

FAMILY NEWSLETTER

Issue 74 • Fall 2023



SEASON OF DISCOVERY



Leaders in FA research and clinical care, along with FARF co-founder Lynn Frohnmayer (middle) and Chief Scientific Officer Isis Sroka (third from right)

2023 FA RESEARCH HIGHLIGHTS

CANCER AND FA: WHAT TO KNOW AND WHAT TO DO

POWERFUL COMMUNITY STORIES

WHAT'S NEXT FOR FARF: 2023-2027 STRATEGIC PLAN

HOW TO FUNDRAISE THIS HOLIDAY SEASON



UPDATE FROM HQ

We are excited to embark upon another exciting era for the Fanconi Anemia Research Fund (FARF). The board of directors approved our 2023-2027 strategic plan in May. This plan builds on our success in researching the genetics of FA and sets the foundation for significant growth in FA cancer research.

The primary objective of this five-year plan is to increase the impact of our research by collaborating with more partners and institutions worldwide. To achieve this, we will enhance our research administration, support services, fundraising, and governance capabilities. Our aspirations are ambitious, yet firmly rooted in our legacy of success, compassion, and an unwavering sense of urgency. I want to highlight a few of our efforts.

A rebrand for FARF

One of our strategic goals is to expand the organization’s brand beyond FA by revitalizing our identity with a cancer focus. While FA leads to bone marrow failure and a number of other complications, it is at the core a cancer-predisposition or cancer-susceptibility disease caused by mutations in genes involved in DNA repair. This means that the research into FA will not only benefit those with FA, but also has the power to affect cancer research overall. The work we have done over 30+ years has resulted in moving FARF from the grassroots, orphan disease space into a larger research arena, which is hugely positive for people with FA because it means more people

working on our disease.

As we move more into the FA cancer research space, we are excited to refresh our name, mission, and the visual identity to match. We want to assure our FAMilies that our services, research priorities, and programs will continue as they always have. And our vision remains the same: a future where we can prevent and treat the primary cause of death and disability in people with FA, enabling them to live full and productive lives.

We look forward to sharing updates on the rebranding process with the FA family community. Our goal is complete the rebrand by mid-2024.

An investment in data

Another priority is to create partnerships that will build the infrastructure needed for a robust FA cancer international data-sharing effort. To this end, we have partnered with Data for The Common Good (D4CG). D4CG will establish the world’s first Fanconi anemia data commons by collecting data from registries in North America, Europe, and other parts of the world and harmonizing the data, allowing the information to be combined and

shared for research and discovery.

Two consortia: one focused on cancer, one on gene therapy and editing

This year we made incredible progress on developing the FA Cancer Consortium (FACC), which launched last year. The mission of the FACC is to drive scientific research on FA cancers and enable all people with FA to have access to accurate cancer diagnosis and therapy. This project is a major focus of our strategic plan. This year we have focused on infrastructure, while supporting the launch of the FA Cancer Screening study at the National Institutes of Health (page 12), as well as educational and empowerment programs in partnership with Christine Krieg and Eunike Velleuer from Germany (page 12).

While this is well underway, we very recently funded another crucial consortium: gene therapy and gene editing. While cancer remains our biggest problem, gene therapy and editing offer great potential for a safe therapeutic option to treat FA-related bone marrow failure and address the core DNA repair issue in FA. Read more about this project on page 7 and stay tuned for updates.

Meanwhile, our FA family community got some much-needed love

While research is well underway, our bond as an FA family community grew even stronger. This summer we returned to Camp Sunshine for our Annual Family Meeting after being away for four years. It was a joyful gathering of several dozen families, speakers, and staff who came together for a few days of bonding, learning, and collaborating. We were thrilled to reconnect with old friends and meet new families who are embarking on their FA journey. We are already busy working on next year’s meeting, when we hope to see even more first-time and returning families.

A couple updates to the FARF team

We have had some staffing changes this spring. Rosie Holcomb, who worked with families in our Community Programs Department for two years, has moved to our fundraising department as Development Officer. With her fundraising background and experience with families, we are already impressed to see Rosie excelling in her new role. To fill her previous position, we hired Taylor Schreiner as our new Community Support Program Manager. Taylor resides and works in Meridian, Idaho and has quickly become a valuable member of our team, demonstrating her skills right from the start.

At FARF, we remain committed to creating a better future for individuals with FA by continuing to advance research and provide education and support services. Thank you for your support!



Mark Quinlan
Executive Director



Read about the research team in Spain working on head and neck cancer (pg. 6)



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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.



SEASON OF Discovery

GIVE TO SPARK BREAKTHROUGHS

Share your story this holiday season

OPTION
1

Make a personal fundraising page



Add a personal webpage on FARF's holiday campaign site. All you have to do is sign up, add a photo, and send to friends and family. The text is already programmed for you. This is also a great way to remember loved ones.

Pros of this choice: fast, easy, you get notifications every time a gift is made, see progress toward your goal, and can send personal thank you to your donors in real time.

OPTION
2

Send a letter to your community



Prefer to send a hard letter to your community? We've got a template ready for you on the next page! Just send us your family update, mailing list, and photos. We'll do the rest and send them with your OK. Bonus: letters are great additions to your annual holiday postcard.

Pros of this choice: most personal, people like receiving mail, FARF covers postage costs.

OPTION
3

Send an email and/or share via social media



Looking for the most streamlined way to share updates and raise funds? We've got email and social media templates for you to copy, paste, edit and send (they'll be in your inbox soon). Bonus: sending on Giving Tuesday (11/29) makes a major impact.

Pros of this choice: fastest and easiest, see immediate results.

Combine the options that work best for you

Add your page here:



Other ways to make an impact:

- Partner with our team to inspire major gifts in your community
- Plan with us for your own family's giving

Email info@fanconi.org to get started!

Dear Friends and Family,

[\[Insert greeting and personal family update here\]](#).

As you may know, our family has been confronted with the challenges of Fanconi anemia (FA), a rare and relentless DNA-repair disease that leads to bone marrow failure, leukemia, and cancer. This year, we find ourselves reaching out [once again], not just with hope but with renewed determination to make a difference.

The holiday season is upon us, and it's the time when we turn to our dear friends and family, seeking your support for the Fanconi Anemia Research Fund (FARF). Why? Because FARF has given us something we cherish deeply – hope. Amidst the uncertainty and fear that often come with an FA diagnosis, FARF has been our beacon of hope, driving progress in research and providing unwavering support to families like ours around the world.

Since its inception in 1989, FARF has relentlessly pursued its mission to discover effective treatments and ultimately find a cure for FA, all while offering education and support services to affected families worldwide. However, none of this can happen without the essential element of funding.

In our tight-knit community of families affected by this rare disease, we are working tirelessly to extend the lifespans of our loved ones. Research moves forward because of families like ours, and we are honored to have incredible friends like you standing with us. You are an integral part of the breakthrough we hope to achieve.

When you contribute to the Fanconi Anemia Research Fund:

- You empower FA families to navigate their diagnosis, connect with others worldwide who share their journey, and envision a brighter future.
- You invest in better outcomes not only for those with FA but for everyone affected by cancer. Your support fuels research into the intricate complexities of DNA repair problems that impact us all.
- You drive innovation in gene therapy, gene editing, and advancements in bone marrow transplants. In 2023, FARF took a monumental step by funding a groundbreaking gene therapy consortium, uniting the brightest minds dedicated to getting to the root problem of FA.
- You enable the advancement of critical clinical trials that offer hope to both children and adults living with FA. This year, FARF supported the first-ever clinical trial for a drug targeting FA head and neck cancers.

We humbly request your support in our quest to find a cure for FA, not only for [child's name], but for all those affected by this relentless disease. Your tax-deductible gift can be returned using the enclosed envelope or made securely online at [\[Insert Donation Link Here\]](#).

Thank you from for helping us spread hope and love within our community. As you celebrate the holiday season with your family, know that you are playing a significant role in our journey toward a brighter future.

Wishing you and your loved ones a season filled with peace, love, and joy!

With heartfelt gratitude,
The [\[Your Family Name\]](#) Family



More than 70% of FARF's income is generated by holiday gifts. Many of these are the result of families like yours asking your communities to make a gift in honor of your family. The median sized gift made during the holidays is \$60.

We know asking your community for this kind of support can be a challenge. We also know it's so, so important to keep asking. This time of year especially, people look for ways to help, and we've seen the incredible power of communities rallying around our FA family.

