FAmily Newsletter

Issue 72 • Fall 2022

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

RESEARCH MOVES FULL STEAM AHEAD

READ ABOUT OUR LARGEST INVESTMENT IN RESEARCH YET

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

FAmily Newsletter A semi-annual publication of the Fanconi Anemia Resarch Fund

Cover photo: *FARF researchers and clinicians gather at the 2022 Scientific Symposium. From left: Juan Bueren, Paula Rio, Carmem Bonfim, Parinda Mehta, Susa Wells, Reinhard Kalb*

Eight-year-old Norah – who lives with FA – and her brother Ellis put on their sun hats and opened an organic, fresh squeezed lemonade stand this August. *See more on page 28.*

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FARF staff at the Scientific Symposium/FAdult Retreat in September 2022

Since our last newsletter, the biggest highlight for the FARF team has been reconnecting in person with the FA community again after three long and difficult years apart. In June, we held our Annual Leadership Meeting in Arizona and then in September, we gathered for our 34th Scientific Symposium and Retreat for Adults with FA in Texas.

The major takeaway from our leadership meeting in June was that it's time for FARF to develop a new strategic plan as we continue to grow. I am energized to work with our stakeholders over the next several months to clarify our organizational strategy, design pathways to action, and discover new ways to achieve a more significant impact. More to come on this exciting endeavor!

The last in-person Symposium and Adult Retreat took place in 2019 in Chicago. We held virtual events in the two years we could not meet in person. Each of those had its largest audience in history, with more than 700 participants. These events showed us just how important it is to open this event to researchers, doctors, and FA families who may not be able to join us in person. Because of this success, we included live streaming of our Symposium presentations in Austin this year, which meant dozens could attend virtually along with our nearly 300 in-person attendees.

Our recent in-person meetings and hybrid virtual events are a testament to what many of you know to be true from personal experience: we are stronger when we are united as a community. At our recent Symposium and Adult Retreat, there were people in the room who were present at the very first Symposium and several people who have been to nearly all of them! At the same time, I met new researchers, doctors, individuals with FA, and family members who were attending their first FA meeting ever.

While the meetings felt like a homecoming after so much time apart, they also marked what felt like an invigorating fresh start. The last few years have challenged us in ways we could never have imagined. And yet, during that time, we funded the most extensive research projects in FARF history. Most recently, we launched the Fanconi Anemia Cancer Consortium (FACC).

The FACC is a collaborative partnership between the FA community and a network of expert FA clinicians and physician scientists who have expertise and experience in the diagnosis and management of FA cancers and FA cancer research. The FACC aims to streamline cancer care decision-making processes for patients with FA through evidence-based research. This coalition will be housed at the National Institutes of Health (NIH). While housed at the NIH, it will involve international collaborators working to establish a comprehensive patient care strategy for FA cancer (read more on page 6).

As we are all aware, significant investments in research like this cannot happen without fundraising. A huge thanks to each of you who have fundraised for FARF in the past year! Our ability to drive quality research and provide outstanding support services is directly tied to the power of your stories and communities. The next three months are of particular significance at FARF: nearly 2/3 of all donations made are from now until the end of the year. We need your help to make that happen! Please 1. Consider sharing your story via year-end fundraising (see next pages for details); 2. Partner with our team to inspire major gifts in your community; and/or 3. Plan with us for your own family's giving.

When we look back on all the progress made under such difficult circumstances, we see how powerful we really are. Our optimism and commitment are unwavering as we build a better future for individuals with FA. As always, I am humbled by everyone who supports our efforts, and you are what makes our community great.

Mark Quinlan

Executive Director

MORE RESEARCH MEANS MORE FUNDRAISING EFFORTS

HERE'S HOW YOU CAN HELP

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.

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. 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!

[YOUR FAMILY UPDATE + PHOTOS GO HERE]

As you know, _____ has/had Fanconi anemia (FA), a rare DNA-repair disease that leads to bone marrow failure, leukemia, and cancer. There's currently no cure, but there is very promising research. That is where your support means so much. Each year at this time, we write to our friends and family to fundraise for the Fanconi Anemia Research Fund (FARF).

We do this because FARF gives our family something we never thought we'd have with this diagnosis: hope. We fundraise because FARF funds research for better treatments and a cure which we desperately need. They provide support services to families like ours around the world. FARF was started in 1989 to find effective treatments and a cure for FA and to provide education and support services to affected families worldwide. FA research cannot move forward without funding.

As a rare disease community, we are working constantly to extend the lifespan of people with FA. Research happens because families like ours write letters, and amazing friends like you support us. You are part of the breakthrough. When you give to the Fanconi Anemia Research Fund:

- You help FA families navigate the FA diagnosis, connect with other FA families around the world, and feel hope for the future.
- You invest in better outcomes for everyone touched by cancer. By funding FA research, you're helping to unlock the mysteries of DNA repair problems that impact all of us. This year, FARF launched the FA Cancer Consortium, a break-through collaborative cancer care program
- You support research in gene therapy, gene editing, and advances in bone marrow transplants.
- You fund clinical trials to advance therapies for kids and adults with Fanconi anemia.

We humbly ask for your support to find a cure for _____ and others with FA. You can send your tax-deductible gift back in this envelope or give online at https://fundraise.fanconi.org/holidays

Thank you so much for helping us spread hope and love in the community. We wish your family a peaceful holiday season!

The _____ Family

FARF INVESTS IN MAJOR CLINICAL PROJECT

WHY WE ARE FOCUSED ON CANCER

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

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

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

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

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

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

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

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

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

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

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

CANCER RESEARCH AND

FANCONI ANEMIA
CANCER CONSORTIUM

INTRODUCING THE FANCONI ANEMIA CANCER CONSORTIUM

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

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

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

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

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

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

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

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

"In my humble opinion, this disease should have been called Fanconi Cancer."

— Lynn Frohnmayer, FARF Co-Founder

FANCONI ANEMIA
CANCER CONSORTIUM

A CLOSER LOOK AT THE FIRST THREE FUNDED PROJECTS IN THE FA CANCER CONSORTIUM

NIH Center Comprehensive Program for Natural History of Development of Squamous Cell Carcinoma in Fanconi Anemia

Neelam Giri, MD, and Sharon Savage, MD
National Cancer Institute

People with Fanconi anemia have an extremely high risk of developing squamous cell cancers of the oral cavity, vulva, anal area, and esophagus. The risk of these cancers starts around teen years and increases throughout life with the highest risk for oral cavity cancers in people ages 20s and 30s. Oral cavity cancers arise in areas of changes visible as white or red spots. We plan to screen teens and adults with FA for cancers at regular intervals and study the visible spots scientifically to identify early changes before progression to cancer. This will help in designing treatments to prevent the development or progression to cancer. People with concerning changes or cancer will be discussed at the tumor board in coordination with FARF and referred for treatment at NIH or elsewhere. Regular screenings and early treatment will offer better chances of cure, will have fewer side effects and result in better quality of life.

