



Issue 75 • Spring 2024

FAMILY Newsletter



Update from HQ

WE ARE EMBARKING ON A NEW CHAPTER FOR OUR ORGANIZATION, AND I AM THRILLED TO REAFFIRM OUR UNWAVERING DEDICATION TO OUR MISSION. WHILE THE NAME OF THE DISEASE REMAINS UNCHANGED, THE LANDSCAPE OF CHALLENGES FACED BY THOSE AFFECTED HAS EVOLVED, DEMANDING INCREASED FOCUS ON FA CANCERS. AS THE FOREMOST ORGANIZATION SUPPORTING RESEARCH ON FA, WE MUST RISE TO MEET THESE CHALLENGES WITH RENEWED VIGOR AND CONVICTION.

With this imperative in mind, we have made the decision to rebrand our organization as the Fanconi Cancer Foundation (FCF), reflecting our expanded focus on cancer prevention, detection, and treatment. This decision was not made lightly, but we believe it to be the right one. FCF remains steadfast in our commitment to providing resources, education, and community for those affected by FA, while deepening our understanding of all facets of the disease. Together, we will persevere until we find a cure.

One of the highlights each year is the Scientific Symposium and Retreat for Adults with FA, a weekend that never fails to inspire. Last fall, in Vancouver, Canada, we witnessed unparalleled collaboration and camaraderie among attendees from across the globe. The energy in the room was palpable as individuals with FA and the research community came together to share insights and forge connections.

This Symposium highlighted the importance of collaboration, particularly in areas such as psychosocial research and clinical care. Witnessing the passion and dedication of everyone involved was truly humbling.

Equally impactful was the concurrent Adult Retreat, providing a nurturing environment for learning, sharing, and support. Discussions on mental health, fertility, and navigating healthcare journeys were invaluable.

Of course, events are one facet of our activities; research is at the core. Recently, we funded in-vivo gene editing technologies to tackle the core of our disease's DNA repair problem. Additionally, our collaboration with the University of Chicago on the FA Data Commons demonstrates our commitment to facilitating global research efforts. You'll read more about these projects in this newsletter.

Amidst our scientific endeavors, we remain deeply committed to providing emotional support to FA families worldwide. The recent gathering in Curitiba, Brazil, highlighted the profound impact of community support organizations. We are inspired by the dedication of these families and pledge to stand by them in their journey.

As we set our sights on the road ahead, we're fully aware of the challenges awaiting us, but our resolve remains unshakeable. We're incredibly thankful for the unwavering backing of our community. Together, we hold the key to making lasting changes in the lives of those affected by this disease.

With gratitude and determination,

Mark Quinlan

Executive Director



ADVANCING RESEARCH TO HELP
PEOPLE WITH FA LIVE FULL LIVES



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Get Ready for International FA Month this May

May is Fanconi Anemia (FA) Month, a time dedicated to raising awareness and funds for research and support initiatives to improve the lives of individuals affected by FA and associated cancers. We invite you to join us in making a difference this May by participating in our FA Month campaign.

Did you know that you can set up your very own personal fundraising page in less than 5 minutes? Simply visit fundraise.fanconi.org/FAMonth to get started! Once you're there, you'll have the option to choose how you want to fundraise:

GET OUTSIDE:

Lace up your shoes and complete a run, walk, hike, or bike ride in honor of FA Month. Share your journey with friends and family to raise awareness and funds for FA research.

GET SOCIAL:

Host a party, organize a gathering, or plan a creative event to celebrate FA Month and raise funds for a great cause. Share your event on social media and encourage others to join in the fun!

GET CREATIVE:

Whether it's a bake sale, a craft fair, or a unique fundraising idea of your own, let your creativity shine and fundraise in a way that's meaningful to you.

fundraise.fanconi.org/FAMonth

Talking Points to use this FA Month

Sharing your story and highlighting the importance of FCF's work can inspire others to join the cause during FA Month. Feel free to personalize these talking points with your own experiences and emotions. Use the talking points below that are most relevant to your story and most meaningful to your community.

INTRODUCTION:

- Hi everyone, during this FA Month, I'm excited to tell you about Fanconi anemia (FA) and the amazing work of the Fanconi Cancer Foundation (FCF).

PERSONAL CONNECTION:

- Our journey with FA started [insert time frame] when [insert family member's name] was diagnosed with this rare disease we'd never heard of before. Since then, we've faced many challenges, but we've also found hope and support through organizations like the Fanconi Cancer Foundation.

UNDERSTANDING FA:

- FA is a rare inherited disease that can lead to bone marrow problems, leukemia, and a much higher chance of getting cancer. It's caused by mutations in one of 23 genes involved in DNA repair, including ones linked to breast cancer.

RESEARCH ACHIEVEMENTS:

- FCF was started in 1989 by parents whose three daughters were diagnosed with FA. They've done a lot to improve treatments like bone marrow transplants, which have increased lifespans dramatically.
- FCF has helped fund over 260 research projects worldwide, trying to learn more about FA and find better treatments. They're also working with world-renowned groups like Stand Up To Cancer to find new ways to prevent, detect, and treat cancer in people with FA.
- Recently, FCF recruited the world's leading experts in gene therapy and gene editing to tackle the root problem of the disease, which could be a game-changer for treatment.

COMPREHENSIVE SUPPORT SERVICES:

- FCF does more than just research. They also help families like ours with support, information, and programs to cope with the many challenges of this disease.
- Additionally, there's an instrumental cancer study at the National Institutes of Health (NIH) that focuses on cancer screening in people with FA, providing crucial insights for early detection and prevention.

IMPACT OF RESEARCH ON CANCER UNDERSTANDING:

- Studying FA can teach us a lot about how cancer works, which could lead to better ways to detect and treat cancer in everyone, not just those with FA.

PERSONAL STORY AND GRATITUDE:

- [Insert personal story about your family's journey with FA and how FCF has helped]
- We're so grateful for the support and resources provided by FCF. They've made a big difference in our lives and the lives of many others affected by FA.

CALL TO ACTION:

- This FA Month, let's come together to support FCF's important work by spreading the word and raising money for FA research and support programs.
- Your donation, no matter how big or small, can make a real difference in the lives of people with FA and associated cancers.