2023 RESEARCH UPDATES TO KNOW ABOUT

NEW PROJECTS AWARDED IN 2023

CANCER THERAPEUTICS

Clinical Trial to Investigate the Safety and Efficacy of Afatinib When Administered as Therapy in FA Patients

Investigators: Jordi Surrallés, PhD; Ramon Garcia Escudero, PhD

Institutions: Santa Creu and Sant Pau Hospital Research Institute and Research Institute of the Hospital 12 de Octubre, Spain

Amount awarded: \$324,733

Individuals with FA have a high risk of developing head and neck squamous cell carcinoma (HNSCC) at young ages. Often these individuals cannot tolerate conventional chemotherapy and radiation treatments due to toxicity-related issues. This study is the first clinical trial for investigating a potential therapy for FA-related HNSCC. It will investigate the efficacy and safety of the drug Afatinib when administered to people with FA who are diagnosed with unresectable and/or advanced squamous cell carcinoma of the oral cavity, oropharynx, hypopharynx, or larynx.

DATA INTEROPERABILITY

Building a Fanconi Anemia Data Commons

Investigator: Sam Volchenbom, MD, PhD, MS

Institution: University of Chicago

Amount awarded: \$315,962

Studying a rare disease such as Fanconi anemia is challenging: data must be captured from as many treatment locations as possible. No single institution can have a breakthrough; it requires sharing as much data as possible from as many individuals as possible. Since 2015, Data for the Common Good (D4CG) has been building data commons based on the latest technological breakthroughs and leading international efforts to improve pediatric cancer and rare disease research through better data collection and storage. Through this grant funding, D4CG – in partnership with FARF and other worldwide stakeholders – will establish the world's first Fanconi anemia data commons by collecting data from registries in North America, Europe, and other parts of the world and harmonizing those data to a new international consensus standard, allowing the information to be combined and shared for research and discovery.

GENE THERAPY AND GENE EDITING

Transforming Treatment of Inherited Bone Marrow Failure in Fanconi Anemia by Precise In Vivo Genome Editing

Investigators: Paula Río, PhD; David Liu, PhD; Jacob Corn, PhD; Andrew Deans, PhD; Hans-Peter Kiem, MD; Branden Moriarity, PhD; and Toni Cathomen, PhD

Institutions: Instituto de Investigación Sanitaria Fundación Jiménez Díaz; Harvard University; ETH Zurich; St. Vincent's Institute Fitzroy; Fred Hutchinson Cancer Center; University of Minnesota; and Medical Center - University of Freiburg, Institute for Transfusion Medicine and Gene Therapy

Amount awarded: \$1,258,190

This project aims to design and test in vivo gene editing as a novel therapy for Fanconi anemia-related bone marrow failure. Developed in collaboration with FARF, this project forges a consortium comprised of seven international world-renowned researchers and an industry partner who will investigate base and prime editing-based correction of FA gene mutations. These state-of-the-art editing technologies are unique in that they do not introduce double-strand breaks, which makes them a safe and effective option for editing FA cells.

People with FA who have bone marrow failure are currently treated with allogeneic hematopoietic stem cell

transplants. However, these procedures remain somewhat limited due to high cost, lack of appropriate donors in some regions, and heightened risk of long-term health effects, such as an increased risk of cancer. In vivo gene therapies for FA offer promise and great potential for a safe, easily accessible, and cost-effective therapeutic option to treat FA-related bone marrow failure that can be used worldwide. This consortium will test gene editing technologies for all major FA mutations using laboratory-based techniques over the next two years. The goal is to rapidly develop a translational protocol that will eventually be tested in clinical trials.

Development of in Utero Therapies for Fanconi Anemia

Investigator: Agnieszka Czechowicz, MD, PhD

Institution: Stanford University

Amount awarded: \$250,000

Correcting FA mutations in all cells of the body may prevent issues such as bone marrow failure and cancer in people with FA. Since mutations in FA genes start during the gestational process, the ideal time to correct genes may be in utero. The goal of this study is to use laboratory-based experiments to determine whether gene editing in utero (during gestation) can correct FA gene variants in various tissues of the body.

FOUR PROJECTS WRAPPED UP

BONE MARROW FAILURE

Understanding Clonal Hematopoiesis in Fanconi Anemia to Improve Patient Surveillance Strategies

Investigator: Grant Rowe, MD, PhD

Institution: Boston Children's Hospital

Funded in 2021

This grant focused on understanding the development of blood cancers in individuals with Fanconi anemia. Dr. Rowe and his research team developed a human model of Fanconi myelodysplastic syndrome and acute myeloid leukemia to examine genetic mutations that occur in Fanconi anemia-associated blood cancers. Dr. Rowe's team found new pathways that promote the rapid growth of leukemia cells in Fanconi anemia as well as a potential new approach to therapy that could benefit individuals with FA.

GENE EDITING

Correction of Fanconi Anemia Mutations Using Digital Genome Engineering

Investigators: Branden Moriarity, PhD; Beau Webber, PhD; John Wagner, MD

Institution: University of Minnesota

Funded in 2020

Transplanting healthy stem cells from related siblings or matched donors is the current standard of care for people with Fanconi anemia (FA) who are diagnosed with bone marrow failure. However, this treatment carries significant risks caused by the toxic preconditioning regimen and immune-mismatch related complications. The goals of this study were to optimize and apply a paradigm shifting new technology, termed base editing, to correct mutated FA genes in cells. Results from this pre-clinical study showed that base editing can proficiently correct the most common FA mutation, which is prevalent in those of Spanish Romani ancestry. In future studies, the team will apply base editing to correct other mutations and hopes to translate this approach to new clinical trials over the next few years. This team is also a part of the newly funded gene editing consortium.

DIAGNOSIS

Severe Spermatogenic Failure as a Sentinel for Early Diagnosis of Late-Onset FA

Investigator: Csilla Krausz, MD, PhD

Institution: Fundacio Puigvert, Spain

Funded in 2020

Manifestations of FA typically appear during childhood. However, in a subset of individuals with FA, diagnosis is delayed until adulthood because individuals have no symptoms or present with subtle findings that may be overlooked. It has previously been described that infertile

males with azoospermia (the absence of sperm from ejaculate) can have a high frequency of late-onset FA due to FANCA mutations. Mouse models suggest that apart from FANCA, other members of the FA pathway also play a role in the production of sperm.

The goal of this study was to diagnose late-onset FA using genomic analysis in a highly select group of infertile men with severe spermatogenic failure (SSF) before the appearance of severe clinical complications. Dr. Krausz and her team performed genetic analysis on a select group of infertile individuals showing mild hematological alterations and fertile controls. The research team's results showed a significantly higher frequency of pathogenic FA gene variants in infertile men than in controls. This observation suggests a link between azoospermia, FA gene variants, and published epidemiological data showing higher comorbidity rates, including cancer, in azoospermic men with respect to the general population.

ANIMAL MODELS

A Porcine Model for Fanconi Anemia

Investigators: Markus Grompe, MD; and William Fleming, MD, PhD

Institution: Oregon Health and Science University

Funded in 2019

Drs. Grompe and Fleming and their research team have created a FANCA porcine model that exhibits an FA phenotype. The pigs demonstrate extra dew-claws on their front limbs and cells that show extreme sensitivity to DNA damaging agents in tissue culture. Importantly, blood lymphocytes show the classic formation of radial chromosomes/aberrations seen in human FA. The animals also demonstrate clear evidence of an evolving hematopoietic phenotype. The pigs also exhibit reduced bone marrow colony forming units, abnormal peripheral blood counts, and kidney abnormalities. To date, no pigs have shown signs of squamous cell carcinoma.

OTHER RESEARCH ACTIVITIES AND EFFORTS

2023 FANCONI ASSOCIATED NEUROLOGICAL SYNDROME (FANS) FARF SPARKS MEETING

One manifestation of Fanconi anemia, Fanconi Associated Neurological Syndrome, or FANS, involves central nervous system abnormalities that affect a subset of individuals with FA. These abnormalities result in brain lesions that can lead to weakness, seizures, and cognitive issues. In October 2021, FARF held a focused workshop with clinicians, researchers, individuals with FA, and their families to develop a better understanding of FANS and map out what needs to happen to develop treatment options. As a result of this initial meeting, FARF funded a research grant in 2022 to examine the immune profiles of individuals with FA affected by FANS to find the underlying cause and potential therapies to treat this condition.

A second meeting was held on August 9, 2023 as a continuation of the initial meeting. The second meeting focused on research advancements and assessments of recent clinical findings, with the goals of pushing research forward, maintaining engagement with the clinical and research communities, and providing a forum for families to share feedback and ask any questions they may have. Throughout the meeting, parents, clinicians, and researchers shared their perspectives on care coordination for individuals with FANS, next steps for treatment options, updates on research cohorts, and potential overlaps between FANS and other similar conditions.

Future next steps include publishing a manuscript describing the condition and adding a chapter on FANS to the FA Clinical Care Guidelines.