Amount funded: $1,107,464

Building Collaborative Partnerships to Understand Fanconi Anemia Tumor Pathogenesis, Prevention, And Treatment

Agata Smogorzewska, MD, PhD
The Rockefeller University

This team will facilitate collaborations among all current and future participants of the Fanconi Anemia Cancer Consortium (FACC). The goal is to gather information and samples from past, present, and future patients to fully understand how tumors develop in FA patients and facilitate new prevention and treatment strategies. This team envisions a world where every tumor from every FA patient is studied and collectively contributes to eradicating cancer.

Amount funded: $193,475

Cytology Based DNA Analysis to Investigate the Malignant Potential of Oral Lesions in Patients With Fanconi Anemia

Martial Guillaud, PhD, and Denise Laronde, PhD
BC Cancer Research Institute

Researchers will run samples collected by brushing lesions through an automated system to detect abnormal DNA content and malignant changes. By identifying high-risk lesions, closer follow-up and early intervention can be used to prevent malignancies. The goal is to establish a centralized lab at BC Cancer to process samples to identify the risk of malignant transformation for FA patients.

Amount funded: $304,300 (this grant is supported by our partner organization, Fanconi Canada).

GRANTS THAT WRAPPED UP THIS YEAR: WHAT DID WE LEARN?

CANCER

Towards Improved Clinical Management of FA-Related Cancer via a Novel Functional Genomics Approach

Josephine Dorsman
Amsterdam UMC

The aim of this grant was to address the challenge of FA head and neck cancer. The team of researchers from Amsterdam used whole exome and whole genome sequencing of DNA in FA cancer cell lines to show that specific changes that happen in FA cancer can be targeted therapeutically. The results demonstrated that the amplification of chromosome 11q22.2, which is associated with the overexpression of the *BIRC2-3* gene, is common in FA head and neck cancers. The research team is now working to determine whether chemotherapy approaches targeting *BIRC2-3* can be used as a treatment for FA head and neck cancers.

The Amsterdam team is in the process of applying for additional grant funding to continue the study.

Afatinib Therapy for Head and Neck Squamous Cell Carcinomas in Fanconi Anemia

Jordi Minguillón and Jordi Surrallés
Research Institute Hospital de Sant Pau

The Spanish research team identified the EGFR inhibitor, afatinib, as a potential drug option to treat FA head and neck squamous cell carcinoma (HNSCC) in a drug screening study that was funded by FARF in 2016. In a newly concluded FARF grant that was funded in 2019, they showed that afinitib has high efficacy and specificity for targeting FA cancer cells in preclinical laboratory studies. Data from this grant provided key information that enabled the team to apply for orphan drug designation from the European Medicines Agency (EMA), which will enable them to develop the first clinical trial for people with FA who have been diagnosed with HNSCC sometime in the future.

The Spanish research team is currently working to develop a Phase II clinical trial for afatinib treatment of FA HNSCC.

Treating Fanconi Anemia Cancer with Proton Precision Therapy

Yi Zheng and Mathieu Sertorio
Cincinnati Children's Hospital Medical Center

The goal of this grant was to determine whether proton radiation therapy is a viable option for treating FA head and neck squamous cell cancer (HNSCC) when compared to x-ray radiation therapy. The team showed that HNSCC cells that do not express FANCA are more sensitive to proton therapy when compared to x-ray radiation, although it is too early to know whether these preclinical findings can be translated clinically. The preclinical models developed in this study will allow further analysis of the role of proton radiation therapy in targeting FA HNSCC in future studies.

Dr. Sertorio has secured start-up funding and an additional $100,000 grant from the University of Cincinnati Cancer Center that will enable continuation of this work.

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INVESTING IN CANCER, EVERY STEP OF THE WAY

FARF is committed to finding answers and improving outcomes for those affected by FA cancer. Part of that commitment means investing in every step of the cancer journey:

- **Education and empowerment:** what do individuals with FA and families need to know about cancer risk and how can they be empowered in their own healthcare when it comes to cancer prevention?
- **Prevention and screening:** how often do patients need to be screened for cancer and what are some ways to prevent the development of cancers?
- **Detection and diagnosis:** how are cancers detected and what do patients do once they receive a diagnosis?
- **Treatment:** what treatments are available and where can patients find experts in FA cancer?
- **Tissue donation:** where does tissue collected from biopsy or surgery go to further advance research?

These are all questions FARF is helping to answer by working with leading experts in both the FA and cancer fields. The FA Cancer Consortium is a multi-institutional effort to provide support for each step of this journey.

LET'S START WITH EDUCATION AND EMPOWERMENT

Readers of this newsletter are probably familiar with the long-term study "Reducing the Burden of Squamous Cell Carcinoma", which was started by Ralf Dietrich (FA Germany) and Dr. Eunike Velleuer in 2006. The data they gathered after years of collecting samples from brushing the mouths of people with FA proved that using the brush is an effective oral cancer screening tool.

Now, Dr. Velleuer and Christine Krieg, who replaced Ralf as Executive Director of the German FA Support Group, have further developed oral exams as screening tools for both the medical and patient communities.

They now have tools available for doctors to perform mouth exams and brush screenings and are working to help implement this program around the world.

In addition, they have produced a number of educational and empowerment tools to help individuals with FA and their family members be more active in preventing cancer. We know that it's very common for people with FA to have lesions in their mouths, but lesions are mostly non-cancerous. That's why the materials that Christine and Eunike have created are so helpful: they teach patients what to look for and when they should seek help or go in for a biopsy.

You can find materials for both yourself (or your FA child/ren) and for medical professionals on their website: www.fanconi.de/icare. To the right, you'll see the first page in their Self Screen packet.

They are also in the final stages of developing an app that will be released next year. The app will allow you to record results from your exams easily, set reminders to check a spot you may see, and easily send photos/notes to your medical team.