Members of FCF leadership:
The Board of Directors, Scientific
Advisory Board, and FA Adult Council

While the name of the disease remains unchanged, our approach must align with the most pressing challenges faced by the community living with it

INTRODUCING THE FANCONI CANCER FOUNDATION

A New Era in FA Research & Impact

In 1989, Lynn and David Frohnmayer founded the Fanconi Anemia Research Fund (FARF), determined and desperate to find a cure for their three daughters diagnosed with Fanconi anemia (FA). Since then, their vision has grown into a vibrant community of FA families, researchers, clinicians, donors, fundraisers, staff, and volunteers, all dedicated to improving outcomes for people with FA.

Together, we've achieved remarkable milestones. Life expectancy for individuals with FA has more than doubled (!), and advancements in cell transplant procedures, driven by research supported by FARF, have transformed outcomes. Through our collective efforts, we've identified 23 FA genes, including the pivotal breast cancer genes, *BRCA1* and *BRCA2*, linking our rare disease to broader cancer research.

Amidst our successes in addressing bone marrow failure, we recognize a sobering reality: FA is not just a blood disorder, but a cancer susceptibility syndrome. Faulty DNA repair due to FA mutations significantly elevates the risk of cancer, emerging as the most pressing challenge facing the FA community.

"While the name of the disease remains unchanged, our approach must align with the most pressing challenges faced by the community living with it," explains Isis Sroka, PhD, Chief Scientific Officer at FCF. "As the leading foundation dedicated to supporting research on this disease, we must intensify our focus on the urgent and currently unsolved problem of cancer to discover solutions."

While our commitment to the FA community remains unwavering, our name change reflects a strategic increase in focus towards combating cancer within our community. The Fanconi Cancer Foundation is dedicated to preventing, detecting, and treating cancer in individuals with FA, recognizing that understanding FA-associated cancers can inform cancer treatment beyond our immediate community.


Our expanded mission does not diminish our dedication to addressing other facets of FA. FCF will continue to provide vital resources, education, and support, while deepening our understanding of the complexities of FA, including bone marrow failure, FA Neurological Syndrome, mental health, well-being, and other FA-related issues.

Central to our strategy is the cultivation of innovative partnerships. By collaborating with leading physician-scientists, industry partners, fellow patient-driven organizations, and funders, we aim to accelerate cancer research and ultimately transform outcomes for individuals with FA.

At the heart of our mission is community. It is our collective resolve, fueled by your support, that propels us forward.

We are immensely grateful for your enduring support, spanning the past, shaping our present, and guiding us toward a future in which everyone affected by FA lives a full life.

Join us as we embark on this new era with renewed energy and purpose.



Research Opportunities and Open Clinical Trials



Participating in research isn't just important for better understanding Fanconi anemia—it's a way for you to join forces with researchers in developing new treatments and therapies. By getting involved in clinical trials and research opportunities, you not only contribute to the collective knowledge about FA, but also have the opportunity to potentially benefit from treatments that could improve your (or your child's) quality of life.

Additionally, being part of research can empower you with a sense of control and involvement in your own healthcare journey. If you're considering participating in a clinical trial, resources such as scholarships offered by FCF can help alleviate the financial burden associated with transportation and housing costs. Read about current clinical trials and research opportunities and take a step towards shaping the future of FA treatment. Your participation matters.



FA researchers and clinicians in Spain are working on gene therapy and gene editing.

CANCER TRIALS: SURVEILLANCE AND EARLY INTERVENTION

FANCONI ANEMIA CANCER SCREENING STUDY

Location: National Institutes of Health, Bethesda, MD

Eligibility Criteria: Open to all individuals aged 12 and older with FA. Additionally, individuals aged 8-12 who have a history of persistent visible oral lesions, recent onset swallowing difficulty, or other concerning symptoms are eligible to participate.

Objective: The aim of this study is to conduct mouth inspection and brush biopsy screening combined with comprehensive cancer screening for individuals with FA at regular intervals. The goal is to assess whether this approach enhances early cancer diagnosis and improves overall clinical care. Participants will undergo screening for esophageal, gynecological, anal, and skin cancers. Additionally, brush biopsy of persistent oral lesions will be performed for diagnostics and analysis.

Contact Information: *Neelam Giri, M.D.* / Phone: (240) 276-7256 / Email: girin@mail.nih.gov

EARLY DETECTION STUDY FOR FANCONI ANEMIA-RELATED ORAL CHANGES

Location: The Rockefeller University, New York, NY

Eligibility Criteria: Open to individuals with FA aged 12 years and older

Description: This study aims to identify changes in the mouth before they develop into cancer using a noninvasive brush. The study involves a single visit to Rockefeller University Hospital, including oral examination, camera documentation, oral brushing of six normal-appearing sites (as well as any present lesions), a blood draw, and a skin biopsy (only for adult patients who had a bone marrow transplant). The study team is also available to travel to participants. Samples collected from participants will be used to understand the disease better, leading to the development of new preventive and treatment strategies, as well as noninvasive early detection of cancer.

Contact: *Yu-Chien Lin* / Phone: 212-327-8613 / Email: ylin@rockefeller.edu



CLINICAL TRIALS FOR HEMATOLOGIC ISSUES

ACETALDEHYDE EXPOSURE AND DNA DAMAGE IN THE ORAL CAVITY OF FA PATIENTS BEFORE AND AFTER CONSUMPTION OF A LOW ALCOHOL DOSE

Location: University of Minnesota, Minneapolis, MN

Eligibility Criteria: This study is open to FA patients aged 21-45 who are occasional alcohol drinkers and non-smokers. Participants must be willing to attend a single clinic visit lasting approximately 7 hours, consume one alcoholic drink during the visit, and provide samples of saliva, mouth cells, and urine.

Objective: The aim of this study is to investigate the effects of acetaldehyde exposure on DNA damage in the oral cavity of FA patients before and after the consumption of a low dose of alcohol. By examining specific types of DNA damage induced by alcohol consumption, the study seeks to understand how this may influence cancer formation in individuals with FA.