UPDATES TO THE FA CLINICAL CARE GUIDELINES

To keep the FA Clinical Care Guidelines as current as possible, we are updating the chapters on an ongoing basis. We have recently completed updating the first two chapters:

- Chapter 2 updated version (Diagnosis)

- Chapter 3 updated version (Hematologic Issues)

Because we are updating these continually, we will not be printing a new version of the Guidelines. We recommend checking online for the most up-to-date version or printing the PDFs of the updated chapters to keep with your book. We will always email you when a new update is made.

[Access the full Guidelines here \(fanconi.org/explore/clinical-care-guidelines\)](https://fanconi.org/explore/clinical-care-guidelines)

FANCONI ANEMIA CANCER SCREENING STUDY

Enrollment is currently ongoing for a FARF-funded Fanconi anemia cancer screening study at the National Cancer Institute. The study aims to provide oral mouth inspections and brush biopsy screenings, combined with comprehensive cancer screening, for individuals with FA above the age of eight. The cancer screenings will include brush biopsies of persistent oral lesions and screening for esophageal, gynecological, anal, and skin cancers, as clinically indicated. If you are interested in joining the study, please visit the Fanconi Anemia Cancer Screening Study enrollment website.

<https://marrowfailure.cancer.gov>

CANCER AND FA

What to Know and What You Can Do

Cancer is undoubtedly a terrifying topic, one we'd rather not dwell on constantly, and that's completely understandable. At FARF, we recognize the apprehension surrounding cancer and want to help alleviate the burden of FA families constantly thinking about it. We, in collaboration with the FA research and medical community, dedicate ourselves to addressing this issue relentlessly so we can find solutions as swiftly as possible. While researchers and others are tirelessly tackling the challenges of cancer, we encourage you to take a few steps to stay informed—without becoming overwhelmed—and to maintain a sense of empowerment.

What to Know: 8 FA Cancer Facts to Remember

1 Fanconi anemia is a DNA repair disorder and cancer pre-disposition disease.

- Even though the disease is called "Fanconi anemia", FA is a cancer-predisposition or cancer-susceptibility disease caused by mutations in genes involved in DNA repair.

2 People with FA have an increased risk for certain types of cancers.

- If cancers develop in a person with FA, they are particularly prevalent in the following areas:
 - Blood-related cancers such as leukemia (thanks to research, outcomes are much better than even 20 years ago)
 - the mouth and throat region (tongue, oral mucosa, larynx, esophagus)
 - the genitalia and the anal area
- Some individuals with FA also develop tumors in the skin, breast, and liver.

- Some people with variants in FA genes such as FANCD1/BRCA2, FANCN/PALB2, and FANCS/BRCA1, may need additional screening for tumors that can also develop in the brain, kidney, or blood.

3 Standard cancer treatment in people with FA is very complicated.

- Surgery remains the most effective treatment for cancer in FA. The earlier cancer is detected, the less invasive the surgery will be, and the better the quality of life. Regular screenings are the best way to detect changes early.
- Chemotherapy and radiation have typically not been used due to potential toxicities associated with these therapies. We now know, however, that in some cases, a special designed treatment protocol for people with FA can involve these types of treatments safely.

4 Educating yourself and being proactive are key. This means regular check-ups and at-home screenings.

- Though there are no specific FA studies on the impact of lifestyle factors, we can apply what we know about the general population as healthy preventative measures, especially: don't smoke and exercise regularly.
- Regular check-ups (every six months) at the dentist, ENT doctor, and gynecologist are very important for people with FA.
- Cancer doesn't develop overnight, but usually over the course of years. Sometimes it can develop more rapidly, which is why regular check-ups and at-home screenings are so helpful at intercepting it.

5 You'll need to help educate your doctors about FA and cancer risk.

- You need to be checked by doctors more thoroughly and earlier than people without FA. Many doctors not affiliated with FA centers will be unfamiliar with the increased risk of cancer that happens at an earlier age in people with FA. Educating your local treatment team about your increased risk, by using educational materials provided by FARF, may be needed. This will ensure their diligence with monitoring your health closely and implementing the appropriate early detection screening protocols.

6 If you've had a bone marrow transplant and experienced graft-versus-host disease (GvHD), early detection for cancer becomes even more important.

- If you have had a bone marrow transplant (BMT), your risk of developing tumors may increase, especially if you've have had significant acute and/or chronic GvHD disease and/or very severe mucositis (inflammation of the lining of the mouth). In this case, it is even more important to regularly attend cancer screening appointments.

7 If you see a spot in your mouth that you're worried about, try to stay calm. Most spots are harmless. If it's still there after three weeks, there are several options for next steps:

- Reach out to your primary care (FA specialist), ear nose and throat physician, or any other specialist taking care of your oral cavity, such as an oral surgeon.
- If you are located in the United States, you can reach out to Dr. Neelam Giri at the National Institutes of Health to enroll in the FA cancer screening study: girin@mail.nih.gov.
- If you are outside of the United States, you can contact the FA Cancer Awareness Team, Christine Krieg and Eunike Velleuer-Carlberg, who will help direct you to the appropriate professional: Christine.Krieg@fanconi.de and Velleuer@uni-duesseldorf.de.

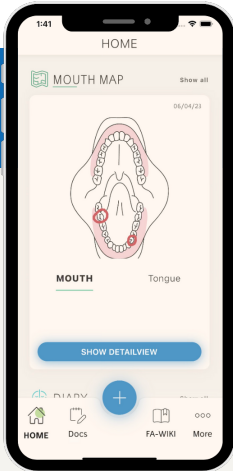
8 If you are diagnosed with cancer, you are not alone. We are here to help.

- We know your doctor may not be an FA expert, especially when it comes to cancer. That's why we formed the FA Virtual Tumor Board, so that your doctor can meet with FA experts to help decide the best treatment plan for you. You can reach out to FARF and we can help connect your doctor to the tumor board.
- There are many support services specific to cancer. We can help you access resources you may benefit from, including support groups, navigating insurance and disability, connecting with other adults with FA, locating FA expertise, and more.



WHAT YOU CAN DO: 2 CONCRETE WAYS TO TAKE CHARGE

While researchers work to find treatments, prevention and early detection are crucial.



Download the FAexam app



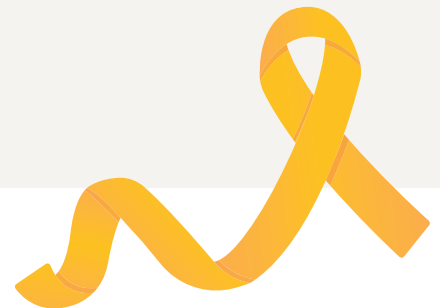
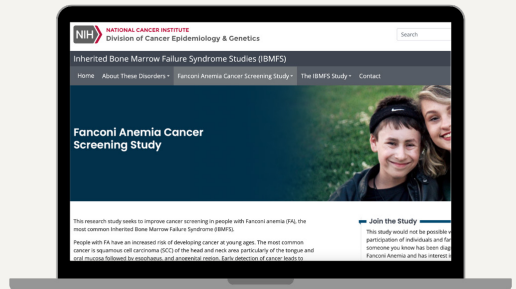
One way to take charge is by performing self-screenings of your mouth, in addition to seeing your dentist and ENT. You can do this easily by using the FAexam app, free to download in the App store or by visiting www.fanconi.de/faexam. See more on the next page.



Join the Cancer Screening Study at the NIH

Another way to support prevention and early detection is by signing up for the cancer screening study at the NIH, funded by FARF. This is the best comprehensive cancer screening study out there for people with FA. We encourage everyone with FA to sign up (currently open to ages 12+, or 8+ if there are concerns, such as a lesion that is still present for three weeks or more). You can sign up at <https://marrowfailure.cancer.gov/fanconi-anemia/participation.html>

You can always check the FARF website, www.fanconi.org for the latest information and educational materials like the Clinical Care Guidelines, as well as easy to follow flyers and graphics.





Introducing FAexam the essential screening app for people with FA

When it comes to managing life with Fanconi anemia (FA), knowledge is power. That's why FA researchers, adults with FA, and the FARF team have been working to increase education and empowerment for all people with FA.

We're proud to introduce FAexam, a brand-new app designed to assist individuals with FA in performing and documenting oral self-examinations.

THE POWER OF AT-HOME SCREENING

Driven by Christine Krieg, Executive Director of the German FA Support Group, and Eunike Velleuer, FA clinician and researcher, this app is a product of their long-running study "Reducing the Burden of Squamous Cell Carcinoma."

Through this 15+ year study, the team has seen hundreds of people with FA, inspecting their mouths for any spots or changes. During these visits, Christine and Eunike began educating people with FA on how to conduct their own exams at home, which can be very helpful in monitoring oral health between visits

to the dentist or ENT.

It's important to note that these self-screenings are complementary to regular, six-month visits to dentists or ENTs. They are not meant to replace regular doctor visits, but serve as an additional tool for care.

