and Marcella Crewe

Emily graduates from college
- Cheryl Cummins
- Daniel Curtis and Stephanie Shaff
- Donna DellaRatta
- Harry and Kaaren Demorest
- Jerry Dennerline and Margaret Sarkissian
- James and Glenda Douglass
- Mike Drennan
- Roy and Jan Dwyer
- Lee and Esther Eman
- Steinwachs Family Foundation
- Ford Family Foundation
- John Frohnmayer
- Dr. Sheryl Gardner
- Geckos’ Hospitality, LLC
- Linda P Gilmore
- The Giustina Foundation
- Janine and Joe Gonyea III
- Dr. Michael Greenberg
- Rachel and Kristian Gutulisrud
- Ronald Kabrowski and Mary Ann Hall
- Owen Hall and Margaret Kasting
- Richard Hansen
- Beverly Harms
- André Hessels and Rutger Boerema
- Dr. Charles and Linda Hollen
- Dr. Tracy Hull and Carl Engelman
- Brendan Ittelson
- John Ittelson and Bobbi Kamil
- Baila Janock
- Albert and Leslie Jeffrey
- Bob and Evelyn Jensen
- Richard N Johnson
- Robert and Constance Johnson
- Dr. Carole Kirkpatrick
- Erik Kjos-Hanssen and Turid Frislid
- Michael and Nancy Knutson
- Rebecca Lacy
- Dean and Bev Lahr
- Steve and Cyndy Lane
- Robert and Anna Langtry
- Barry and Laura Levine
- Brian Horrigan and Amy Levine
- Anne and Josh Lewis
- Burt and Atleea Lewis
- Ronald and Anne Lewis
- Michael London
- Col Gregory & Lt Col Lynnette Lowrimore
- William and Jacquelyn Lucarell
- Kristine La Cour Rasmussen
- Maria Marx and Steve Pulliam
- Brian and Helen Matthews
- Barbara Mayer
- Daniel and Angie McMahon
- David Meadows
- Jeffrey and Mel Miller
- Mary Anne Moore
- Dr. Jim and Marilyn Murdock
- Bernard and Phyllis Nash
- Don Niederpruem
- Ronald and Fredi Norris
- Northern California Swap Meets, Inc.
- Richard and Lucy Novak
- Gerald and Mary O’Shaughnessy
- Mark and Elizabeth Page
- Jerry Parsons
- David and Nancy Petrone
- Paul and Angelia Pless
- Peter and Janice Pless
- Melissa Pope
- Stan and Linda Potter
- Pete and Molly Powell
- Peter Rappoport and Marcia Marley
- George and Kathryn Reardon
- Robert and Mary Redpath
- Diane and John Render
- Paul and Katherine Rooney
- Bill and Alice Rose
- Deanne and Richard Rubenstein Sr.
- S&P Global
- Ron and Alice Schaefer
- Phyllis and Paul Schirle
- Chris and Heidi Schmitz
- Colleen Scholl
- Sharon Schuman

Donor Newsletter 2022     21

Sustaining Life Donors
- Philip and Penny Knight

Legacy Society
- Carol Ceresa
- Mira Frohnmayer & Sandy Sweet
- Clint Johnson
- Nigel & Ann Walker
- Pamela Wharton
- Anonymous

$1,000,000
- Philip and Penny Knight

$125,000+
- Kendall & Taylor Atkinson Foundation with the Nash Family

$45,000 – 50,999
- Norman and Linda Brenden
- Pat and Stephanie Kilkenny

$15,000 – 27,999
- John and Martina Hartmann
- Orion and Lisa Man
- Kevin and Lorraine McQueen
- Elizabeth Rohlfing
- Sanders Family Foundation

$10,000 – 14,999
- Lisa Dalton
- Lynn Frohnmayer
- Mira Frohnmayer and Sandra Sweet
- Betty Massoni
- Patricia Peterson
- Nigel and Ann Walker

$5,000 – 9,999
- Rachael Alaniz and Kevin Gatzlaff
- Jeanne Altman
- John and Kate Armentrout
- Atlas Insurance
- Mary Beale, MD
- Chris and Sharon Brezski
- Mauro and Kerrie Cazzari
- Joseph and Nancy Chou