Contact Information: Study Team / Phone: 612-626-8654 / Email: alcohol-study@umn.edu

ANTIBODY-BASED CONDITIONING WITH TCRAB T-CELL/CD19 B-CELL DEPLETED ALLOGENEIC TRANSPLANTATION FOR FANCONI ANEMIA PATIENTS WITH CYTOPENIAS

Location: Stanford University, Stanford, CA

Eligibility Criteria: This study is open to FA patients of all subtypes, aged 2 and above, who have developed cytopenias (reduced blood cell counts) and do not have an HLA-identical matched sibling donor for bone marrow transplant (BMT). Participants must not be receiving other experimental therapies at the time of enrollment and should not have active cancers or concerns for high-risk bone marrow disease.

Objective: The objective of this study is to prepare patients for a stem cell transplant by utilizing an antibody-drug instead of radiation or chemotherapy, aiming to make transplants safer. Prior to BMT, patients will undergo treatment with standard immune suppression and an antibody-drug called JSP191, replacing genotoxic irradiation or busulfan treatment. Blood stem

cells will be collected from healthy donors and purified to remove problematic T-cells. These purified stem cells will then be administered to the patient via intravenous infusion.

Contact Information: Bone Marrow Failure Program Team / Phone: 650-497-8953 / Email: bmf@stanfordchildrens.org

A DOSE ESCALATION STUDY OF FP-045 IN PATIENTS WITH FANCONI ANEMIA

Location: Foresee Pharmaceuticals (Locations at Stanford and Minnesota)

Eligibility Criteria: This study is seeking adolescents and young adults aged 14 to 18 with FA who have mild to moderate bone marrow failure and no prior history of bone marrow transplant. Participants must be in the initial stages of bone marrow failure.

Objective: The objective of this study is to evaluate the safety and tolerability of FP-045, an aldehyde activator, in individuals with FA. FP-045 may hold promise as a treatment for those in the early stages of bone marrow failure.

Contact Information: Bassem Elmankabadi, MD / Phone: 562-310-8718 / Email: [Bassem.elmankabadi@foreseepharma.com](mailto:elmankabadi@foreseepharma.com)

STEM CELL TRANSPLANT FROM DONORS AFTER ALPHA BETA CELL DEPLETION IN CHILDREN AND YOUNG ADULTS

Location: Stanford University, Stanford, CA

Eligibility Criteria: This study is open to individuals aged one month to 60 years old who are eligible for allogeneic hematopoietic stem cell transplant (HSCT) according to institutional guidelines. Additional inclusion and exclusion criteria apply; refer to study information for details.

Objective: The objective of this study is to improve the safety and efficacy of allogeneic HLA-partially matched related or unrelated donor HSCT when matched donors are unavailable. Participants will undergo a stem cell transplant using donor cells manipulated through an investigational device. Follow-up will occur for two years to assess outcomes.

Contact Information: Alice Bertaina / Email: scgt_clinical_trials_office@lists.stanford.edu

ELTROMBOPAG FOR PEOPLE WITH FANCONI ANEMIA

Location: National Heart, Lung, and Blood Institute (NHLBI), Bethesda, MD

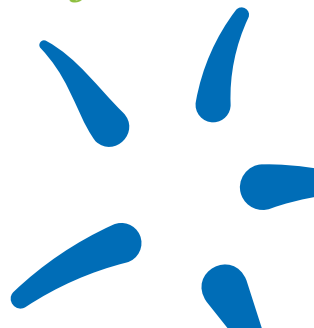
Eligibility Criteria: Individuals with Fanconi anemia aged 2 years or older, weighing over 10kg, and experiencing clinically significant cytopenias (low blood counts) are eligible. Additional criteria apply; refer to study information for details.

Objective: This study aims to investigate the effectiveness of Eltrombopag (EPAG) in improving peripheral blood cell counts in patients with FA. The hypothesis is that EPAG may positively affect morbidity and mortality by improving blood counts and DNA repair mechanisms impaired in FA patients.

Contact Information: Bretagne Cowling / Phone: 240-550-3587 / Email: bretagne.cowling@nih.gov



FA clinicians performing an oral cancer screening in Brazil.





LONG TERM EFFECTS ON RECIPIENTS OF HEMATOPOIETIC STEM CELL TRANSPLANTATION

Location: Stanford University, Stanford, CA

Eligibility Criteria: This study is open to individuals who are scheduled to receive or have completed a hematopoietic stem cell transplant (HSCT). Participants must be willing to transfer follow-up care to Lucile Packard Children's Hospital (LPCH) if HSCT was completed elsewhere. Participants with relapsed malignant diagnoses post-HSCT and not undergoing work-up for a new HSCT are not eligible.

Objective: The goal of this study is to establish systematic follow-up care for HSCT recipients by collecting data and tissue samples, creating a comprehensive database, and monitoring survivor's clinical status throughout their lifespan.

Contact Information: *Nivedita A Kunte* / Phone: 650-497-2038 / Email: nkunte@stanford.edu

REGISTRY-BASED STUDIES FANCONI ANEMIA REGISTRY

Organization: Fanconi Cancer Foundation

Eligibility Criteria: Open to all individuals with Fanconi anemia

Description: The Fanconi Anemia Registry serves as a participant-driven resource aiming to empower and unite the FA community through shared knowledge. Registry participants have the opportunity to complete surveys about their disease experiences. The overarching goal is to aid the FA community in developing recommendations and standards of care, while also serving as a resource for researchers interested in FA.

Contact: *Andrea Ronan* / Phone: 541-687-4658 / Email: andrea@fanconi.org

CANCER IN INHERITED BONE MARROW FAILURE SYNDROMES

Location: National Cancer Institute (NCI), Bethesda, MD

Eligibility Criteria: Open to all FA patients, their first-degree relatives (siblings, parents, children, and grandparents)

Description: This study aims to provide information on cancer rates and types in inherited bone marrow failure syndromes, including FA. It involves questionnaires, clinical evaluations, laboratory tests, medical records review, and cancer surveillance.

Contact: *Neelam Giri* / Phone: 240-276-7256 / Email: girin@mail.nih.gov

NATURAL HISTORY OF FANCD1/BRCA2

Location: National Cancer Institute (NCI), Bethesda, MD

Description: This subgroup study is part of the National Cancer Institute's Cancer in Inherited Bone Marrow Failure Syndromes. It focuses on individuals with FA associated with mutations in FANCD1/BRCA2 to determine their natural history.