In addition to research, education and empowerment are key to intercepting cancer.

Because people with FA are at a higher risk of cancer than those in the general population, it is essential to be proactive. That means not only practicing good oral hygiene, but also actively participating in screenings. The goal is to prevent any potential diagnoses from occurring too late, ensuring timely interventions and treatments.

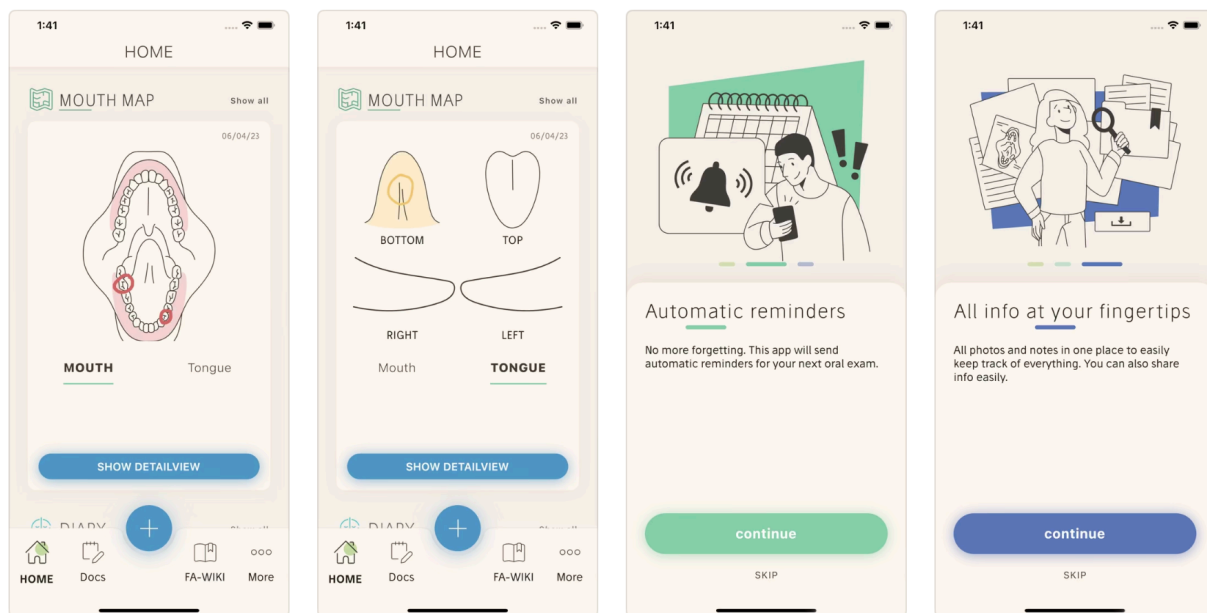
Of course, when facing something as terrifying as cancer, it's natural to resist engaging with anything cancer-related. That's where the empowerment piece comes in.

Enter: FAexam. This app provides the necessary guidance and resources to perform thorough oral self-examinations and it's designed to empower users to learn about their care, participate in prevention, and even track their emotional well-being.

WHO IS THE APP FOR?

For those with a heightened sensitivity of the oral mucosa and who may experience oral lesions at an earlier stage, the app serves as a valuable tracking tool. It was designed for people with FA, but could even be used by others with higher risk of oral cancer, as well as physicians.

Our recommendation is to initiate oral self-screening around age 16. Parents can also use the app to monitor their children's oral health.



SEE WHAT'S INSIDE THE APP

- **Step-by-Step Guide:** Follow a detailed, user-friendly guide (and videos) on how to perform thorough oral self-examinations. FAexam allows you to draw directly onto a mouth map, ensuring clarity and precision during your self-examinations. Additionally, color-coded elements provide visual cues, making it easier to identify and understand different areas of concern.
- **Automatic Reminders:** Receive timely reminders to check in and perform your oral self-exam, ensuring consistency and a proactive approach to your oral care.
- **Documentation Management:** Easily track areas of concern and compare changes over time. Export your oral exam records and documentation to share with your care team.
- **Info Library:** Access a comprehensive library of resources about Fanconi anemia, oral self-exams, and oral care tips.
- **Mood Tracker:** Track your moods and emotions related to your oral health journey, helping you monitor the impact of your self-care routine.

HOW TO GET ACCESS:

You can download the app in the App Store for iPhone or the Google Play Store for Androids.

You can visit the Info Library and watch the video about oral screenings at www.fanconi.de/faexam.

Note: this app is a collaborative project between individuals with FA from all over the world, the Fanconi Anemia Research Fund and the German Fanconi Anemia Support Group.



SCIENTIST SPOTLIGHT

Name: **Ramon Garcia-Escudero**

Institution: **Molecular and Translational Oncology Division at CIEMAT, Centro de Investigacion Biomedica en Red de Cancer, and Research Institute Hospital 12 de Octubre, Madrid, Spain.**

Area of expertise: **Disease models, biomarkers and therapies for head and neck cancer**



Ramon Garcia-Escudero, PhD

WHAT I'M WORKING ON

In order to prevent, treat, and cure cancer, we have to understand how it starts, progresses, and metastasizes. To do this, we need accurate disease models, comprehensive analytical technologies, access to patient samples, and systematic experimental and clinical approaches.

Very importantly, we need collaboration between different laboratories and experts in the oncology field.

In my laboratory, we can generate and analyze different types of mouse models, including mice that share similar mutations to patients. In these mice, we can reproduce some of the non-genetic risk factors that lead to disease, and we can reproduce growth of human tumors. These animal systems are key to testing antitumor compounds in a preclinical setting.

We also work to integrate knowledge from genomics research using preclinical models and human samples to search for new early diagnostic tools and therapeutic opportunities. I hope that our research activities will be translated into new and better clinical interventions for FA patients.



Ramon's Lab

WHAT MOTIVATES ME TO WORK ON FA

I believe our role as scientists is to translate our expertise to society. For me, this means focusing research into new methods that would improve people's quality of life. That's why helping FA patients by diagnosing, preventing, or curing their cancers is a major aim of my work. I am convinced that scientists, clinicians, patients, families, foundations, and all stakeholders will achieve this goal by working together.

WHEN I'M NOT IN THE LAB, YOU COULD FIND ME...

Either with my wife Cati and my son Miguel, walking and biking in the mountains in Madrid, or chatting and eating with my friends.

MY MESSAGE TO THE FA DONOR COMMUNITY

Cancer is a disease that has struck my own family. Resilience, work, hope: these are the key words that came to my mind when thinking about FA families. Your support of FARF and other FA funding organizations like the Spanish Fundación Anemia de Fanconi (<https://anemiadefanconi.org/>) is essential to helping us find new advances and treatments. Thank you.

TWO NEW INTERNATIONAL SUPPORT GRANTS AWARDED



Each year, FARF awards up to \$10,000 for one-year projects to international FA support organizations or individuals wishing to establish support organizations or projects internationally.

The 2024 grant cycle will open early next year, with a deadline in May 2024. See [Fanconi.org](https://fanconi.org) for the latest updates.

AWARDED GRANTS IN 2023

GROUP: Brazilian FA families

COUNTRY: Brazil

PROJECT: FA families in Brazil, led by an adult with FA and a father of an FA teen will use their grant in two ways: holding a family meeting in Brazil in 2024, and establishing a Brazilian FA Support Group. Because Brazil is such a big and populous country with FA patients from all socioeconomic levels, organizers know that bringing FA families together in person is a very effective way to bring FA experts to the people who need them most. The larger goal of the project is to develop a dedicated Brazilian FA patient and family association, aimed at disseminating information, building a patient registry, conducting fundraising campaigns, and fostering international collaborations. This association will not only enhance local support but also contribute to global FA awareness and knowledge-sharing efforts.

AMOUNT AWARDED: \$10,000

GROUP: Instituto Nacional de Pediatría, Laboratorio de Citogenética, Mexico

REGION: Latin America (organized by doctors and researchers in Mexico)

PROJECT: In many countries, the first major obstacle for FA patients is getting the actual diagnosis. Dr. Sara Frias and her team, based in Mexico, have been working hard to spread FA awareness and access to diagnosis in Mexico. They have trained cytogeneticists not only in Mexico, but also in Bolivia, Costa Rica, and Argentina. Their mission is to give Latin American patients with FA access to diagnosis so that they have the opportunity to receive treatment, education, and support to have a better quality of life. To do this, their grant will allow them to train cytogeneticists from five Latin American countries, who will then be able to perform diagnostic testing for FA in their respective countries. This will enable many more FA patients in these countries to finally have an accurate diagnosis and a path for treatment and support.

AMOUNT AWARDED: \$10,000

PROJECT HIGHLIGHT: PORTUGAL HOSTS THEIR FIRST FA FAMILY MEETING!