Emily graduates from college
- Cheryl Cummins
- Daniel Curtis and Stephanie Shaff
- Donna DellaRatta
- Harry and Kaaren Demorest
- Jerry Dennerline and Margaret Sarkissian
- James and Glenda Douglass
- Mike Drennan
- Roy and Jan Dwyer
- Lee and Esther Eman
- Steinwachs Family Foundation
- Ford Family Foundation
- John Frohnmayer
- Dr. Sheryl Gardner
- Geckos’ Hospitality, LLC
- Linda P Gilmore
- The Giustina Foundation
- Janine and Joe Gonyea III
- Dr. Michael Greenberg
- Rachel and Kristian Gutulisrud
- Ronald Kabrowski and Mary Ann Hall
- Owen Hall and Margaret Kasting
- Richard Hansen
- Beverly Harms
- André Hessels and Rutger Boerema
- Dr. Charles and Linda Hollen
- Dr. Tracy Hull and Carl Engelman
- Brendan Ittelson
- John Ittelson and Bobbi Kamil
- Baila Janock
- Albert and Leslie Jeffrey
- Bob and Evelyn Jensen
- Richard N Johnson
- Robert and Constance Johnson
- Dr. Carole Kirkpatrick
- Erik Kjos-Hanssen and Turid Frislid
- Michael and Nancy Knutson
- Rebecca Lacy
- Dean and Bev Lahr
- Steve and Cyndy Lane
- Robert and Anna Langtry
- Barry and Laura Levine
- Brian Horrigan and Amy Levine
- Anne and Josh Lewis
- Burt and Atleea Lewis
- Ronald and Anne Lewis
- Michael London
- Col Gregory & Lt Col Lynnette Lowrimore
- William and Jacquelyn Lucarell
- Kristine La Cour Rasmussen
- Maria Marx and Steve Pulliam
- Brian and Helen Matthews
- Barbara Mayer
- Daniel and Angie McMahon
- David Meadows
- Jeffrey and Mel Miller
- Mary Anne Moore
- Dr. Jim and Marilyn Murdock
- Bernard and Phyllis Nash
- Don Niederpruem
- Ronald and Fredi Norris
- Northern California Swap Meets, Inc.
- Richard and Lucy Novak
- Gerald and Mary O’Shaughnessy
- Mark and Elizabeth Page
- Jerry Parsons
- David and Nancy Petrone
- Paul and Angelia Pless
- Peter and Janice Pless
- Melissa Pope
- Stan and Linda Potter
- Pete and Molly Powell
- Peter Rappoport and Marcia Marley
- George and Kathryn Reardon
- Robert and Mary Redpath
- Diane and John Render
- Paul and Katherine Rooney
- Bill and Alice Rose
- Deanne and Richard Rubenstein Sr.
- S&P Global
- Ron and Alice Schaefer
- Phyllis and Paul Schirle
- Chris and Heidi Schmitz
- Colleen Scholl
- Sharon Schuman

Ariauna graduates from high school
- Jared graduates middle school
- Thomas and Diane Sciarretta
- Diane and Robert Charles Scott
- Mark and Kelly Scruggs
- Heinz and Susan Selig
- Ruthellen and Peter Sheldon Jr.
- Ted and Sarah Silver
- Karen Smith
- David and Tanner Sobelman
- Molly Stapelman
- Steven and Mary Swig
- James Tallman
- Jean Tate
- Cathy and Joseph Terhaar
- The Jane and Arthur Flippo Foundation
- The Marzilli Family Fund
- Tina Thoman
- Peter Toal
- Mary Ann Tonkin
- Barbara Trueman
- Susan Vandermeys
- Juan and Jennifer Villaveces
- Thomas Waters
- Charles Weaver
- Sandy Welch and Bob Griffiths
- John and Mary Helen Willettt
- Robert and Julie Williams
- Gregory Wood and Cheryl Townsend
- Wood Anne Yull

AbbVie
- Assila Al-Marshoudi
- Victor and Mary Albino
- Arbella Insurance Foundation
- Stephanie Austin and James Niess
- Leslie Badger
- Robert and Julia Ball
- Margaret Barnes
- Israel and Mary Jo Becerra
- Frank Benisti
- Dr. Marv and Carol Berkman
- Domenico Bertolucci and Federica Bonati
- Talin Bingham and Dana Midby
- Drs. Chris Holzapfel and Bill Bradford
- Nancy Bravo and John Christensen
- Adam Breninger
- Sylvia Bronner

The photos throughout the donor honor roll give us a big reason to celebrate: these are kids, teens, and adults with FA graduating earlier this summer. We love to see and share these milestones!
Kendra graduates from 5th grade