Contact: *IBMFS Study Team* / Phone: 1-800-518-8474 / Email: NCI.IBMFS@westat.com

INTERNATIONAL FANCONI ANEMIA REGISTRY (IFAR)

Location: The Rockefeller University, New York, NY

Eligibility Criteria: Open to all individuals with FA

Description: The IFAR aims to study the nature, diagnosis, and treatment of individuals with FA. Information collected will aid in better understanding FA, diagnosing, and treating the condition.

Contact: *Agata Smogorzewska* / Phone: 212-327-8612 / Email: fanconiregistry@rockefeller.edu

The New and Improved FA Registry

IMPROVEMENTS:

- Streamlined to focus on essential information
- Emphasis on cancer screening, diagnosis and treatment.
- Less redundancy with other FA studies
- Shorter and easier to fill out
- Incentive program roll out



We value your time and participation. Once you've completed your surveys, we'll send you a \$50 gift card to say thank you!

THIS IS WHERE WE'RE AT



183

people with FA have signed up for the registry (900+ receive this newsletter)

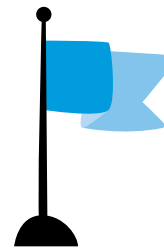


46

of these 183 are actively entering their information with the new surveys

WHAT NEEDS TO HAPPEN NEXT

Getting registered is the first step, then entering your data is **vital** to providing the critical information that clinicians and researchers need to truly make a difference. More than 1,500 patients are enrolled in FCF family services. Taking on cancer and FA takes all of us.



2024 GOAL:

50

new participants!

HOW TO JOIN THE REGISTRY



Visit fanconiregistry.iamrare.org to create your private account



Answer questions about your personal info and experience with FA. Come back to complete at any time.



Know that you're helping researchers find answers faster

Fanconi anemia is a rare disease and can be hard to diagnose and treat. Research is the key. And the key to research is you.

Nobody understands FA like the people who live it every day, that's why it is so important for you to provide your information. You can make a difference.

JOIN THE FA REGISTRY TODAY: [HTTPS://FANCONIREGISTRY.IAMRARE.ORG](https://fanconiregistry.iamrare.org)

Caregiver Corner: Opportunities for Caregivers

VIRTUAL SUPPORT SESSION: LIVING WITH UNCERTAINTY

Join FCF and Allison Breininger for Living With Uncertainty, a virtual session on May 18th at 10am PT. A common phrase in the FA community is “I’m just waiting for the other shoe to drop.” Living with this amount of uncertainty can take a toll. This session will be a group discussion about what it’s like living with the unknown and ways we can find support as we do. Visit the Events Page on the FCF website to register.

LAST CALL FOR CAMP APPLICATIONS

The Family Retreat is only a few months away and we can’t wait! If you would like to join us at the Painted Turtle in Lake Hughes, CA, this is your last call to submit your application before the May 1st deadline. We hope to see you there for presentations by leading researchers and physicians specializing in Fanconi anemia (FA), support groups aiding in coping with the disease, and the chance to connect with other families impacted by FA.

TRIAGE CANCER: CAREGIVING SESSION

Join Triage Cancer for a free webinar about caregiving on June 27. This webinar explains the rights of caregivers at work, how to replace lost wages while acting as a caregiver, and practical tips to support caregivers. You can register at www.triagecancer.org/webinars.





LONGTIME FCF SUPPORTERS LOOK TOWARD THE FUTURE

There's nothing quite like the fierce determination of parents to a child affected by Fanconi anemia.

Our founders had three daughters with FA and to this day, the majority of our funding comes from FA family communities. One such family community from Colorado has been working on this cause for nearly 20 years and has raised an outstanding \$3.1 million for FA research.

The Kendall and Taylor Atkinson Foundation (KATA) was founded in 2006 in memory of Kendall and Taylor, a brother and sister diagnosed with FA in 1990 at the ages of three and seven. Their mom and KATA co-founder Jeanne Atkinson shares, "Their diagnosis was an agonizing blow which led to a whirlwind of uncertainty, information gathering, and decision-making. We were told that without a bone marrow transplant they would not likely live to adulthood. Our lives were forever changed."

Kendall was in college in 2004 when she received her transplant with an unrelated, mismatched donor. Tragically, the transplant protocol proved too toxic, and Kendall died four weeks later.

Just a year later, high school senior Taylor received his transplant. 106 days later, Taylor presented with graft-versus-host disease, where the donor cells were attacking his own cells. Taylor died nine months later.

To honor their children's memory and help others with FA live longer and better lives, Ken and Jeanne Atkinson began the KATA Foundation. Surrounded by an incredible team of dedicated board members and volunteers, they have consistently raised hundreds of thousands of dollars to support research every year. Their signature event, a country-western gala appropriately dubbed "Hoot 'N' Holler" brought hundreds together in support of the

cause, and other events like the Art Howe Gold Scramble, Old Quincy Barn Dinner, Hope Floats lantern launch, and Hoop 'N' Holler showcased the fun-loving creativity of the community and its spirit of generosity.

After Ken's unexpected and tragic death in 2016, the community continued to rally around the family and their mission to better the lives of those with FA. The impact of this Colorado group on the FA community is undeniable.

Since Kendall and Taylor underwent transplant 20 years ago, outcomes have significantly improved thanks to research funded by FCF and the KATA Foundation. KATA has supported cancer prevention studies, the development of preclinical models, the head and neck cancer trial, and most recently, the gene editing project, among many other projects.

This year, after decades of volunteer-driven fundraising and support, the KATA Foundation will hang up its proverbial hat and officially 'call it a night'. While KATA will no longer host their events, their legacy and impact will carry on with the establishment of the KATA Fund within the Fanconi Cancer Foundation, a dedicated fund to advance FA research.

Jeanne Atkinson reflects, "With immense gratitude to our donors, volunteers, sponsors, and our great God who was behind it all, we recognize that our accomplishments stem from the loyal support of our community. We are overwhelmed by the generosity we've received and are at peace with this transition. We look forward to the future with FCF, knowing how much more can be accomplished."

We are endlessly grateful to the Atkinson family, the KATA board, and the entire KATA community, whose years of effort and support have made a true, lasting difference. Thank you.