Our partners in Portugal successfully held their first meeting of FA experts and families this year, sparking new collaborations and ideas to continue spreading awareness.

Beatriz, the leader of the Portuguese group, shared her thoughts and takeaways from the meeting: "I want to express my gratitude to FARF for making this meeting possible. It fills me with pride to say that all FA families, doctors, and researchers hailed our event as a resounding

success. Doctors now recognize the importance of early cancer prevention through regular mouth inspections, and FA families feel the warmth of our community." What's next for the FA community in Portugal? Their immediate goal is to translate and disseminate the FA Clinical Care Guidelines in Portuguese. Beatriz has also been diligently reaching out to FA doctors with the ultimate goal of creating a reference center for FA follow-up and care in Portugal.

ANA TABAR RECEIVES 2023 WINN/BYRD AWARD FOR ADULTS WITH FA



Ana grew up in the Dominican Republic, and in response to the critical needs for access to medication, diagnosis, treatment, and education for those with FA there, she established Un Corazon por Fanconi in 2018.

Through this organization, she facilitates a supportive WhatsApp group for more than 73 families impacted by FA from 12 countries in Latin America. She uses her graphic design background to create educational materials in Spanish, and organizes virtual, educational sessions for the Latin American FA community.

While serving on FARF's Adult Council from 2020-2022, Ana helped plan and execute two meetings for Adults with FA (while keeping the international voice at the forefront of planning) and participated on the FARF diversity, equity, and inclusion committee. In addition, she is the recipient of two FA international grant awards, and acts as a representative for the Latin American FA community at the annual International Summit.

Last year, Ana and her husband welcomed their beautiful daughter, Violeta, to the world.

As Ana embraces motherhood, she continues to strengthen FA community support and advance awareness among the medical community in Latin America.

She plans to use the award to do just this. "I know how important it is to educate doctors about the different characteristics, diagnosis, risks, and treatment of the disease because this education leads to more efficient and successful treatments for our Dominican patients. In addition, raising

awareness in the medical community helps us to identify more patients," Ana explains.

Ana's leadership in the Spanish-speaking FA community, as well as her efforts to educate more doctors about FA in the Dominican Republic, exemplify the spirit of the Amy Winn and Christopher T. Byrd Award for Adults with FA. Thank you, Ana!



Participating in a blood drive

Egil Dennerline is Honorary Recipient

This year, the committee had multiple outstanding candidates for the award. Therefore, they have decided to recognize an honorary winner, Egil Dennerline.

Egil was diagnosed at age 16 and now describes himself as one of the "old guys" with FA at age 49. He is a musician, writer, a husband, a father, and friend to many. He also serves on the FA Adult Council, bringing an international and mature perspective to the group. Congratulations, Egil!





THE FA CONNECTIONS THAT CHANGED EVERYTHING

By Vicki Athens

Our journey to the diagnosis of Fanconi anemia (FA) started in 1986 when we conceived a child via *in vitro fertilization (IVF)*. The pregnancy was normal until the sixth month, when the ultrasound showed intrauterine growth restriction. This meant that at 37 weeks, our son stopped growing. Andrew was born at 38 weeks, and his birth weight was 5 lbs. 4 oz.

In my heart of hearts, I knew something was wrong. His pediatrician thought he was just small. However, he was a very challenging newborn. He had a poor sucking reflex, had problems with every formula, and couldn't tolerate my breast milk. He didn't sleep through the night for six years and had terrible gastric distress.

Fifteen months after he was born, while on a ski vacation, my mother – who is Greek – observed that her grandson just wouldn't eat. She took him to a pediatric gastroenterologist who immediately ordered genetic testing. A DEB test and other testing revealed chromosomal breakage, and he was confirmed to have Fanconi anemia by Dr. Arleen Auerbach at The Rockefeller University.

I learned of his diagnosis while seeing patients. The news was devastating as I learned from Dr. Auerbach that the prognosis was not good in the long term. At the time, 50% died before the age of 10, and only a bone marrow transplant would ultimately allow for a longer life. Minimal information was available to us, both as physicians and parents. Dr. Auerbach put me in touch with David and Lynn Frohnmayer.

AN INTRODUCTION TO THE FROHNMAYER FAMILY

Talking to Dave and Lynn Frohnmayer, who had already started the FA Research Fund, helped us deal with the scant information available at the time. I wanted to be proactive in our son's diagnosis, so I organized the first Family Meeting in Washington, DC.

Approximately 20 families joined to hear Dr. Blanche Alter and a few other physicians discuss and explain FA to the families. From there, we had a family meeting at Disney World in Florida. Nancy Cincotta was able to organize future FA meetings at Camp Sunshine.

Through the years, many families, including ours, spent a significant amount of time fundraising for research. Our family and friends raised over half a million dollars over 10 years. That was a drop in the bucket compared to your families today and the Frohnmayers over all these years.

Camp Sunshine helped our family get through the hard times, with Nancy Cincotta at the helm of support for all the families. It was there that we started taking skin biopsies and blood to distribute cells for the multiple research centers. I flew blood samples and skin biopsies to Amsterdam from three boys who had chromosomal breakage syndrome that was FA similar but not exactly FA. It is still an enigma to this day! My son's cells showed mosaicism in Dr. Hans Joenje's lab. He was one of the early cases.

At age 11, Andrew was diagnosed with Non-Hodgkin's Lymphoma. Our hematologist consulted with many of



Andrew at Camp Sunshine

our FA-associated pediatric cancer and bone marrow specialists to determine the correct chemo for treatment. Interestingly enough, because Andrew had stem cell mosaicism, the chemo killed off the FA stem cells and left the good healthy stem cells.

He has been in remission since then and is now 35 years old. While his bone marrow has been stable, he has urinary retention, has to catheterize himself every day, and has endured frequent falling and difficulty walking in the last few years. He now has a mild progressive neuromuscular disorder. This is presently being seen in some FA patients and may subsequently be FA neurological syndrome (FANS).

Our family is deeply indebted to the Frohnmayers, Nancy Cincotta, the FA board and families we have met through the years. Every one of you has helped sustained us.

Special thanks to Vicki and Family

We'd like to give a shout-out to express our gratitude to Vicki. Thanks to her idea and planning, the Family Meeting was instituted and went on to become a celebrated tradition and lifeline of this community. We've held a meeting every year since she started the first one.

In addition, Vicki and her family have raised funds and donated generously to continue FARF initiatives over the years. Thank you!



OUR PATH THROUGH FANCONI ANEMIA AND MENTAL RESILIENCE

By Jen Aitkens

Bryan, Jen, London, and Sydney

It was a regular Wednesday in early 2019, with all of us heading out the door for school and work. However, our daughter London was suffering from a stomachache. She had been experiencing it for a while, so we decided to take her to Urgent Care for a checkup. While there, on a whim, they decided to perform some blood work to rule out any serious issues since the doctor hadn't identified a clear cause for her stomachache. We left with some advice: rest and drink plenty of fluids.

During this time, her blood was sent to the lab, then

to another lab, and yet another. Soon after, we received a phone call that would forever change our lives: "Her platelet counts and red and white blood cell counts seem extremely low. We need you to go to Children's Cancer Hematology to have her seen by one of our doctors."

At this point, our thoughts were a whirlwind. What did they mean by low? Why the cancer center? What is happening?

My husband Bryan and I were overwhelmed, looking at this little person and hearing the word "cancer." Both our

families had been affected by it, so we understood the potential devastation.

Still in disbelief and shedding tears, we went downtown to meet with doctors and nurses who discussed potential scenarios with us—anemia, Fanconi anemia, aplastic anemia, leukemia, cancer, and more. My mind went blank, and I started questioning why. Why her? What is happening? Why?

Doctors conducted more blood work, tests, and a bone marrow biopsy—the first of many to come. After one of the most emotionally challenging weeks of our lives, the results arrived: Fanconi anemia (FA), complementation group C. No cure, potential for cancer, and a shift in life expectancy. All those words hit us like bullets. That explained her small stature, why her teeth weren't falling out like her sister's, why her hair might not be growing.

We felt numb. Our daughter, our London—our fearless, fierce peanut, our blue-eyed beauty—FA.

We listened to the details, the positive and negative aspects, what her life would be like. The doctors did their best for a family whose world had changed in an instant, for a little girl whose world would never be the same, and for a sister who would do anything to restore that world for her.

We learned that this is a genetic disease, meaning Bryan and I inadvertently passed on this disease to her, when we are supposed to shield and provide for her. All because two of our cells, out of millions, came together and caused FA. This is where the struggles with mental health—including depression, anxiety, and rage—began for me. What did I do to her—why her? Why not me?