Celeste Brusati
Carol Ceresa and Melvin Matsumoto
John and Cheri Courtinage
Merri Ann and Bud Crowther
Gaylord and Judith Davis
Kathie Davis
Robert Douglas
Bill and Mary Douthitt
Bill and Karen Early
Dr. Jesse and Nancie Ehrlich
Mary Ellen Eiler
Dr. Jesse and Nancie Ehrlich
Bill and Mary Gilland
Clay and Lori Gilmore
Sylvia Giustina
Deborah Goldman, PhD
Dr. & Mrs. Javier Gonzalez
Winston and Sheila Gouloud
Paul and Kathy Graham
Brian Anderson and Sultana Graham
Barry Gratz
Ronald and Linda Greenman
Barry and Denise Groce
Maureen Hales
John Heschmeyer
Dennis and Chris Hill
Jeffrey Hoffman
Rita and Joseph Hogan
Steven Holmes and Kerry Robinson
Bruce Howard
David David and Susan Lesyk
John and Jennifer Hutchens
Gil and Judy James
Nelson Kepsky and Sandy Wellington
Carolee and Jerry Kolbe
Peter and Rebecca Kovach
Drs. Christianne and Reed Kratka
Brent and Michelle Laing
Dr. Jay and Tina Lamb
Eugene and Renee Lemmon
Mark and Tricia Lensmeyer
Ed and Ann Lichtenstein & Emily Strother
Bob and Beth Lowe
David and Jolene Loy
Ann Lymann
Alicia MacArthur
Don and Ann Mack
Jack and Gail McAllister
Brian and Karen McKay

Don and Susan McLaughlin
Fredericka Mirenda
Kelly and Gerald Mlachak
Craig and Lynne Moore
Patrick and Myra Morrow
Janet and John Musco
Ole and Olea Obie
Odyssey Foundation
Carolyn Perry and Doug Hunt
Donald and Linda Petting
Steve and Patrice Philpott
Juanita and John Postlewait, PhD
Michael Pugh and Loralee McKee
Mary Putney
Lynn and Shirley Quinlan
Tom and Kay Reed
Betty Rinck
Mark Ritchie and Lisa Mingo
Neil and Emily Robison
Andrew and Gaye Saxon
Kelly Semkew
Matthew and Diane Senator
Gary Haftek
SFM Mutual Insurance
Company
Paul and Dana Skiller
Gerald W. Slippo Jr.
Norm and Kathy Smith
Patricia Smullin
Betty Soreng and Eben Dobson
Tom and Virginia Sponsler
Michael Starr
Gerald Stockford
Annelise Stoker
Dan and Linda Sullivan
Michael and Janice Sullivan
Gail Swanson
Scott Swanson
Daniel and Ann Sweeney
Margaret Taft
Sheri and George Tichi
Bruce and Lorene Timperley
Jim Totorolla and Peggy Kelley
United Way of Lane County
Roger and Jean Upson
Dr. Jill Walker
Pamela Watson
Helena Webster
Kenneth Weinberg, MD
Marc Weiner
Sandy Weiner
Mathew and Katherine Whelan
Yvonne Wilshid
Dr. Kathleen Wiley and Bob Carolan Williams
George Wingard
Connie and Harry Wonham
Charles and Leslie Wright
Wesley and Susan Wycoff
Thomas and Marjorie Zabornoy
Matthew and Mary Zuck
Cecelia Zurhellen

Mason graduates from 5th grade

Alexis graduates from preschool

Donna Alspaugh
Lisa Allen
Norm Andresen
Jeanne Atkinson
Tom and Patti Barkin
Melissa Beard
Charlene and Jeffrey Bender
Robert and Margaret Berdahl
Ryan and Amy Blumhorst
David Bouderaux
Bob Boulwin
David and Margy Buchanan
Scott and Rachel Butler
John and Shirley Byrne
Daniel and Sally Caldwell
Scott and Maria Carreras
Ryan and Ashley Carson
Dan and Lydia Christensen
George and Cherie Clancy
Mary Sue and Kenneth Coleman
Denny and Jeanne Collins
Don and Donald Coon
Joe and Regina Corgio
Janet Crawford
John and Donna Crosiar
Bradley and Cynthia Curby
Bill and Pat Danks
Peter and Heidi Davidson
Ted and Diane Dearborn
Richard and Susan DellaValle
Stan and Sarah Dietzel
William and Christa Dinsenbach
Elaine Doherty
Verne and Donna Duncan
Oscar Duque and Yanira Ramirez
Dr Andrew Eichenfield
and Nancy Cincotta
Erik and Joanne Ela
George Evans and Pauline Andrews
Thomas Ferguson and Peggy Leathers
Dr. Robert Finkelstein and Nancy Hausman
Gordon and Carol Fleming
Shawn and Doreen Gummeo
Thomas Foley and Charlene Padden
Diane Frewer
Anne Marie Frohnmayer
and Tom Bandar
Daniel and Dolores Gardner
Christa Gensler
Tim Gleason and Jenny Ulum
Mike and Jenny Goldstein
Susan and Larry Gordon
Mrs. Marion Gratza
Bradley and Sara Green
Melinda Grier and Jerry Lidz
Craig Grinnell