Walker's Journey

BY KARA GIANDOMENICO



OUR WONDERFUL BABY BOY

When our son, Walker Avery Gronau, took his first breath on April 27, 2020, our world, as we knew it, changed forever. He was so alert and instantly exuded an old soul, observing us with these mesmerizing oceanic blue eyes. Chris and I had both lost our mothers prior to his birth, and we like to think he had a little bit of both of them in him, sent as a gift from them.

Walker was always so calm. Even early on, he had a way of making everyone around him feel loved, without an ounce of shyness. He would go up to other children and parents, gently gesturing that he wanted them to play.

SOMETHING FELT 'OFF'

We couldn't pretend we didn't have concerns about Walker's health early on. He endured stomach issues almost daily. Consults with gastro specialists got us nowhere, hearing that it was a minor and common issue. But holding him as he shook and cried countless times until it was over never seemed 'minor' or 'common' to me.

At around 15 months, we became concerned that he was still not speaking. We took him to his pediatrician, agreeing to start him with in-home speech therapy along with occupational therapy, which was a blessing.

One afternoon, I captured a picture of him playing. I observed just how dark the circles under his eyes were becoming, his skin giving off a yellow complexion, his ribs more distinctly sticking out. However, once again, our worries were redirected, this time with doctors saying he was simply a picky eater and probably not sleeping enough. Deep down, we feared it was not that simple.

In the meantime, we watched Walker obsess over dinosaurs, dig holes with his trucks, and collect rocks of all shapes and sizes. My husband Chris and I made it our mission to give Walker all our attention, especially in the evenings. We'd chase him around the house and let him hide, pretending not to see him. After baths, Chris would take Walker to get in his PJs, and we'd all sit together reading the books he had picked out. Afterward, we'd do our special goodnight handshake and blow three kisses upward to his three grandparents who were now angels in heaven.

FINALLY, A DIAGNOSIS

In November of 2022, Walker got sick with RSV, and I had just given birth to our second child, Easton. Initially, Walker's ongoing fevers were dismissed by doctors. But by December, our demands for further testing were finally heard. We had no idea just how life-changing these flagged labs would be. Suddenly, life seemed to move too quickly. By January 2023, Walker was seen twice a week and doing bloodwork every other week.

When life changes like that, you expect a two-year-old to get over the constant oncology visits. But when I tell you this kid just went with the flow, even looking forward to seeing his doctor to play hide and seek, it makes your heart melt.

By May 24th, after five months of pokes and three biopsies, we now had a diagnosis. We listened stunned as his doctor described Fanconi anemia (FA). I don't think a single parent wouldn't feel heartache at such an outcome. The drive home was quiet. I was already searching for information about FA and other families' stories. Right when we were feeling most alone, I came across the Fanconi Cancer Foundation. To say we felt connected to a community and more understood is an understatement.

TRANSPLANT

On June 5th, we had our first good news in almost six months. Walker's now 10-month-old brother, Easton, was a 10/10 match for a bone marrow transplant. We struggled with feeling celebratory, knowing how serious this procedure would become for Walker and the guilt for

how this would also affect Easton. By July 26th, Walker and Easton were officially ready for what we thought was our new beginning. Strange to think on the 25th, all four of us were laughing and playing in the kitchen for the last time ever, feeling so eager and hopeful.

As always, Walker did everything asked of him during his week of chemo. On August 1st, Easton would have his bone marrow harvest. Leading up to the transplant, Walker now had a .03 white blood count. Chris and I were so unaware of complications we never could have predicted. The transplant procedure on the next day seemed flawless.

OUR WORLD CRASHING DOWN

However, over the next few days, Walker expressed severe abdominal pain. For a child who never complains, the pain level that he experienced was something I never could have prepared for. From one afternoon all the way until morning, Walker would not only still have the stomach pain, but now fevers and continuous vomiting. I voiced my concerns as I laid holding him the entire night. His condition was apparently normal for a bone marrow transplant. But at 8 am, doctors called for Rapid Response as Walker became unresponsive in the nook of my arm, still hand in hand. Walker was immediately moved to the pediatric intensive care unit, in which they would attempt to intubate him, but as they did, he coded. Chris was walking in circles and I was being held up by staff, watching as they attempted to save him for approximately an hour.

Our resilient boy just couldn't take any more. Walker took his last breath and we watched the twinkle in his eyes dwindle away, still in his favorite dinosaur pajamas. I laid with him, singing his favorite song. Before letting him go, I said for the last time, "no more ouchies".

Walker's fight and strength made him the definition of heroic. To this day, I tell Walker's story about his beautiful soul, his courage and the will to smile under any circumstances. While we will never know the path Walker's life would have taken with FA, we do, however, know such a child existed with all the love anyone could have given.



My name is Blue Mohr and I'm a 27-year-old living with Fanconi anemia (FA). I'm from Austin, Texas, though I am currently living in Washington, D.C. where I'm pursuing a Master of Public Health degree from the George Washington University with concentrations in epidemiology, cancer, and public health communication and marketing.

A BIT ABOUT ME

I received an early diagnosis in late 1997 from Dr. Arleen Auerbach through DEB chromosome breakage tests. This diagnosis was later confirmed in early 2000 after the birth of my sister, who does not have FA. Subsequent testing identified that I had FA, subtype FANCA. I credit my parents, both molecular geneticists, and the medical team present at my birth for this timely diagnosis.

I had a very happy childhood. My parents encouraged both me and my sister to have a number of hobbies, most of which I have either kept up with or added to as I grew up. I started playing the cello when I was six years old, and while my right hand gave me some trouble with holding the bow, I think I did very well! I continued playing cello until I graduated from my undergraduate university. I also enjoy reading, sewing, knitting, crochet, painting, and

From Diagnosis to Life With FA

jewelry making and repair. I am a huge fan of cats in general and my family's cats in particular. I hope that when I am settled in one place for longer than two years, that I will be able to welcome cats into my own home.