ORAL SELF-EXAMINATION FOR INDIVIDUALS WITH FA

Deutsche Fanconi-Anämie-Hilfe e.V.

www.fanconi.de/icare

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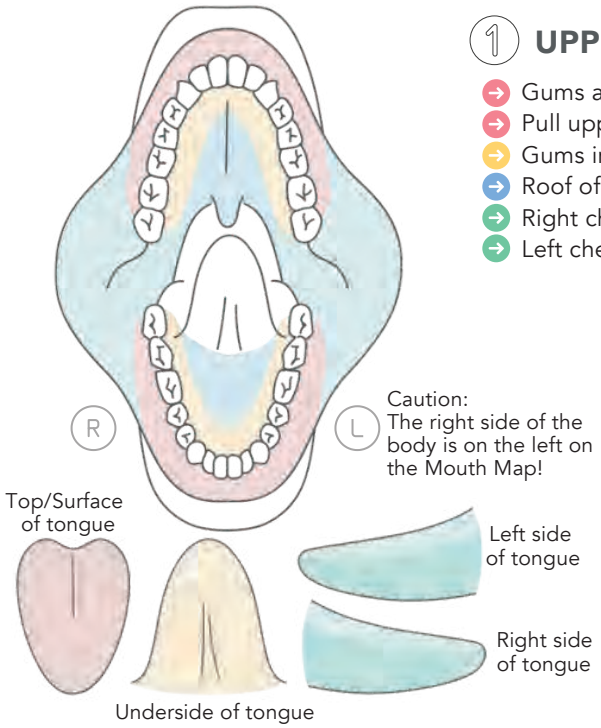
Individuals with FA often have visible spots in their mouths that come and go and are nothing to worry about. In rare cases, these spots (called lesions) are premalignant or already cancerous. Consistent and thorough observation can lead to early detection of important changes that can be monitored and/or treated effectively. Therefore, in addition to regular visits to the dentist and ENT (Ear, Nose and Throat specialist), monthly self-examination or examination by a family member with documentation is recommended.

PROCEDURE OF AN ORAL SELF-EXAMINATION



1 UPPER JAW

- Gums around the outside of the teeth
- Pull upper lip upwards as far as possible
- Gums inside of the upper jaw, by upper teeth
- Roof of the mouth, including back towards the throat
- Right cheek (pulling cheek out to view as far back as possible)
- Left cheek (pulling cheek out to view as far back as possible)

2 LOWER JAW

- Gums, around the outside of the teeth
- Pull lower lip out and down as far as possible
- Gums inside the lower jaw, by lower teeth
- Floor of the lower jaw, where tongue rests (lift tongue)

3 TONGUE

- Surface of tongue as far back as possible
- Underside and tip of the tongue
- Complete right side of the tongue
- Complete left side of the tongue

In progress

App for oral self-examination!

Coming soon to the iPhone App store and Android Play store

HOW TO EXAM?

- Examine systematically.
  e.g. always from right to left and top to bottom
- Illuminate the areas as much as possible
  e.g. use a headlamp, cell phone, flashlight or use an illuminated magnifying mirror
- Documentation: Use the mouth map and take pictures

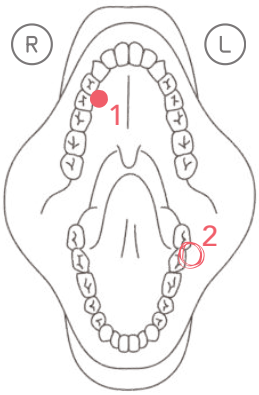
WHAT SHOULD YOU LOOK FOR?

Note all visible spots that look different or don´t "look right".
Find examples of lesions at: www.fanconi.de/icare_en

WHAT TO WRITE DOWN

Are these new spots? How long have you noticed them? What changes do you see? What colors are the spots? What size and texture? Do they hurt or bleed? Can you imagine a reason for them?

EXAMPLE OF DOCUMENTATION USING A MOUTH MAP



Mark, number, describe and take a picture!

Date:
02/04/2022

Number 1:
Has been there since February 2021, no changes

Number 2:
Has been there about a week, slightly sore and a bit painful, white-reddish, about 0.2 inch

Download the mouth map (self-examination documentation sheet) at: www.fanconi.de/icare_en

EXAMINATION SCHEDULE

- Semi-annual dentist check-up if the oral mucosa is inconspicuous.
  In case of abnormalities check-up once per quarter
- Perform oral self-examination once per month

ALL INFORMATION ON: WWW.FANCONI.DE/ICARE

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THREE NEW GRANTS AWARDED FOR INTERNATIONAL SUPPORT PROJECTS

Although the Fanconi Anemia Research Fund (FARF) is based in the United States, Fanconi anemia (FA) research, families, and support organizations span the entire globe.

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. These awards occur annually and require submission of a full application.

The 2023 grant cycle will open early next year, with a deadline in May 2023. See Fanconi.org for the latest updates.

AWARDED GRANTS IN 2022

GROUP: Portuguese Fanconi Anemia Research Network (PFARN)
COUNTRY: Portugal
PROJECT: The Portuguese Fanconi Anemia Research Network recently received an FA support grant to focus on bringing FA families and physicians together and creating guidelines on adult care. First, they will organize the first FA meeting so that families and professionals can meet and learn from each other. They will then create guidelines to aid in the transition from pediatric to adult care. They hope that stronger relationships between FA professionals and families will lead to better clinical practices.
AMOUNT AWARDED: $9,975

GROUP: The Nate Foundation
COUNTRY: Zimbabwe
PROJECT: The Nate Foundation was awarded a second grant to continue providing information, counseling, and medical support for Fanconi anemia patients. With this new funding, the Nate Foundation plans to extend their FA awareness campaign at medical facilities in Zimbabwe and organize the first meeting for FA patients and families. The meeting will provide the opportunity for information sharing and the launch of a more formal patient support group. They are also working to develop a list of FA patients in the country, which will help to establish a clearer picture of patient demographics in Zimbabwe.
AMOUNT AWARDED: $9,000

GROUP: The Argentine Fanconi Anemia Group (GAAF)
COUNTRY: Argentina
PROJECT: The Argentine Fanconi Anemia Group (GAFF) was established in 2020 for families to share their experiences, concerns, and difficulties in order to improve their quality of life. Additionally, GAAF hopes to create a network between the medical community, researchers, and patients to help update guidelines and treatments. With this support grant, GAAF will hold virtual conferences to share information amongst doctors and scientists, plan trips to meet Fanconi anemia patients face to face, grow social media presence, and create educational materials.
AMOUNT AWARDED: $10,000

COMPLETED PROJECTS

GROUP: The Nate Foundation
COUNTRY: Zimbabwe
Project: In May 2022, the Nate Foundation completed their first support grant projects. They used the funding to spread awareness about FA in the medical community in Zimbabwe. The FA Clinical Care Guidelines, along with brochures in the three main languages in the country, were distributed in the medical community and to patients. The group focused on growing their online presence and created an FA theme song in the three main Zimbabwean languages to aid in reaching and educating FA families.

Three seminars educated 105 medical personnel on FA care, and with the aid of a contracted data analyst, the group learned there were no FA patients officially registered in Zimbabwe. This prompted them to create their own registry, which is part of their 2022 grant.

GROUP: Nicolaus Copernicus University in Torun, Ludwik Rydygier Collegium Medicum in Bydgoszcz
COUNTRY: Poland
PROJECT: Researchers in Poland used this grant to hold the first FA Family Meeting in April 2022. The event hosted 10 FA family members, nine physicians, 10 speakers, 21 researchers, and two medical students. Each of the families received a copy of the FA Clinical Care Guidelines. One mother expressed gratitude for the event and shared that this meeting provided her with a better understanding about FA and treatments available to her son. The meeting led to productive conversations on how to improve FA diagnostics in Poland. A second meeting is already being planned for 2024 with hopes of reaching more FA patients and their families.