London, the incredible tiny superstar she is, just kept saying, 'It's okay. It will be fine. It's not your fault. We will get through this. We got this, Mom and Dad!'

Four years later, she is still this vibrant, amazing 11-year-old, whom you would never know is sick upon meeting her. You wouldn't know that every six months, she undergoes a battery of tests, including a bone marrow biopsy, and every three months she has her blood drawn to monitor her numbers. And you wouldn't know that after each time, the nightmares and distressing thoughts resurface. As any parent knows when dealing with a child struggling with a rare disease, your mental health takes a toll. That's why therapy is a monthly ritual in our household.

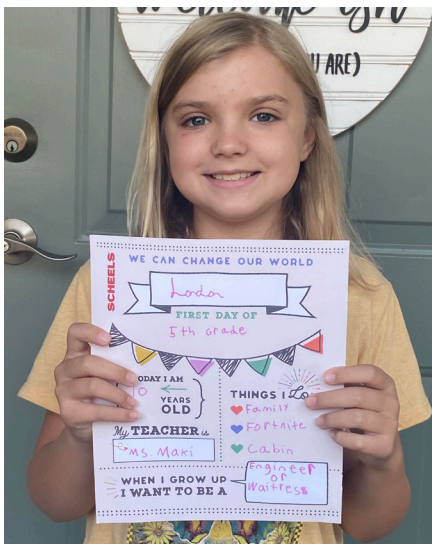
London aspires to change the world of FA. She's launching a YouTube channel to raise awareness about it. Her friends, our other daughter Sydney, and our neighbors all proudly wear her bracelets to support her and the FA community, contributing to research funding. A dear friend of ours composed a beautiful song about her and her battle with FA. We play it during fundraising events.

We share our story and information about this disease with anyone and everyone, in hopes that when the time comes; when FA presents its challenges, we are prepared to combat it. We are London's FA Warriors. We've got this!

Thank you for taking the time to read our journey.

The Aitkens

London, Sydney, Bryan, and Jen



EMBRACING RESILIENCE AND GRATITUDE WHILE LIVING WITH FA

By Egil Dennerline



I was just 16 when my world turned upside down. Being told that I had an incredibly rare, incurable, and life-threatening disease felt like a surreal nightmare. As a teenager, all I wanted was to skateboard, attend concerts, and hang out with friends. But instead, I found myself facing a diagnosis of Fanconi anemia (FA), a condition that doctors said might limit my life expectancy to just 23 years. It was a harsh reality check, and my family was also deeply affected. The weight of this new reality pressed upon us like a siege, and we each reacted in our own ways. For me, it was denial and secrecy.

As a teen and through my 20s, I kept my diagnosis hidden, scared to be seen as weak. Gradually, and over many years, I realized that what I perceived to be my greatest weakness might also be my greatest strength. But only if I started opening up, accepting my journey, and breaking free from silence.

I am 49 years old. Thirty-three years, one stem cell transplant, and 11 cancers after my diagnosis, I'm a thick-skinned old-timer in the FA community. Recently, a doctor reminded me that I'm now one of the oldest FA patients worldwide and that statistically speaking, my time is running out. Well in my world, statistics have not always been the best measure of outcomes. I've defied expectations before, surviving beyond my mid-twenties and into my late forties, experiencing life in ways

I never thought my diagnosis would allow. As such, I will continue to dream and set goals as long as

I possibly can. So, what can I take away from this journey?

PEOPLE AREN'T NUMBERS

Every patient is unique, and I've stumped statisticians numerous times throughout my journey. While statistics can serve as guardrails, they don't necessarily define individual cases. I stand as living proof that exceptions to the rules do exist. We are not mere data points but individuals with our own paths to tread.

EMBRACE LIFE FULLY

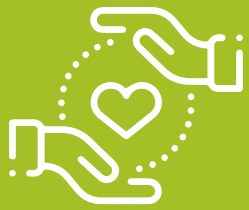
Even in the face of pain, sickness, uncertainty, waiting, and anxiety, I've learned it's crucial to embrace life to its fullest. I strive to find something to hold onto, a handle amidst the chaos. Whether it's the love of family, cherished friendships, the joy of storytelling, creating music, or simply the beauty of light filtering

through leaves, these joys, these moments, become as essential as the medications and treatments I receive. They remind me that life is worth fighting for. Each day with my wife, Nanna, is a precious gift, as is every smile from my daughter, Flora.

PERSPECTIVES CHANGE

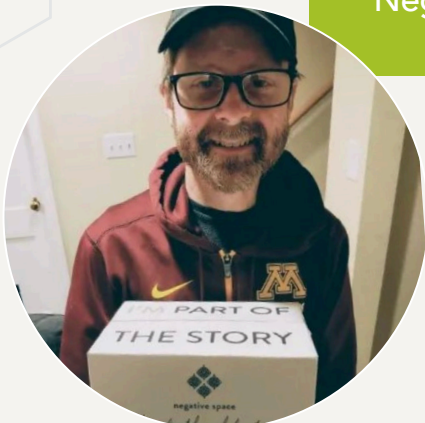
Over the years, FA has profoundly altered my perspective on living with a life-threatening illness. Shedding my fear of opening up has allowed room for valuable lessons. These insights have come over time, through different life-stages and shifting viewpoints.

Finding my "FA tribe" was one of these transformative lessons for me. If at all possible, no one should have to go through living with FA alone. That's not living, that's surviving. Reach out to your tribe and to your community. It took me forever to get there, but I'm forever grateful to all of you that I did.



CELEBRATING 100 CAREGIVER BOXES AND COMMUNITY CARE

At FARF, we do our best to support all of those impacted by FA, including caregivers. One way to recognize the caregiver's integral role within the FA experience is by sending thoughtfully curated caregiver boxes by Allison Breininger, founder of The Negative Space.



Sean

Caregiver boxes are one of our favorite ways to remind caregivers that they too are part of the story. "It's exciting to partner with FARF in sharing these gift boxes. Our hope is to let caregivers know they are seen, supported, and that their story matters, and these boxes are just one way that we do that" says Allison.

We are excited to announce that we have officially sent 100 of these boxes to caregivers who are new to FA and could use a comforting reminder that they are seen during a tough time. One caregiver said that receiving this box was "the warmest feeling in the world," while another said, "after the week I have had, this really helps."



Caregiver box

We are proud to support caregivers through our partnership with The Negative Space in this way. Remember, you too can practice community care by nominating a caregiver to receive one of these lovely gift boxes. To nominate an individual to receive a caregiver gift box, please contact communitysupport@fanconi.org.

IN THIS TOGETHER GRIEF SUPPORT GROUP IS OPEN

“No amount of time exists that will heal the hole Riley’s loss left, but something that helped was connecting with others who had also lost someone they loved.”



Riley

Another important way to support caregivers is by providing a safe haven to grieve and a chance to connect with others who’ve walked a similar path. FARF offers free, virtual, peer support grief groups for those aged 18+ and based in the United States who have experienced a significant loss in their life due to FA. These sessions aren’t about erasing pain, but rather about embracing it with kindness, compassion, and care.

We are grateful to Tina Mack, who has openly shared about her experience in our recent grief support group. Tina’s daughter Riley passed away in 2020, and as Tina so beautifully writes, “My forever journey as a grieving mother began just over three years ago. No amount of time exists that will heal the hole Riley’s loss left in the very fabric of my being, but one of the few things that has made a difference in my grief journey is connecting with others who understand the depth of my pain in a way that most people do not. For that reason, when I saw that FARF was establishing a virtual grief group last fall, I applied right away. It was so meaningful to my experience that the participants and group facilitators all lost someone they love to FA.

Although our backgrounds differed in many ways, this common factor brought us closer immediately, and there was no limit to our dialogue. Our facilitators were wonderful. They listened with intent, drew out

discussions respectfully, and created a welcoming and warm environment. The topics and activities felt relevant to me, and there was an appropriate balance between structured plans and open-ended discussions.

The other members of our group were supportive and, collectively, we created a place of trust where we could share our feelings freely and without judgment. I felt heard, and I hope I extended that same gift to others in the group. It’s normal for a person to feel disconnected in many relationships after their loved one dies. Even within the insular world of FA, we can feel left behind as new families become a part of the community and research advances; we may even feel that our Fanconi warriors will be forgotten.

I’m so grateful FARF is offering grief-based programming to support those of us who have lost someone precious to this terrible affliction. It truly reminds us that we are forever FAMily. I would strongly recommend these groups to others who are grieving—no matter how long it has been.”

If you or someone that you know may benefit from our peer support grief groups, you can contact us at communitysupport@fanconi.org, or apply on our website. Our Fall cycle begins in October. Applications are open and accepted on a rolling basis.