KEEPING UP TO DATE WITH FA ADVANCEMENTS

I am very lucky that I am one of a growing number of FAdults who have not undergone bone marrow transplantation (BMT). Because I was diagnosed so early, my parents were able to keep a very close eye on my health, and enrolled me in clinical studies in order to push BMT as far into the future as possible. Their reasoning was that BMT technology and procedures would advance quickly, and the longer we were able to avoid BMT, the better outcomes I would have. I agree with this reasoning, as BMT outcomes and survival rates have improved phenomenally over the past 20 years. At around the age of 13, I began taking the androgen Oxandrolone to stimulate bone marrow function. Due to my positive response to the medication, I have continued using it, thus far averting the need for a bone marrow transplant.

I am currently enrolled with Dr. Neelam Giri's Fanconi Anemia Cancer Screening Study at the National Institutes of Health, which aims to improve cancer screening for FA patients, as we are at a much higher risk of developing several types of cancers in comparison to the general population. I'm very proud to be a part of this study, as cancer is an increasing concern

for those of us who have survived to adulthood, especially post-BMT. As part of this study, Dr. Giri and her incredible team continue to screen me not only for signs of developing cancer, but also for issues with my bone marrow, for which I am incredibly grateful. Not only does this study allow me to get regular screenings – something which I otherwise wouldn't be able to afford as a relatively poor graduate student – it's also a convenient 45-minute metro ride from my current home.

MY PERSONAL INTEREST IN FA RESEARCH, MENTAL HEALTH, AND ADVOCACY

As a student in the field of public health, I hold a special interest in the research conducted by Dr. Giri and her team, Dr. Lindsey Romick's investigation into metabolic alterations in FA, and the research led by Dr. Megan Voss and Dr. Kathleen Bogart on the psychosocial experiences of FAdults. Of these studies, the latter holds particular significance to me, as I have long advocated for a greater emphasis and support for mental health in the context of living with FA.

The dedication of these researchers and the insights they provide have not only motivated me to pursue a Master of Public Health but also inspired me to give back by becoming a member of the FAdult Council and participating in the emerging FA Advocacy Program.

Through the FAdult Council, I have the opportunity to support the FCF staff and Board of Directors by offering insights gained from my experience as a member of the FA community. This enables us to assist FCF and researchers in delivering the best resources, knowledge, and care to the entire community. The Advocacy Program operates on a similar premise, allowing FAdults and FAmilies to share their experiences and stories with scientists, facilitating the creation of focused studies that benefit the entire community.

I'm honored to help advance these initiatives and encourage you to participate where and however you can!



Advocacy:

Thank You and Welcome to FCF Leadership

YOUR DEDICATION HAS BEEN INVALUABLE



Orion Marx, a pivotal figure on our board, has held roles such as Vice President and President, significantly shaping FCF's strategic direction through active participation in committees like the Executive, Budget, Investment, Nominating, and Development Committees. Notably, his exceptional fundraising skills, exemplified by raising \$1,000,000 through Team Bravery's limit-pushing challenges, have profoundly contributed to organizational growth and staff development. Orion's leadership and dedication have left an enduring impact on FCF.



Aileen Carlos brought invaluable legal expertise to the board, offering guidance on contracts, HR, and policy matters. She served on committees such as the International, Winn-Byrd, and Scholarship Committees. Aileen's contributions, including spearheading the International Grant Support Program and fostering the FA Adult Council, have been instrumental in advancing our organization's mission.



Read more about the Board!

WELCOME BOARD OF DIRECTORS

Welcome aboard to our three outstanding new board members!



Adam Becker brings firsthand experience to our team, having joined the FA community in 2015 when his son Zachary was diagnosed with FA. With a career focused on scaling good teams, Adam currently serves as the VP of Services for Digimarc, championing sustainability and community improvement in his work.



Will Bloxom, an adult with FA from Salisbury, Maryland, has shown remarkable resilience, undergoing a transplant as an adult during the pandemic. He participated in the first FA gene therapy clinical trial in 2015 and has volunteered with Be The Match, exemplifying his commitment to advancing FA research and support.



Zar Toolan, with an impressive background in finance and leadership, brings a wealth of expertise to our board. Zar's extensive philanthropic endeavors, including his participation in marathons to raise funds for FCF in honor of his niece Avery Marx, highlight his dedication to making a difference.

WELCOME FA ADULT COUNCIL

We're thrilled to welcome our newest members to the FA Adult Council, each bringing unique perspectives and passions to our community.



Lexi Marshall, a former Division III softball pitcher turned pension actuary, brings her expertise in mathematics and chemistry to the table, along with a fervent commitment to patient education and self-advocacy.



Blue Mohr, a Public Health student from Texas, infuses their studies with a passion for creative expression, advocating for health equity and community-oriented care.



Louise Dagleish, a British photographer and advocate, challenges stereotypes surrounding FA by amplifying voices within marginalized communities and advocating for improved patient experiences. Her dedication to fostering understanding and resilience is inspiring.



Evan Connelly, a budding scientist from Milwaukee, Wisconsin, not only shares his personal journey with FA but also actively engages in research and community-building, blending his love for technology and music along the way.

THANK YOU

We extend our gratitude to **Amy Vangel**, **Michelle Watkins**, and **Daniel Kold** for their dedicated service on the FA Adult Council. Throughout their tenure, they played integral roles in orchestrating impactful FA Adult Meetings, prioritizing the warm reception of new members and fostering meaningful connections among FA adults. By attending leadership meetings and offering their lived experience as adults with FA, they helped shape FCF's strategic initiatives, community outreach, and services.

Fundraising Shoutouts

“We are speechless at the hard work, drive, determination, and heart that they put into each of these challenges.”



LIBI GRACE'S CONFETTI CELEBRATION SPARKS HOPE

Celebrating birthdays presents a wonderful opportunity to raise funds for a cause you care about. At just one-year-old, Libi Grace is already off to a great start! Following her confetti-themed party, Libi's mom, Krissie, reached out to her community to share: “Our hearts are SO full after the fun we had! If you're wondering how to love on Libi from afar, the very best gift she could receive is a chance at a cure and further research to fight Fanconi anemia.” We're thrilled to have played a part in Libi's celebration and extend our gratitude to the Wisniewski family for exceeding their goal, raising nearly \$1,700!