SCIENTIST SPOTLIGHT

Kathryn Pennington with son Kyle

Name: **Kathryn Pennington, MD**
Institution: **University of Washington Medical Center, Seattle**
Area of expertise: **Gynecologic cancer**

My work

I am a gynecologic oncologist who cares for patients with vulvar cancer, cervical cancer, vaginal cancers, as well as ovarian and uterine cancers. I also perform research. My main research goal is to make discoveries that will translate to improved patient care and improve the lives of individuals with gynecologic cancer.

Individuals with Fanconi anemia (FA) have a significantly increased risk of developing anogenital squamous cell cancers, including vulvar, cervical, vaginal, and anal cancers. Treating anogenital cancers in individuals with FA can be challenging because they have extreme sensitivity to radiation and platinum-based chemotherapy, which are often used for treating these cancers. Because FA is a rare disease, not enough is known about the ideal way to treat these cancers in individuals with FA.

I am developing a comprehensive registry of anogenital squamous cell cancers in FA with detailed data, treatment, and long-term clinical outcomes, along with corresponding comprehensive molecular profiling of tumors (in partnership with Dr. Agata Smogorzewska at the Rockefeller University). This database will be extremely valuable to the FA community and is an important step in learning how to best treat these cancers.

What motivates me to work on FA

Due to my expertise in anogenital cancers, I was asked to join the Scientific Advisory Board at FARF in 2019, and I immediately felt welcomed by your amazing community. I am truly in awe of how much the FA community has already accomplished in learning how to treat this rare and challenging disease, and how you all have supported each other. I believe we can make even more progress and I want to be a part of it!

When I'm not in the lab, you could find me

Doing surgery or taking care of patients in the hospital or in clinic. When I'm not at work, I spend time with my husband, 10-year-old son, and three cats. I enjoy hiking and spending time in nature. I really love animals, and observing wildlife is one of my favorite things to do.

Anything else you want FA families to know?

I have so much hope that we can continue to improve the lives of individuals with FA. I am inspired to help in any way that I can. If you have FA and have been diagnosed with an anogenital cancer, please consider participating in our registry. I would love to talk to you about it!

THE FA COMMUNITY CELEBRATES FARF CO-FOUNDER LYNN FROHNMAYER'S 80TH BIRTHDAY

We collected every birthday message and compiled them into a book to present to Lynn at the Symposium Banquet dinner

In the Fanconi anemia (FA) community, the name "Frohnmayer" carries a legacy like no other. Lynn and David Frohnmayer founded the Fanconi Anemia Research Fund (FARF) in 1989 as a means to support the work of a handful of researchers. This is how 'the FA research fund' was created.

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

Lynn has now spent half of her life working to cure FA. She has lost all three daughters to this disease, and her husband David to cancer. In August, she turned 80 years old. We invited the FA community to celebrate all that the Frohnmayers have made possible, and join us in taking FA research and treatment to the next level.

The gifts and birthday messages poured in! By the end of August, the community raised more than $150,000 for research! In addition, four new donors joined the FARF Legacy Society by pledging planned gifts to advance research.

Thank you for celebrating Lynn's living legacy as FARF's beloved co-founder. Gifts now allow us to make progress today and estate gifts allow us to plan for the future – one in which every person affected by FA can live a long and prosperous life.

Lynn with FARF leadership celebrating her birthday

HENRY FENYO
RECEIVES 2022 WINN/BYRD AWARD FOR ADULTS WITH FA

Congratulations to Henry Ryan Fenyo, recipient of the 2022 Amy Winn and Christopher T. Byrd Award for Adults with Fanconi Anemia.

Henry is a recent high school graduate with plans to attend St. John's University in Queens, New York. He plans to earn a degree in Special Education with a minor in social justice. More specifically, he will be part of a program that helps students examine systems that cause poverty and teaches them to be proactive in advancing social justice.

Henry aspires to be a lawyer who advocates for children with disabilities. As someone living with Fanconi anemia, he knows the challenges and sometimes isolating experiences that come with a rare disease. His own experiences shaped him into someone who wants to fight for others because everyone deserves justice and fairness. "To me, that's the essence of law," states Henry.

One of Henry's goals is to start a charity that will provide hearing aids to children who cannot afford them. Having access to his hearing aids early in life made a huge impact on Henry's ability to learn in school.

Over the summer of 2022, he was working as a teacher at the preschool he attended shortly after learning about his hearing loss. During his time teaching, Henry interacted with and mentored nine-year-olds on the autism spectrum. "It is so rewarding to work with children in my own community in a field I wish to enter after college."

Henry is planning to use this award to help pay for his tuition and plans to put some of it away to start his charity.

"I grew up with so much love and support. Now, I wish to give back."

Henry participating in a charity walk

Henry attending Students Day at St. Johns University

THREE BONE MARROW TRANSPLANTS, TWO BROTHERS, ONE DISEASE: MEET THE JOHNSON FAMILY

By Rebecca Johnson

Rebecca, Michael, Craig, and Brett

THE BEGINNING OF MICHAEL AND BRETT'S FANCONI ANEMIA JOURNEY

Our journey with Fanconi anemia (FA) began February 7, 2016 – a night we remember vividly. It was the first time – but not the last – that we would wonder if our son Michael would make it through the night.

What we thought was just a bad bruise from sledding turned into an ambulance ride to the nearest children's hospital, where we heard the words "your son has cancer; we think it is leukemia." Within the following six months, we came close to losing Michael two more times, but ultimately he went into remission from acute myeloid leukemia (AML).

Two years later we would hear those dreadful words again, only this time Michael would battle an even more rare form of AML: acute promyelocytic leukemia (APML). Over the next nine months, he traveled for outpatient chemo, was in and out of school, and endured fluctuating blood counts.

This led us to ask the big question: WHY? Why two different forms of leukemia, with one more rare than the other? This question was answered following genetic testing. He has a double mutation of the *BRCA2* gene and a diagnosis of Fanconi anemia.

Our world changed even more when our oldest son, Brett, received genetic testing and we learned he too has the double mutation of *BRCA2*. We now had another diagnosis of Fanconi anemia and even more unanswered questions.

CONNECTING WITH FARF AND FA SPECIALISTS

Thankfully, we found the Fanconi Anemia Research Fund (FARF) and received some direction and guidance. Finding FARF was a life saving moment for our family. The staff introduced us to some amazing families, doctors, and a new support system. FARF led us to the University of Minnesota and a care team like no other.

In February 2021, we met Dr. MacMillan, who took the lead on both Brett's and Michael's care. She recommended a bone marrow transplant (BMT) for both boys as soon as possible. We returned home that day in February trying to find words to share with our families and our co-workers. We started to navigate health insurance with a diagnosis no one had heard of.