THANK YOU, DR. DAVIES



Dr. Stella Davies, a trailblazer in the Fanconi anemia (FA) field, recently concluded her six-year tenure on the Board of Directors at FARF. Throughout her term, she brought about transformative changes and unwavering dedication, just as she has as leader of the FA program at Cincinnati Children’s Hospital.

Stella’s innovative approach to uniting science and ‘the human element’ has helped shape FARF events. With her engaging talk show/game show style, she seamlessly merged education, creativity, and fun, captivating both researchers and the FA community. Notably, her brainchild, “FARF Tank,” increased engagement and grant opportunities for young researchers in the FA field. She also helped to establish the International Grant program, which extends support to the FA community beyond US borders. Additionally, Stella served on the Executive Committee and Strategic Planning Committee, helping FARF usher in a new chapter of growth.

Stella’s commitment to her patients with FA and advancing research on the disease leaves a lasting impact on the entire community. She has contributed significantly to improving the paradigm of care for bone marrow failure and other manifestations of FA, including Fanconi Anemia Neurological Syndrome. In addition to being published widely in peer-reviewed publications, she has mentored several residents, post-docs, and graduate students, multiplying her impact by training the next generation.

Beyond her professional achievements, Stella’s compassionate nature and unwavering dedication make her stand out. She fearlessly tackles challenges, making a tangible difference in the lives of FA patients. Known for her amazing style and boundless energy, Stella is truly a beacon of hope and inspiration to countless individuals and families affected by FA and clinicians and researchers in the field.



A new chapter for the next generation

We are excited to present the Fanconi Anemia Research Fund's (FARF) strategic plan for 2023-2027. This plan continues the remarkable progress we have made in understanding the genetics of FA and sets the stage for exponential growth in FA cancer research.

Since our founding in 1989, FARF has raised over \$32 million for research, provided support to thousands impacted by FA, pioneered life-saving therapies, and made the ground-breaking discovery that the 23 FA genes we have identified, when working properly, constitute the body's defense against cancer. Building upon these achievements, we are now ready to embark on a reimagined approach to FA cancer research.

Our 2023-2027 strategic plan elevates FA cancer research within a consortium model, multiplying our efforts through collaborations with research centers all over the world. To achieve this, we will enhance our capabilities in research administration, support services, fundraising, and governance.

The aspirations outlined in this plan are ambitious, yet firmly rooted in our legacy of success, compassion, and an unwavering sense of urgency. With your support, we will accelerate progress for individuals affected by FA and FA cancer.

Thank you for your ongoing commitment and generosity as we embrace this new phase.

Sincerely,



Mark Quinlan

Executive Director



This plan sets the stage for exponential growth in FA cancer research, and is firmly rooted in our legacy of success, compassion, and an unwavering sense of urgency.

2023-27 Strategic Goals

FOCUS ON RESEARCH

GOAL 1: Accelerate FA cancer research and therapeutic approaches through external partnerships

- With partners, develop FA Cancer Consortium resource sharing and governance structure
- Identify novel innovative prevention and therapeutic approaches for FA cancers
- Test novel prevention and therapeutic approaches

FOCUS ON COMMUNITY

GOAL 2: Accelerate research through increased advocacy, community engagement, and psychosocial support

- Build community advocacy program to advance FA cancer research
- Accelerate research on well-being and develop partnerships to enhance psychosocial support efforts
- Continue to foster the international FA collaborative network to expand community engagement and access to support

FOCUS ON SUSTAINABILITY & GROWTH

GOAL 3: Achieve a stable, sustainable development base

- Secure founder-transition funding base
- Stabilize current revenue streams
- Develop sustainable systems for managing revenue streams

GOAL 4: Diversify and expand funding sources

- Expand current revenue sources
- Investigate and establish new revenue streams
- Investigate and pursue external partnerships


GOAL 5: Evolve brand "beyond FA" by connecting FA research impact to cancer community

- Carry out rebranding process and repositioning of FARF as cancer-focused organization
- Create comprehensive marketing and communications plan to align with cancer focus

FOCUS ON PEOPLE

GOAL 6: Create optimal adaptive environment for people and leadership to contribute

- Create enabling processes and structures to support the strategic plan through anticipated stages of development
- Build and support a working environment that attracts and retains top talent and helps employees advance FARF's work
- Implement diversity, equity, and inclusion (DEI) policy across organizational activities and stakeholder groups



Take a look at the complete Strategic Plan by visiting fanconi.org and choosing "Our Impact" in the menu bar.

COMMUNITY FUNDRAISING LIST

From January through August 2023, the FA community has raised more than \$700,000 for the Fanconi Anemia Research Fund! 179 community fundraisers raised funds with 85 raising at least \$500. 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.

Note: if you held a fundraiser on Facebook, thank you! Please know that your funds raised do get to us, but without names, so we often don't know who to credit. Thankfully, Facebook is changing this soon. In the meantime, please feel free to reach out to us and let us know if you've raised funds via Facebook.

\$100,000+

John and Kim Connelly
Lynn Frohnmayer
Kevin and Lorraine McQueen

\$25,000 - \$99,999

Todd and Kristin Levine
Orion and Lisa Marx

\$15,000 - \$24,999

Mauro and Kerrie Cazzari
Rachel, Talia and Alan Grossman
Callie Toal and Family
Gerard and Cynthia Vandermeys

\$10,000 - \$14,999

Judith Hoffman and Lawrence Backman
Rachel and Zachary Gratz-Lazarus
Charles and Kathleen Hull
Andrea and Robert Sacks

\$5,000 - \$9,999

Glen and Teresa Alessandri
James and Jennifer Armentrout
Stephen and Jennifer Klimkiewicz
Keith and Jessica Loo
David and Stacy Ownby
Joe and Jacqueline Vona

\$1,000 - \$4,999

Michael and Jennifer Aggabao
Jennifer and Bryan Aitkens

Tyler Morrison and Rachel Altmann
Amanda Barber
Adam and Marissa Becker
Darryl Blecher and Diana Fitch
David and Sarah Borden
Richard and Tena Boson
Chris and Jennifer Branov
Ryan and Rebecca Brinkmann
Stanley Gilbert

David and Kim Chew
Joeseph and Nancy Chou
Egil Dennerline and Nanna Storm
Greg and Lauren DeWerff
James and Crystal Eubank
Scott and Windy Farmer
Brittney Ferrin
Andrew and Jennifer Gough
Owen Hall and Margaret Kasting
Andre Hessels and Rutger Boerema
Maria and Bill Katris

John and Karilyn Kelson
Caroline Nguyen
Timothy and Mary Ann Lana
Robert and Anna Langtry
Eugene and Renee Lemmon
Brian Horrigan and Amy Levine

Kristina Mack
Alaina Mercer
Ronald and Fredi Norris
Susan Ortiz
Peggy Padden

Mark and Diane Pearl
Kirstine la Cour Rasmussen
Pedro and Marina Ravelo

Neil and Emily Robison
Les and Nancy Ross
Lindsey Sablosky family and friends
Ron and Alice Schaefer
Bradley and Darlene Starner
Michael and Beth Vangel
Nigel and Ann Walker
Ira and Terry Walker
Jessica and Ezekiel Werden

Up to \$999

Peter and Donna Abramov
Brian and Carly Adel
Rachael Alaniz and Kevin Gatzlaff
Ronald and Juanita Arroyo
Serge Arsenault
Jeanne Atkinson
Cindy and Owen Bagaason
Gerald and Julie Barbier
Mark and Linda Baumiller
Israel and Mary Jo Becerra
Angela Bedoya Family and Friends
Donna Behlke
Domenico Bertolucci and Federica Bonati
Rodrigo and Junia Bires
Randolph and Nancy Bloxom
Sean and Allison Breininger
Elizabeth and Richard Butts
Monica and Tony Cabral
Robert and Barbara Capone
Mary Eilleen Cleary and Gleaves Whitney
Lauri Cohen
Stuart Cohen and Deane Marchbein
Mark and Annelie Crean

Bill and Pat Danks
Tony, Levi, Katherine, Gideon and Jacob DiCamillo
Oscar Duque and Yanira Ramirez
Chloe Eminger
Jillian Falco
Carole Felmy
David and Mary Ann Fiaschetti
Nanette Foster and Nicolaus, Courtney, Kaelynn and Ryan Vannostran
Daryn and Carol Franzen
Brian and Cindy Fuller
G. Mitzi Gerber
Allen Goldberg
David Guidara
Valeen Gonzales
Carmen Gonzalez
Gary and Heidi Grassi
Madeline and Bryn Gregg
Rachel and Kristian Guttulrud
Eric and Elisabeth Haroldsen
Robert and Victoria Hathcock
Nikki Hill
Stephanie and Thomas Hutter
Shane and Colleen Irvin
Jeff and Beth Janock
Stan and Michelle Kalemba
Ashleigh Kamsickas
Angie Keaton
Chad and Libby Kriner
Brian Kuell
Peg LeRoux
Larry and Gayle Licari
Tanner and Jessica Lindsay
William and Jacquelyn Lucarell
Rose Maple
Aaron and Nicki Marsters
Patricia Massuch and Louis Stollsteimer
Kelly McKenna
Daniel and Angie McMahon
James and Holly Mirenda
Ian and Tricia Mitchell
Kelly and Gerald Mlachak
Kate & Daniel Montgomery
Griff and Cecilia Morgan
John and Betty Mozisek
Tony and Lina Nahas
Lisa and Jack Nash
Alice Nicholson
William, Kelli and Kit Owen
Seth Parelman