VANDERMEYS GOLF TOURNAMENT TEES OFF A SUCCESS

The Play for FA community achieved an incredible feat, surpassing their goal and raising nearly \$40,000 at the Play for FA Golf Tournament this October! This achievement speaks volumes about the hard work of the Vandermeys family, the participation of 86 golfers, support from 11 sponsors, the numerous FA families in attendance, and the unwavering dedication of the Play for FA community. Each year, the tournament grows in both size and impact, reaching more individuals within the FA community and beyond. We can't express enough gratitude to the Vandermeys family for not only raising substantial funds, but also for being outstanding representatives and advocates for the FA community.

PROGRESS TAKES WORLDWIDE DETERMINATION

Finding answers in the care and treatment for a disease like FA requires a united front. We couldn't make significant progress without the amazing organizations worldwide and their supporters who are working right alongside us to make a difference in the lives of those with FA. We would like to give a special thank you to Fanconi Canada and Lisa Mingo, who recently marked an impressive fundraising milestone of \$225,000 CAD in honor of her son, Dylan. This showcases the profound impact one family can make within an organization, all thanks to the generosity of Fanconi Canada's incredible donors!



RUNNING TOWARDS A CURE FOR FA

The Fiaschetti family showed their remarkable support of the FA community during the 2023 Pell Bridge Run last autumn! From David's impressive performance in the race to their volunteer efforts in making the run a reality, and their proactive fundraising endeavors with FCF, their collective contributions are sincerely appreciated. Why do the Fiaschetti family host their annual Pell Bridge run fundraiser? As they express, "When your loved one is afflicted with a life-threatening disease, you run toward better treatments, hoping for a cure." With the steadfast support of their community from Rhode Island and beyond, the entire family raised over \$12,700. Thank you, Fiaschetti family!



LINDSEY'S LEGACY

We extend a heartfelt shoutout to Leah Drouin and her family and friends for their participation in a 5K race in honor of Leah's sister, Lindsey, who bravely faced FA and left an indelible mark on this world. Lindsey, a graduate of Wheelock College, embraced life to the fullest, while also being a steadfast support to her friends and a beloved aunt, sister, and daughter. In October, the team, proudly known as Lindsey's Legacy, took part in the Hartford, Conn. Marathon, raising over \$2,400 for FA research in Lindsey's memory! Whether you ran, walked, donated, or cheered from the sidelines, your support was noticed. Thank you, Leah, and everyone who contributed to honoring Lindsey's Legacy.





REMEMBERING A FRIEND OF THOSE WITH FA

We would like to remember and thank Bridget Kelly McDermot from Westford, MA. She was a devoted wife and mother, loving daughter and sister, amazing aunt, proud dog mom, loyal friend, successful business leader, athlete, advocate for women and girls, and an extraordinary person. In lieu of flowers, her community's cumulative generosity of over \$14,000 to FCF is deeply appreciated. Bridget and her husband Mark supported Team Autumn, standing by their friend's daughter who lives with FA. The amount of lives Bridget touched is evident through the kind words and generous gifts we received to better the lives of Autumn and the FA community.

A TRIBUTE TO CALLIE'S 25TH BIRTHDAY

Last September, the Toal family stepped up their fundraising endeavors. Peter's participation in a half marathon, dedicated to his daughter Callie, who bravely lives with FA, marked a major moment as he crossed the finish line on her 25th birthday. Their remarkable initiative garnered over \$22,000 in support of FA research and awareness. Peter and Callie, your compassion and determination inspire us all. Thank you!

Upcoming Events

MAY

FUNDRAISER: FA MONTH (VIRTUAL)

- All Month Long – Open to all!

FA CONNECT | LIVING WITH UNCERTAINTY

- May 18, 2024 | 10:00 – 11:30 am PT
Facilitated by Allison Breininger

JUNE

FUNDRAISER: COLEY'S CAUSE GOLF TOURNAMENT (IN-PERSON)

- June 21, 2024
Levine Family | Massachusetts

AUGUST

FUNDRAISER: ENDURE FOR A CURE

- All Month Long – Open to all!

ANNUAL FAMILY RETREAT

- August 1 – 5, 2024
The Painted Turtle | Lake Hughes, CA

SEPTEMBER

36TH FA SCIENTIFIC SYMPOSIUM AND ADULT RETREAT (IN-PERSON)

- September 19 – 22, 2024
Sheraton/Le Meridien Charlotte Hotel |
Charlotte, North Carolina

OCTOBER

FUNDRAISER: PLAY FOR FA GOLF TOURNAMENT (IN-PERSON)

- October 10, 2024
Vandermeys Family | Virginia

FA CONNECT | ALL KINDS OF GRIEF

- October 26, 2024 | 10:00 – 11:30 am PT
Facilitated by Allison Breininger

DECEMBER

FUNDRAISER: HOLIDAY APPEAL MONTH (VIRTUAL)

- Month of December

FUNDRAISER: GIVING TUESDAY

- December 3, 2024



In Loving Memory



DILLAN DAHLIEN
5/11/1992 - 9/11/2023

Dillan projected his love for life in everything he did and toward everyone he knew. He enjoyed spending time with his loyal dog 'Bruno', writing music and film scripts, Minnesota Viking football, hunting, fishing, bowling, kayaking and airsoft adventures. Dillan was very talented. He had various platforms where he showcased his talents, including a YouTube channel, a film-making company, and a country/rock band. As the drummer, Dillan kept the rhythm. He is the heartbeat that keeps us all going. He was a child of God and we all loved him so very, very much and every single day, the brotherly love between Dillan, Dustin and Devon could always be felt. He truly was a blessing beyond measure.



ROY MICHAEL HALE PROCTOR
12/25/1987 - 1/18/24

Roy passed after a 24-year battle with FA. Roy graduated from Portland State University with Magna cum laude honors after having his time there interrupted by several medical crises. He was accepted to the doctorate program for Clinical Psychology at UC Berkeley. He focused on hospital psychology, working directly with patients with chronic diseases, stating "Who better than I who have lived it?" Roy was diagnosed with leukemia in 2011. He thought he might be labeled a failure for not achieving his goal of earning advanced degrees. A family friend stated that Roy earned his master's degree in Strength. We hope that he now knows that he did not fail; he inspired.