NOT ONE, NOT TWO, BUT THREE BONE MARROW TRANSPLANTS

Michael was admitted to the University of Minnesota Children's hospital in April 2021 to begin his transplant process and the journey that would take our family 450 miles apart for more than a year. We found temporary housing in Minnesota and I learned how to work remotely.

On April 26, 2021, Michael received his new cells, worked hard to grow new ones, and at day +60 learned that his engraftment had failed. This meant he would need a second transplant. Michael and I finished his 100 days in Minnesota, returned home to Wisconson and waited till October when Brett would begin his BMT journey.

Brett got his new cells on November 10, 2021 and on day +12 was discharged to our Minneapolis apartment. He had a few bumps on the road with skin infections, an early line removal, and a slow-growing white cells. However, on day +100, Brett rang the Bell of Bravery and returned home!

While Brett recovered, Michael returned to Minnesota and began the BMT journey once again. Both boys were in Minnesota at the same time for only about a month as Michael started transplant #2 and Brett continued to recover. Michael received his second set of donor cells on January 26, 2022 and started his journey towards 100 days once again.

On May 5, 2022, he rang the Bell of Bravery and after 13 months, and three transplants, our whole family would be home together in Wisconsin!

LIFE POST TRANSPLANT

We have learned A LOT in the past year. We have learned about FA and the struggles our boys will continue to have. We have learned that the FAmily is amazing and that we are stronger than we ever imagined.

This journey has brought new people into our world that we now couldn't imagine living without. It has reinforced our philosophy of 'one day at a time', and has taught us that it is okay to need help.

FARF has connected us to great doctors, resources, families, and has helped us better understand our roles as caregivers.

For now, both of our boys are fully engrafted and recovering at home in Wisconsin. We make frequent trips back to the University of Minnesota and slowly, we are figuring out what our life looks like post transplant.

We don't take any day for granted and we take the time to say "I love you" as much as possible.

VIOLET'S JOURNEY TO DIAGNOSIS AND TRANSPLANT

By Paige Halverson

Hello, FAmily! My name is Paige, and my three-year-old daughter Violet was diagnosed with Fanconi anemia (FA) in 2020. Violet has three older siblings: two brothers and a sister who do not have FA. Violet's journey to diagnosis and beyond has been eventful to say the least.

VIOLET IS BORN

Our story began when I was pregnant with Violet. We thought all was normal until the scans at 20 weeks. Violet's growth had slowed greatly. There was fluid around her brain, and issues with blood flow in her heart, among other anomalies. This immediately put me in the category of high-risk pregnancy where I was monitored regularly. I was induced at 37 weeks because her doctors believed she would grow better 'on the outside'.

Violet was born weighing 5 lb. 4 oz. While she was small, her other anomalies had seemingly disappeared. Twenty-four hours after birth, Violet was admitted to the neonatal intensive care unit with breathing and blood sugar issues. At this point, her doctors did not seem worried. I was discharged from the hospital without my newborn. After seven long days, Violet was discharged.

The first few months of her life, Violet was monitored with regular appointments to make sure she was gaining enough weight. Her doctors told us she would catch up by the time she was two, but so far, this has not been the case. She was diagnosed with failure to thrive, gross motor delay, and oral aversion by the time she was nine months old. For this she received therapies and early intervention. She also never slept through the night. It was around that time I noticed she had multiple discolorations on her skin. She has both hyper and hypo pigmentation,

as well as many cafe-au-lait spots. This all together is what led us to pursue genetic testing.

I decided to reach out to the Mayo Clinic in Rochester, Minn. The doctors there were more than willing to help us get a diagnosis for Violet. We saw several doctors, including a geneticist and an endocrinologist. They did MANY tests and we returned to Rochester a total of six times. There were many diseases that fit some of Violet's symptoms and features, but not one that seemed to fit them all. This was an incredibly scary time for all of us, as most of these diseases were not promising and did not give us much hope.

FINALLY, A DIAGNOSIS

After nine months of testing and waiting, I received a phone call to set up a video visit. I will forever remember September 18th, 2020. I sat alone while waiting for the doctor to come on the video, and when he did, I could see in his face that this wasn't going to be good news. He said the words 'Fanconi anemia with the complementation group D1'. I had never heard of this, and I tried to listen as he explained, while trying to hold back my tears. Our doctors at Mayo Clinic had also not heard of FA. While some of the doctors tried to quickly educate themselves on this disease, others did not, and I felt I needed to educate them. This is not what I wanted. I trusted our doctors, but I, too, needed to know more. I wanted to feel confidence in the choices that our doctors were making.

CONNECTING WITH FARF AND AN FA CENTER

With the need to learn more about FA, I reached out to the Fanconi Anemia Research Fund (FARF) and quickly got connected to a family support group. From there, we were directed to a comprehensive FA center. Lucky for us, there was one even closer to us than the Mayo clinic. Not only was this center a shorter commute for us, but I also knew we would be with doctors who had experience and knowledge of FA. We met with a specialist at The University of Minnesota, where we were almost overwhelmed with information.

GOING TO TRANSPLANT

We were told Violet needed a bone marrow transplant. With this came a huge flood of emotions, one of which was hope. Violet was seemingly healthy, so others did not understand the urgency and need for a transplant.

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

LIFE AFTER TRANSPLANT

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

Tyson (10), Paige, Violet (3), Emma (7), and Fisher (8)

AM I A CAREGIVER?

FARF continues to grow the support we provide caregivers, including how to return to in-person events. During the recent Retreat for Adults with FA, one of the ways we sought to help caregivers feel seen and important was through partnering with the founder of the Negative Space – and spouse to

MY FIRST EXPERIENCE AT AN FA MEETING AS THE PARTNER OF SOMEONE WITH FA

By Kayla Letham

This was my first time going to the Adult Retreat and as you can probably imagine, I felt overwhelmed. I remember having this sort of 'lost' feeling. The struggles that I saw all these FA adults going through and the strength with which most of them were handling it was inspiring. It was so inspiring that it made my overwhelming anxieties look petty in comparison. Up until this conference, FA wasn't something that had been in the forefront of my relationship with Will (my partner with FA). As a couple, we haven't been through as many of the hardships that I saw others going through.

Before this conference, I hadn't even categorized myself as a caregiver. It was a title I felt I hadn't truly earned. It felt silly to tell anyone I was drowning. At the start of the event, I isolated myself in a corner writing cards and coloring some random picture of a flower. How could I ask for help? I wasn't even sure what I needed.

Perhaps in casual passing or maybe because he knew, Will asked how I was doing. I guess it was an expected question, but I wasn't prepared to answer. Again, all I could think of was how much more difficult this must be for him and how my experience couldn't possibly compare. I told him it was a lot of information and was a little overwhelming but stopped short of voicing my internal screams. Somewhere in the conversation he mentioned how I am the first person he has ever brought to one of these conferences – not even his parents. Without realizing it, his words put an enormous pressure on me to be perfect and not disappoint him.