Chris and Mel Payne
Arianna Pederson and Robert Bright
Rose and David Pennell
Melissa, Dave and Axel Perdue
Marcos and Silvana Pineschi Teixeira
Tim and Ashleigh Pinion
Peter and Janice Pless
P. Michael and Kay Proctor
Lynn and Shirley Quilici
Michael and Stephanie Ramirez
Shelby and Kayla Richardson
Mark Ritchie and Lisa Mingo
Kelsey Robinson
Kevin and Katherine Rogers
Craig and Alisha Rushing
Ty Sanders
Colleen Satterlee
Richard and Dolores Satterlee
William and Connie Schenone
Eric Schlueter
Bryan and Karen Siebenthal
Russell and Rachael Smith
Karin Staab
Tariae and Julian Stephens
Greg and Brandi Stuart
Sharon Swanson
Janice and Kenneth Sysak
Ana Alejandra Tabar Concha, Elvin Estevez Lopez and Violeta Tabar
Devon and Charles R. Tessier
Kathy Tomalesky
Mark and Susan Trager
Lucian Valor
Theresa and Louis Viola
Tyler Vitale
Joe and Wendy Vitiritto
Joseph and Natalie Vitrano
Michael and Kimberly Williams
Robert and Julie Williams
Matt and Krissie Wisniewsk
Jason and Joan Woodle
Kyle and Madison Wright
Wesley and Susan Wycoff

FUNDRAISING SHOUTOUTS

SUPPORTERS ENDURE FOR A CURE

This summer, FA parent Kevin McQueen assembled a team of 10 motivated supporters of the FA Research Fund to take on the epic challenge of America's oldest bike race, RAGBRAI. This team included FARF's own Executive Director, Mark Quinlan, board president, Orion Marx, and board member, Win Gouldin. Through the Endure for a Cure team's 524-mile cycle across Iowa, nine nights of sleeping in an RV, 100-degree weather forecasts, and facing headwinds that tested their teamwork, we are inspired by the Endure for a Cure team's relentless enthusiasm and enormous hearts! In the end, they exceeded their goal and raised over \$130,000 for FA research and support services, all the while connecting the community and spreading awareness far and wide. We cannot thank you enough, Endure for a Cure team!



"We are inspired by the Endure for a Cure team's relentless enthusiasm and enormous hearts!"



THE ROSS FAMILY BURNS FOR A CURE

The Ross family kicked it into gear this year for FA research! They celebrated Karly's 20th birthday by inviting everyone in their area to 'Burn for a Cure' at their local Orange Theory Fitness studio. Participants completed a grueling workout and ended up raising more than \$1,700! Celebrating a birthday with a fundraiser is not only an incredible way to celebrate this milestone, it's a gift that enables the researchers and clinicians who work to advance treatments even further. Our heartfelt appreciation goes out to Karly and Nancy Ross, the Orange Theory Fitness Rock Hill studio, and everyone involved in making this event possible!

KATA HOSTS THREE AWESOME FUNDRAISERS

The Kendall and Taylor Atkinson Foundation (KATA) remains a steadfast supporter of FA research and support. This year, they blew us away as they organized a series of fundraisers, including Hope Floats, the Art Howe Scramble for KATA golf tournament, and The Old Quincy Barn Dinner. The amount of planning, time, and commitment poured into these events are truly unmatched. Thank you, KATA, for not only sustaining your longstanding dedication to the FA community, but also for amplifying your support this year. We're still tallying the total amount raised, but it's safe to say your efforts have resulted in a six-figure gift that will make a profound impact in the lives of those with FA!



COLEY'S CAUSE REACHES NEW HEIGHTS

We are thrilled to share the remarkable success of the 19th Annual Coley's Cause Memorial Golf Tournament! This unforgettable day, made possible by the incredible Levine family, dedicated golfers, and volunteers, has left a lasting impact. Together, they raised an astounding \$34,000 for FARF alongside awarding \$2,000 in college scholarships! Your support means so much to us and to the numerous families affected by FA. We eagerly anticipate celebrating their 20th tournament next year, and we're confident it will be the best year yet!



"Your support means so much to us and to the numerous families affected by FA."



THE VONA FAMILY HONORS SHAUN

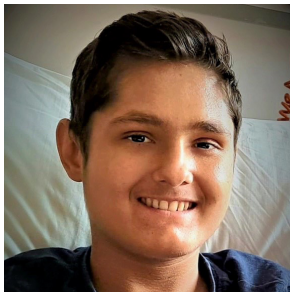
During FA Month, we witnessed numerous remarkable acts of support. This year, the Vona family stood out by organizing a fundraiser with the purpose of raising FA awareness. They not only achieved this goal, but exceeded expectations, raising nearly \$6,000 with over 100 attendees. Every guest was also encouraged to take part in Postmarked with Love, sharing heartfelt letters that provided support and encouragement to the FA community. This gesture not only honored the memory of their son, Shaun, but also heightened awareness of FA. Thank you, Vona family, for the impact you have made within the FA community and the new FA supporters you welcomed in.

TEAM BRAVERY IS NOT SLOWING DOWN

Team Bravery members have outdone themselves once again! Each of them has gone above and beyond to support the FA community. From Buzz's triumph at a 50k in Florida, to Hollywood and Keya's incredible run across the Grand Canyon, and Wingman's adventurous journeys through the Smokey Mountain National Parkway and ride across the state of Iowa with Endure for a Cure. Not to mention, their recent escapades in Alaska as a team! These fearless individuals are constantly gearing up for more epic challenges, all while raising funds and spreading awareness about FA and cancer research. So far they've raised nearly \$100,000 this year! Team Bravery, your unwavering support and courage mean the world to us and the entire FA community!



IN LOVING MEMORY

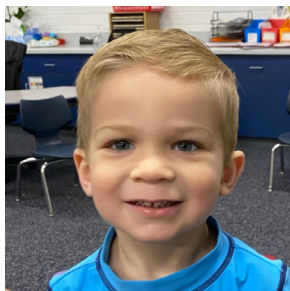


Daniël Beetge

12.05.2007 – 6.11.2023

Daniël always used to say: "It doesn't matter how hard it gets, God will always be with you and give you the strength to get through it." He is not dead but lives with Jesus where he no longer fights the battles of FA.

– Jeanette Beetge, Daniël's mother

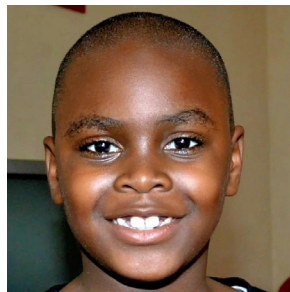


Walker Gronau

4.27.2020 – 8.6.2023

"Walker was such a gift. His family saw the impression he made on those around him from the moment he was born. When he smiled, you saw his whole face light up and it was infectious. Today we remember his story and the wish he stood for. He will be forever recognized for his beautiful soul and a strength that inspired many. Walker's family stands behind the FA community in hopes that Walker's Wish leaves as much of an impression on them as he did for his family."

– Kara Giandomenico, Walker's mother



Ivan Boniface

2.7.2013 – 1.1.2023

"Son, you are really missed, but that best thing I am proud of is your motive of helping your friends, who were sick like you, by giving hope when you were alive. You are not buried, but planted. You will grow, as the Ivan Foundation grows, to support children with FA and other rare blood disorders in Tanzania."

– Winlady Boniface, Ivan's mother

Rohit Bhattacharya

4.8.1993 – 6.23.2023

"We will forever miss Rohit's playful smile, his constant hugs and his unconditional love. He was so kind, giving, and thoughtful even while fighting leukemia." – Prajakta Pardeshi, Rohit's mother

"Let's celebrate our lives. Let's take them as a gift. Let's help each other. That's what gives me meaning."

– Rohit

Melissa Schlueter

9.23.1975 – 6.1.2023

"Melissa was a compassionate, loving, caring and giving person. She was an amazing mother. She continually put the needs of others before her own. She had a way of looking at the positive side of everything."



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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

Donations of Appreciated Stock:

Please contact our office at 541-687-4658 or email info@fanconi.org.

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