JOSIE PROCTOR KEYES
4/5/80 - 1/31/24

Josie's childhood experiences of living near mountains, gardening, swimming, and outdoor activities became lifelong passions. Josie and her sister, Julie, became roommates and fellow students at Portland State University and traveled through Europe together. In 2009, Josie and her husband, Josh, welcomed their daughter, Clover, and in 2016, their daughter Canyon. Josie was consistently healthy until 2020 and was challenged with breast cancer, esophageal cancer, and then lung cancer. On the day of Josie's passing, double rainbows appeared all over her hometown of Heppner, Oregon.

SAEED KHAN 6/18/16 - 1/3/24
(PICTURED WITH HIS FATHER)





WITH THANKS

Family Fundraisers

In 2023, FA families and community members raised more than \$2,800,000 for the Fanconi Cancer Foundation! More than 240 families and community members raised funds through events and appeals. Each dollar donated advances research and family support, making a difference for all those affected by FA and their families. Sincere thanks to every family and individual who worked so hard to raise funds in honor or memory of loved ones.

\$1,400,000 +

Lynn Frohnmayer

\$150,000 +

Fanconi Canada (thank you, Canadian families!)

Stephen and Jennifer Klimkiewicz

Orion and Lisa Marx

Kevin and Lorraine McQueen

\$100,000 +

The Kendall and Taylor Atkinson Foundation with the Nash Family

John and Kim Connelly

\$25,000 - \$99,000

Matt and Jackie Burton

Todd and Kristin Levine

Ian and Tricia Mitchell

Rose and David Pennell

Gerard and Cynthia Vandermeys

Nigel and Ann Walker

\$15,000 - \$24,999

Judith Hoffman and Lawrence Backman

Mauro and Kerrie Cazzari

David and Mary Ann Fiaschetti

Rachel and Zachary Gratz-Lazarus

Grossman Family

Charles and Kathleen Hull

Callie Toal and Family

\$10,000 - \$14,999

Tyler Morrison and Rachel Altmann

James and Jennifer Armentrout

Cassie Carlson

Andrea and Robert Sacks

\$5,000 - \$9,999

Rachael Alaniz and Kevin Gatzlaff

Glen and Teresa Alessandri

Will Bloxom

Joeseoph and Nancy Chou

Egil Dennerline and Nanna Storm

Brian Horrigan and Amy Levine

Kristina Mack

David and Stacy Ownby

Peggy Padden

Mark and Diane Pearl

Paul and Rena Rice

Neil and Emily Robison

Joe and Jacqueline Vona

\$2,000 - \$4,999

Brian Adel and Carly Eade

Michael and Jennifer Aggabao

Jennifer and Bryan Aitkens

Amanda Barber

Adam and Marissa Becker

Darryl Blecher and Diana Fitch



Randolph and Nancy Bloxom
 David and Sarah Borden
 Chris and Jennifer Branov
 Ryan and Rebecca Brinkmann
 Stanley Gilbert
 Evan Connelly
 Mark De Groot and Hanneke
 Takkenberg
 Scott and Windy Farmer
 Andrew and Jennifer Gough
 Andre Hessels and Rutger
 Boerema
 Jeff and Beth Janock
 Maria and Bill Katris
 John and Karilyn Kelson
 Eugene and Renee Lemmon
 Kory and Julie MacMurray
 Alexandra Marshall
 Ronald and Fredi Norris
 Peter and Janice Pless
 George and Kathryn Reardon
 Les and Nancy Ross
 Sablosky Family
 Ron and Alice Schaefer
 Bradley and Darlene Starner
 Joseph and Natalie Vitrano
 Marc Weiner
 Jessica and Ezekiel Werden
 Matt and Krissie Wisniewski
 Jessica and Jonathan Young

\$1,000 - \$1,999

Peter and Donna Abramov
 Cathy Allen
 Richard and Tena Boson
 Sean and Allison Breininger
 Robert and Barbara Capone
 David and Kim Chew
 Valeen Gonzales
 Brian and Margaret Curtis
 Donna DellaRatta
 Greg and Lauren DeWerff
 Chloe Eminger
 James and Crystal Eubank
 Britteny Ferrin
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 G. Mitzi Gerber
 Rachel and Kristian Guttulrud
 Owen Hall and Margaret Kasting
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 Stan and Michelle Kalembe
 Erik Kjos-Hanssen and Turid Frislid
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 Alaina Mercer
 James and Holly Mirenda
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 Susan Ortiz
 Caroline Nguyen
 Janice and Kenneth Sysak
 Pedro and Marina Ravelo
 Mark Ritchie and Lisa Mingo
 Colleen Satterlee
 Mark and Tressa Timmer
 Kathy Tomalesky
 William and Mary Underriner
 Michael and Beth Vangel
 Ira and Terry Walker
 Robert and Julie Williams

Up to \$999

Ronald and Juanita Arroyo
 Serge Arsenault
 Dr. Vicki Athens
 Cindy and Owen Bagaason
 Gerald and Julie Barbier
 Mark and Linda Baumiller
 Israel and Mary Jo Becerra
 Conrad and Joan Bender
 Jasmine Bennetsen
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 Kaelynn and Ryan Vannostran
 Daryn and Carol Franzen
 Lauri Cohen
 Brian and Cindy Fuller
 Allen Goldberg
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 Racquel HannaPurser and Kelly and
 Katelin Hanna
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 Elisabeth Hartmann Nehnevaj
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 Donna Behlke
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 Dan Klug and Elizabeth Bertrandt-
 Klug
 Chad and Libby Kriner
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Tanner and Jessica Lindsay
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 Rose Maple
 Aaron and Nicki Marsters
 Angie Keaton
 Patricia Massuch and Louis
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 Kelli, Richard, Kaley and Lola
 Maurits
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 William, Kelli and Kit Owen
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 Marcos and Silvana Pineschi
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 P. Michael and Kay Proctor
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 William and Connie Schenone
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 Thomas and Marjorie Zaborney



How to Help

Since 1989, donations have helped move Fanconi anemia from a little-known disease with few options to a disease with treatments that buy precious time for children and adults with FA. Donations also have an impact on the lives of many others, as key genetic discoveries indicate potential links between Fanconi anemia and cancer development. From fundraising to monthly giving programs, estate giving, employer-matching, stock gifts, and in-kind, FCF aims to create opportunities for anyone and everyone to be able to contribute what they can, when they can.



Scan to donate now.

541.687.4658 | info@fanconi.org

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