Just then, the caregiver group was starting. I walked in a bundle of nerves, shaking and already holding back tears. I forced myself to sit in the circle of chairs, watching the door, ready to bolt. This looming thought in my head told me I was about to embarrass myself and run out of here crying.

We started with some breathing exercises which suppressed the pit in my throat. Maybe I wouldn't cry

an adult with FA – Allison Breininger. Allison held caregiver-specific support groups and provided tools especially for caregivers.

Kayla Letham, a partner of an adult with FA and a first-time attendee to the meeting, shared a little about her experience as a caregiver at this event.

Kayla and Will

immediately, after all. We talked about the labels for our name badges (this was the first year a 'caregiver' ribbon was offered) and the different meanings of being a caregiver. In this group, I found a place I could be heard and understood without feeling like I was diminishing my partner's struggles. There was so much I had been pushing down that I could've stayed in that meeting for hours. Breathing exercises again. Near the end, I got ready to put on a brave face to go back out into the hall.

I went up to thank Allison on the way out. I finally felt seen, and I was okay with that instead of feeling guilty about it. We talked a bit more and she asked some deep questions, maybe things I was trying to hide even from myself. I have a tendency to push things down and mask my feelings. I wrestled with the idea of how to go back out into the hallway. A hug from Allison and her encouraging words were priceless to me.

Will and I went upstairs to our room to rest before the next thing on our agenda. At this point I was physically, mentally, and emotionally drained. Allison's words rattled around in my brain, and I found myself sharing these overwhelming feelings I had been battling with Will. He made it so easy to talk. Allison helped me break down those barriers with him and with myself.

It's weird to think that before we even attended, I didn't think the caregiver meeting would be something I needed yet. I couldn't be happier that I went. I can't thank FARF and Allison enough for this kind of support.

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BONE MARROW FAILURE

Development of a Safe, Completely Non-Genotoxic Anti-C-KIT (CD117) Antibody-Based Conditioning Regimen for Hematopoietic Stem Cell Transplantation in Fanconi Anemia

Agnieszka Czechowicz
Stanford University

The goal of this grant was to develop a non-genotoxic antibody-based conditioning regimen that can be used to treat people with FA who are undergoing a hematopoietic cell transplant (HCT). If successful, this new technology will ultimately eliminate the need for chemotherapy and irradiation during HCT. Results from this study showed that antibodies targeting the CD117 receptor on FA hematopoietic stem cells (HSCs) enables safe and effective HCT in FA mice when combined with T-cell depleting antibodies. Engraftment of donor cells in mouse models also showed that when specific immunosuppressant regimens are used donor HSCs have a competitive advantage over FA HSC cells. These studies open up the possibility of future immunosuppression-only HCTs for people with FA.

The Stanford team received a grant from the Department of Defense Bone Marrow Failure Research Program in September 2021 to continue their work on antibody-based conditioning in Fanconi anemia and initiated a clinical trial in 2022.

Pilot Study of Metformin for Patients with Fanconi Anemia

Akiko Shimamura
Harvard Medical School

The goal of this clinical trial was to determine whether the drug metformin was efficacious at improving blood counts and safe for non-diabetic patients with FA. The results from the study confirm that metformin is safe and tolerable for non-diabetic patients with FA and showed that 4 of the 13 patients who received metformin for at least one month had a favorable hematologic response, suggesting the drug may improve blood counts for a subset of patients with FA.

The research team recently published results from this clinical trial in the journal, *Blood*, and are working to develop a Phase II multi-institutional clinical trial.

METABOLICS

Metabolic Alterations in Glucose Utilization and Carnitine Biosynthesis Impact Nutritional Status in Individuals with FA

Lindsey Romick-Rosendale
Cincinnati Children's Hospital Medical Center

The goals of this research study were to investigate possible mechanisms that lead to the impaired growth patterns and fat distribution seen in persons with Fanconi anemia (FA). The Cincinnati research team showed that people with FA respond differently to glucose intake following fasting, and this differential response can lead either to excessive burning of or the accumulation of fat. This fat accumulation is primarily observed within the trunk region, rather than being distributed throughout the body. People with FA also presented with significantly lower muscle mass and overall strength compared to non-FA healthy study participants. Results from this study suggest that people with FA lean towards underutilizing fat reserves and instead break down skeletal muscle. Future work on understanding the metabolic alterations observed on this study will inform clinical care practices that affect growth and nutritional status of individuals with FA.

Dr. Romick, in collaboration with Dr. Jim Wells and others, will be submitting an NIH grant to further this work.

NEW STUDY

Psychosocial Experiences of Adults with Fanconi Anemia

We are inviting you to participate in a 30-40 minute research survey about your experiences living with Fanconi anemia (FA) and your emotional and mental health. Findings will be used to develop guidelines to support the mental health of adults with FA.

Will I be compensated?

You will receive a $40 gift card for participating in the study.

To be eligible for this study, you must:

- Be diagnosed with Fanconi anemia
- Be 18 years or older
- Be able to communicate in English or Spanish, may live in any country

The survey is available in multiple formats: online, phone, or paper, in English or Spanish.

To participate, please email limonma@oregonstate.edu or call 541-737-1357.

Who are the researchers?

Kathleen Bogart, PhD, is an Associate Professor of Psychology at Oregon State University. She studies quality of life with rare disorders and has a rare disorder herself. Contact her at kathleen.bogart@oregonstate.edu or 541-737-1357.

Megan Voss, DNP, RN, is a Clinical Associate Professor in the School of Nursing at University of Minnesota. She has been providing nursing care and advocacy to the Fanconi anemia community for many years.

This research is funded by the Fanconi Anemia Research Fund.

University of Minnesota

Oregon State University

Fanconi Anemia Research Fund

NEW GRIEF GROUPS LAUNCHING JANUARY 2023

Grief is part of being human. It's part of knowing love, and we will all at some point experience it. Grief can emerge anywhere in our lives, but for this community grief is all too familiar. Whether it's anticipatory grief, the loss of a loved one, or collective grief, we've all come to know grief in some shape or form while navigating Fanconi anemia (FA).

To be "bereaved" literally means to be torn apart (Dr. Alan Wolfelt). If you are bereaved, you likely know this feeling. No words, written or spoken, can take away the pain you feel. We hope, though, that these groups will help bring you comfort, support, resources, and companionship as you navigate what it means to live with and process your loss.

IN THIS Together

VIRTUAL FANCONI ANEMIA GRIEF SUPPORT GROUPS

IN THIS TOGETHER: PEER LED GRIEF GROUPS FOR THE FA COMMUNITY

FARF provides free virtual, peer support grief groups for those 18+ who have experienced a significant loss in their life due to Fanconi anemia. These groups do not provide formal counseling, but rather a safe, non-judgmental space where members can share their stories, resources, and connect with others who have walked in similar shoes. The goal of these groups is not to erase pain, but to tend to it with kindness, compassion, honesty, and care.