Ryan graduates from kindergarten

Betsy Halpern
Xiaoping Han
Jim Harper
Dale and Carla Harris
Roger and Nonna Haydock
Nancy Heim
John Herman
Richard Hildreth and CaroIene Forell
Dr. Wesley and Joanna Hoskins
Trey Huelsberg
Patricia Hurley
Addepar Inc

Indiana State Employees
Community Campaign
Grant and Suann Inman
Robert and Phyllis Jack
Peter James
Nancy Jansen
Ruth Kaminski and John Garrett
Roger and Sandra Kasch
Amy Katz
Glen and Diane Kellogg
Timothy and Mary Kelly
Molly Kohnstamm
Patricia Krier and Thomas Connolly
Andrew Ladd
Timothy and Mary Ann Lana
Cindy and Michael Leichner Sr.
Clayton Lewis and Joan Biskupic
Kenneth and Betty Liescheidt
Dr. Mark and Marie Litchman
Doug and Diane Livermore
Fred and Donna Long
Stanton and Rosemary Long
Jack and Ellen Maddex
Grace Maguire
Mark and Christine Malcolm
Jules and Wendy Marine
Brian Markham
Mark Mayo
Doris McKee
Roger and Jeanne McNitt
Medical Diagnostic Services
LLC
Sally Melzer
Dr. & Mrs. Phillip Mihm
Jody Miller and Kip Leonard
Ian and Tricia Mitchell
Arthur Molloy and Raya Marefat
Joan Moll
Col. Ellis and Stephanie Morris
Dr. Robb and Audrey Moses
Gail and MGW Mulligan
Greg and Tiffany Muniz
Jack Munro and Kathy Keene
Tony and Lima Nahas
William and Mary Beth Nash
Donald and Joan Nelson
Alice Nicholson
Michelle Norbin

Fieldly graduates from kindergarden

Sharon O’Brien
Dr. Jay and Mary O’Leary
T. K. and Joyce Olson
David Olsson and Judy Giers
Theodore and Laramie Palmer
PayPal Giving Fund
Jim and Patti Petersen
Steven and Carol Pietryk
Jan and Malcolm Pitchford
Michael and Sharon Posner
Merry Prose
Nancy Radcliffe
Ken Raymen
Richard and Barbara Resch
Michael and Kathleen Roberts
Dan and Kay Robinhold
Patrick and Eddy Rogers, Jr.
James and Sheila Rohr
Ozzie and Coralie Rose
Victor and Janice Rosenberg
S. Everett Rushing
Richard and Marilyn Sablosky
Nitin Sallapudi
James and Sandstrom
Frances and Clyde Saylor
William and Marisela Schaecher
Bette Schmaling
Anna Schuermer
Don and Barbara Scoble
James and Kristen Seymour
Bradley Showalter and Huong Nguyen
Jane and Raymond Shultz
John Silk
Alain Silverston
Lynn and Doris Sjolund
David and Sharon Smullin
Alexandra Sobeck
David and Annette Sparks
Molly and Jonathan Stafford
Janet Starr
Ray and Cathie Stanton
Gerry and Heidi Stolp
Jay and Susan Stuart
Paul and Debra Sundsvold
Susan Swain
Renate and John Tilson
Ronald and Ivy Timpe
Janice Trout
Michael Dirk Veleke
Marc and Sally Vomocil
Jim and Barbara Walker
Karen and Christel Warren
Gregory and Deborah Warren
Chet and Carl Weichman
Janette O’Wells
Jessica and Ezekiel Werden
Ed and Eloise Whitelaw
Bobbie Williams
John and Debbie Williams
Philip and Brenda Wisniewski
Gordon Wright and Anne Moffett

22 Donor Newsletter 2022
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!
Our mission is to find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

HOW YOU CAN HELP

Donations Online:
  Donate via our website (www.fanconi.org)

Donations by Phone:
  Call us at 541-687-4658 or toll free at 888-FANCONI (USA only)

Donations by Mail:
  360 E. 10th Ave., Suite 201, Eugene, OR 97401

Donate While Shopping on Amazon:

Donations of Appreciated Stock:
  Please contact our office at 541-687-4658 or email info@fanconi.org.

info@fanconi.org • www.fanconi.org