Groups meet online twice a month for an hour, and involve a mix of open dialogue, education, and activity-based programming. Each group maintains the same cohort of individuals throughout the group cycle, and are led by peer volunteers who have completed a comprehensive grief and loss training.

The following groups may be offered (depending on who applies):

- Child loss
- Partner/Spouse loss
- General Grief group

While we recognize that support groups are not for everyone, we want everyone in this community to know that learning how to cope with the loss of someone you love doesn't have to be something you do alone.

Potential benefits of group:

- Instillation of hope
- Universality and sense of belonging (you are not alone!)
- Imparting of information (insight, helpful suggestions, understanding, and resource sharing)
- Altruism (groups not only provide members with the opportunity to receive support, but to give it as well).
- Safe place for emotional expression and release of feelings

HOW TO JOIN A GRIEF GROUP

If you are grieving and feel that you might benefit from the support of others in a group environment, please complete the member application available at fanconi.org and we will connect with you to ensure our group can meet your needs.

APPLY TO BE A PEER FACILITATOR

"Grief, often the most profound form of sorrow, demands the support and compassion of our fellow human beings" (Dr. Alan Wolfelt, Center for Loss & Life Transition). Grief groups provide an opportunity for peers to help nurture others with compassion and support.

If you are interested in companioning others in their grief as a peer facilitator, we encourage you to apply. We believe that you will find it to be a true privilege to "walk" alongside fellow grievers in this FAmily.

For questions contact Jordan Deines, LCSW and Director of Family Services at jordan@fanconi.org or 541-687-4658x301.

PATH TO A CURE

The path to a cure for Fanconi anemia (FA) is a long and winding one, with many different routes and detours. It starts with research. Each idea or concept builds on the others, taking us closer and closer to better treatments and a cure. Many of today's treatment protocols began 30 years ago as new research ideas funded by the Fanconi Anemia Research Fund.

1 Discovery or idea

It all begins with an idea. Researchers work with FARF to develop a project and apply for funding.

2 Fundraising for research

Community members – many of them FA families – plan galas, run marathons, climb mountains, writes letters, and more to raise funds.

3 Development of a drug or protocol

Researchers begin their work to investigate whether a certain drug or protocol may be useful as a treatment for those with FA.

4 Research is 'translated' for preclinical testing

Once basic research is complete, investigators work on applying it in a clinical setting.

5 Clinical trial

It's time to test the new drug or protocol for safety and efficacy. If proven safe and effective, the drug or protocol is ready to use as treatment.

New treatments & better outcomes for people with FA!

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

FA ADULT COUNCIL WELCOMES FIVE NEW MEMBERS

The FA Adult Council is a permanent advisory board to the FARF staff and board of directors. Comprised of adults with FA of various ages and backgrounds, this group's top objectives are to provide advice and ongoing support, to help people with FA have a voice, and to empower all adults with FA as one community. This year, as two members finished their term, we welcomed five new members.

WILL BLOXOM

Will Bloxom

Will is a 30-year-old from Salisbury, Maryland, where he works in data operations management. He was diagnosed with FA in 1997 at age five and was transplanted in 2020 during the height of the COVID pandemic at Sloan Kettering Memorial Hospital in New York.

He attended Camp Sunshine sporadically as a child and began attending FA Adult meetings in 2017. Will is almost always willing to partake in clinical trials and in 2015 was a participant in the phase 1 gene therapy trial for FA patients at the Fred Hutchinson Research Center. He is also a volunteer with Be The Match, the national stem cell donor registry, where he assists his local representative. Outside of all things medical, Will enjoys gaming, dogs and traveling the world.

FATMA ISSAK

Fatma Issak

Fatma was born in Oslo, Norway. At the time, doctors were unaware of her condition. Only five years later did they understand she was facing major health complications. Due to insufficient medical knowledge in her hometown, Fatma's family traveled to London, Berlin, and Mumbai, before finally finding doctors who could help in New York City at Memorial Sloan Kettering. Fatma's treatment began immediately, with the miracle stem cell donor being her grandmother.

ANDIE KALEMBA

Andie Kalemba

Andie Kalemba is a 19-year-old college student at Butler University. From St. Johns, Indiana, she was diagnosed with Fanconi anemia at 8-months-old and received a bone marrow transplant at age five at Cincinnati Children's Hospital. She works on her campus with the University Program Council. Andie loves her family and friends, her dogs, art, theatre, and helping raise awareness about FA.

DAVID RODWELL

David Rodwell

David is 30 years old and lives in Sydney, Australia. He was first diagnosed with Fanconi anemia in 1994 and had a successful bone marrow transplant in 2004. He has since gone on to become a qualified lawyer working for the New South Wales state government in Australia. In his spare time, David loves watching movies, reading, traveling, and going to the beach.

"I want to give back to the FA community using my life experience and professional expertise. The FA community is very special and I feel ready to step up and be more involved in the community, and a role model for younger people with FA."

DEXTER SHERRELL

Dexter Sherrell

Dexter was first diagnosed with Fanconi anemia at age 45 and received a transplant at Memorial Sloan Kettering in August 2021. Despite low white blood counts through late childhood into early adulthood, Dexter was able to serve in the United States Air Force. After his military service, he worked in the manufacturing industry for a number of years. He then pursued his degree in Business Administration and Ministry Leadership, and eventually transitioned into the business world. He now owns and manages his own businesses.

Dexter enjoys encouraging others, helping them overcome challenging obstacles, and sharing about his faith and health journey through ministry and speaking engagements. He's a proud descendant of Creek nation through his mother. His dream has always been to fly an airplane and to skydive, two goals he is currently pursuing! He lives in Georgia with his wife of 22 years, Mandy.

THANK YOU, OUTGOING MEMBERS

ANA ALEJANDRA TABAR

Ana Alejandra Tabar

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

While on the council, 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.

Moreover, Ana has the gift of making everyone she interacts with feel important and deeply cared for. She brings a warm and joyful spirit to every space she enters and brings the best out of those around her. We are confident that Ana's efforts will be far reaching and in close collaboration with the global FA community. Thank you, Ana, for all of your passion and persistence!

ANGELA BEDOYA

Angela Bedoya

Angela joined the FAdult Council at its commencement in 2019, and has been an integral member ever since.

She has served as a caring mentor and fierce advocate for those in the FA community. She encouraged students to join Be The Match, helped to educate first year medical students about FA, spoke at conferences and events, led patient sessions at FARF's Adult Retreats, and was the 2018 recipient of the Winn Byrd Award for Adults with FA.

Angela's biomedical research background has shaped her ability to see complex problems from multiple angles, and her artistic nature allows her to solve those problems creatively.

Her insight and imaginative thinking have contributed to the design and implementation of impactful programs at FARF, such as Postmarked with Love, our card-making program.

Angela, we are so grateful for all that you've taught us and how you've inspired us to show up for one another.

FUNDRAISING SHOUTOUTS

Reef's family and friends

BRACELETS FOR REEF

This past summer, a group of kindhearted kids came together for a spur of the moment fundraiser to honor and remember their cousin, Reef Sebourn (or "Reefy Brew" to this crew). Through all of Reef's experiences and struggles with FA, he was the golden example of living life to the fullest, spreading joy, and showing love to everyone he met. Seeing his loved ones come together to support FARF is incredibly heartwarming. These kids raised $1,310 during their three days of bracelet sales. Thank you all for keeping Reef's legacy alive and following his lead by spreading joy and light in the world!

LEMONS AND LOVE, THAT'S ALL YOU NEED!

Eight-year-old Norah – who lives with FA – and her brother Ellis put on their sun hats and opened an organic, fresh squeezed lemonade stand this August. They connected with their friends and even some new neighbors while also supporting the FA community. That's what we call a win-win! Altogether, they raised $188 for FA research and family services. Thank you, Norah and Ellis!

Norah and Ellis

> **"Through all of Reef's experiences and struggles with FA, he was the golden example of living life to the fullest, spreading joy, and showing love to everyone he met."**

Coley's Cause supporters

COLEY'S CAUSE

This June, a sea-of-orange in honor of Nicole "Coley" Levine swept over 148 golfers. For 18 years, the Levine Family has held the Coley's Cause golf tournament in memory of their beloved daughter. This year they raised an outstanding $35,000! Alongside many heartwarming speeches at the event this year, Coley's best friend from kindergarten (now a registered nurse) recalled how she "wanted to help others feel better like the nurses did for Coley when she was in New York". And standing by her side for support as she delivered her emotional speech was Coley's NY nurse, Yvette Murillo.

It is easy to see that Coley left her mark on those in her life and is still bettering the lives of the FA community through her memory and loved ones. Over 18 years, Coley's Cause and their devoted community have raised over $514,000 in support of FARF's mission. Thank you for all you do!

A COIN DRIVE AND A CHICKEN DANCE

Last spring, Winslow Elementary School in Henrietta, New York, put on a coin drive for FARF in honor of teacher Mary Ann Lana, whose son Eli lives with FA. Together they raised $2,672 in only five days! As an added bonus and celebration, Winslow's principal even dressed up as a chicken and danced on the roof! Mary Ann's kindergarten class truly got involved and made a difference in the FA community. We are so impressed and grateful for your generosity. Thank you!

Winslow Elementary School students

> **This enduring event shows the dedication of the Hull community to continue to honor Chris and to impact the lives of others with FA like him.**

Tournament winners

CHRIS HULL MEMORIAL SIGMA PI OPEN

This June marked the 22nd Chris Hull Memorial Sigma Pi Open. Born in Ohio, Chris was a 1989 Penn State graduate, a member of Sigma Pi fraternity, and in 1999, at age 33, he was one of the oldest FA patients when he passed away. Now a friendly rivalry between Chris's fraternity brothers and his hometown friends and family of Ohio, this dedicated community gathers each year to remember Chris and to raise funds for FARF. This year, together they raised $8,000! This enduring event shows the dedication of the Hull community to continue to honor Chris and to impact the lives of others with FA like him. We are so grateful to the Hull community and the Sigma Pi fraternity for your continued support. Thank you!

THE LOO FAMILY

We are always touched by those who give back to the FA community during both the highs and lows of life. The Loo Family did just this. To celebrate his birthday, FA father Keith Loo asked for donations to FARF through a Facebook fundraiser. He surpassed his goal and raised $5,831 in honor of his daughter Alexis. Sadly, a few months later, Keith's grandmother, Margaret C. Loo, passed away. In her honor, loved ones made donations to FARF to support Alexis and to give everyone in the FA community hope for a better future. This family's love for each other and support of the FA community has us amazed. Overall, the Loo family raised over $21,000. Thank you! This is what makes research advances possible.

The Loo Family

FAMILY FUNDRAISING LIST

From January through August 2022, the FA family community raised more than half a million dollars for the Fanconi Anemia Research Fund! 209 FA families raised funds, with 76 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.

$200,000+

Lynn Frohnmayer

$35,000 – $50,000

Todd and Kristin Levine
Orion and Lisa Marx

$10,000 – $25,000

Jason Brannock
Charles and Kathleen Hull
Keith and Jessica Loo
Kevin and Lorraine McQueen
Peggy Padden

$5,000 – $9,999

James and Jennifer Armentrout
Mauro and Kerrie Cazzari
David and Kim Chew
Brian Horrigan and Amy Levine
Mark Ritchie and Lisa Mingo
Nigel and Ann Walker
Robert and Julie Williams

$1,000 – $4,999

Michael and Jennifer Aggabao
Rachael Alaniz and Kevin Gatzlaff
Victor and Mary Albino
Tyler Morrison and Rachel Altmann
Adam and Marissa Becker
David and Sarah Borden
Chris and Jennifer Branov
Sean and Allison Breininger
Ryan and Rebecca Brinkmann
Egil Dennerline and Nanna Storm
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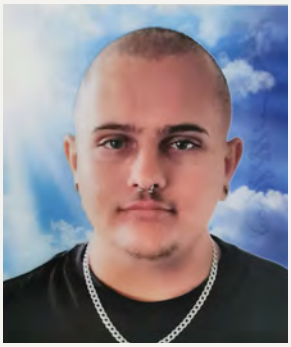

Ryan Godfrey
3.25.1998 to 7.3.2022

Fahad Shah Hamdani
3.22.1999 to 6.22.2022

Hernaldo Adrian Hernandez Lepé
9.14.1984 to 5.16.2022

Loren Hemingway
3.29.1992 to 8.9.2022

"Both quiet and crazy, Loren was described by Dr. Boulad, Loren's transplant doctor, as his most Zen patient. Loren was diagnosed with FA at age 24. He passed away a few months after his 30th birthday. His was a life well-lived!
We miss you Loren.
Love, Mom
(Donna Hemingway)"

Elizabeth Ganz Dorman
1.29.1982 to 5.18.2022

"Liz was thoughtful and warm and had a knack for making those around her smile in tough situations. She is an everlasting source of love, strength, adventure and laughter for her children, Tabitha, Jeremiah, Ari and Nevaeh, and many others lucky enough to know her."
– Jake, her husband

Zayne Nhiwatiwa
10.18.2013 to 4.4.2022

"Zayne had such a warm and welcoming personality. Everyone who had an encounter with him felt like they knew him personally. Easy going, fun loving, full of laughter and sunshine even through pain. A true Angel indeed. Will be sorely missed."
– Prisca, Zayne's mom

Reef Brewer Sebourn
9.25.2017 to 6.4.2022

"The quantity of Reef's years may have been small, but the quality of his 4 years on earth were full of love, excitement and adventure. He definitely lived his life to the fullest."

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