



Family Newsletter

Spring 2022

A semi-annual publication of the Fanconi Anemia Research Fund

issue
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Get involved today!
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- New caregiver services
- New community card-making program
- Updated FA & FARF fact sheet
- Family stories:
 - Navigating diagnosis
 - Mental health in teen years
 - Surviving cancer
- FARF's commitment to diversity, equity, inclusion and more!





Update from HQ

As we continue to make our path forward out of the pandemic, we do so with a focus on strengthening a culture of belonging within the Fanconi anemia (FA) community. This focus became formalized in February when the FARF Board of Directors approved a Diversity, Equity, and Inclusion (DEI) policy statement for the organization. This statement reflects our dedication to building a more equitable and inclusive space for every person in the FA community. Since implementing this policy, we have identified action items to be addressed over the next few years to promote diversity, equity, and inclusion in our work. DEI policies are only as strong as those responsible for carrying them out. I assure you that the team here at FARF is steadfast in ensuring this work is a cornerstone of what we do, and we will remain accountable to the community along the way. For the full DEI policy and action items, see page 24.

As we carry out and develop programs, we are working hard to ensure that all FA community members feel seen and supported by FARF. Throughout the newsletter, you will read about programs recently launched, as well as updates on existing projects, and plans for future initiatives. One of our most impactful programs is our international support grant program. Last fall, we awarded two \$10,000 International FA support grants. One was awarded to a cohort in Latin America, led by Ana Tabar an adult with FA, who will be supporting the FA community in Latin America and working to improve the diagnosis and treatment of those living with FA. The second award went to researchers in Poland to support the first family meeting for individuals with FA and help them create a sustaining FA support organization. Read more on page 10.

We highlight two exciting programs from our Family Services team to help support FA caregivers, as well as families undergoing hardship in their FA journey. For caregivers, we have partnered with The Negative Space – an organization run by FA caregiver Allison Breininger – to deliver packages with items to let caregivers know they are not alone and that they are supported (page 18). Most recently, we launched Postmarked With Love, a community care program in which volunteers create handwritten cards of encouragement to individuals with FA or family members going through particularly difficult times. See page 21.

In addition to these efforts to support families, we continue to make significant progress by funding grants and advancing research programs. You will read about efforts to address central nervous system

disorders that affect some in the FA community, as well as a new research project addressing mental and emotional health in adults with FA. Finally, you'll see a comprehensive research update from 2021 which details all the progress made in research, events, and initiatives last year (page 6).

As we are all aware, none of these projects happen without fundraising efforts. We are now well into our FA Month campaign for 2022. Every May, community members come together to raise funds and awareness for FA. This year, our goal is to engage at least 35 families, friends, or community members to join our fundraising team and together, raise \$100,000 this May. If you've never raised funds before, or you're not sure if your community would be able or interested in supporting you this way, I invite you to join us. There is real power in sharing your story – whichever part(s) you want to share – and giving your friends and family a life-changing way to help.

Finally, I want to thank Amelia Hawkshaw and Duncan Nunes, two founding members of our FA Adult Council who are stepping off to allow others to contribute to this leadership team. Amelia and Duncan have been tremendous assets to the organization, and we look forward to continuing to collaborate with them.

Our commitment is unwavering as we build a better future for individuals with FA. Our focus on inclusivity will make our community more substantial and more powerful. As usual, I am humbled by every person showing up, volunteering, and supporting our efforts. You are what makes us a true community.

Mark Quinlan
Executive Director

Kitt, age 4 and from Minneapolis, had her stem cell transplant earlier this year. Her mom shared this photo and a note that Kitt "is ALWAYS dancing and wants to be an astronaut and go to the moon!" We hope you're recovering well, Kitt!



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Fanconi Anemia Month Kicks off May 1!

There are 31 days in FA Month.
Join us in raising funds and awareness throughout May!

The theme of FA Month is #ThisIsHowIFA! Here is how you can help #FindAnswers:

1. Choose an activity you love or that pushes you
2. Complete it throughout May
3. Share your passion and story with your community to raise funds and awareness for FA!

Whether it's \$50 or \$5,000, the money you raise goes to fund our incredible FA researchers, bring our FA families together, and keep our organization running.

Our goal is to raise \$100,000 by June 1, 2022



Here's how it works:

Get ready...



Choose your activity or challenge: Do something you love! Whether you want to do an activity for all 31 days or one event to show us how you FA, join the cause!

Get set...



Your page is automatically created. Take a look and personalize it how you'd like!

Let's go!



Share! Invite your friends to do something awesome and give!

You Rock!



You've made a difference! People with FA benefit from your efforts.

Need some inspiration?

Here are some ideas to get you started and celebrating 31 days of FA!

Share Your Story

Telling your story to your community is incredibly powerful. There is only one you! Tell your story on your page, share on your social media, write a letter to the ones you love, or show your story through a video or timeline of photos.

Get Outside

Whether you want to do an activity every day for 31 days or want to do one challenge in the month to celebrate, there are many outdoor activities to choose from! You could hike, run, bike, walk your dog, start a garden, or have a beach day. Let the outdoors motivate you!

Be Creative

Create your own masterpiece in May! Whether it's a painting or drawing, a science project, a Lego sculpture, or a scrumptious bake, you can create one big masterpiece or practice a skill throughout the 31 days of May. The possibilities are endless!

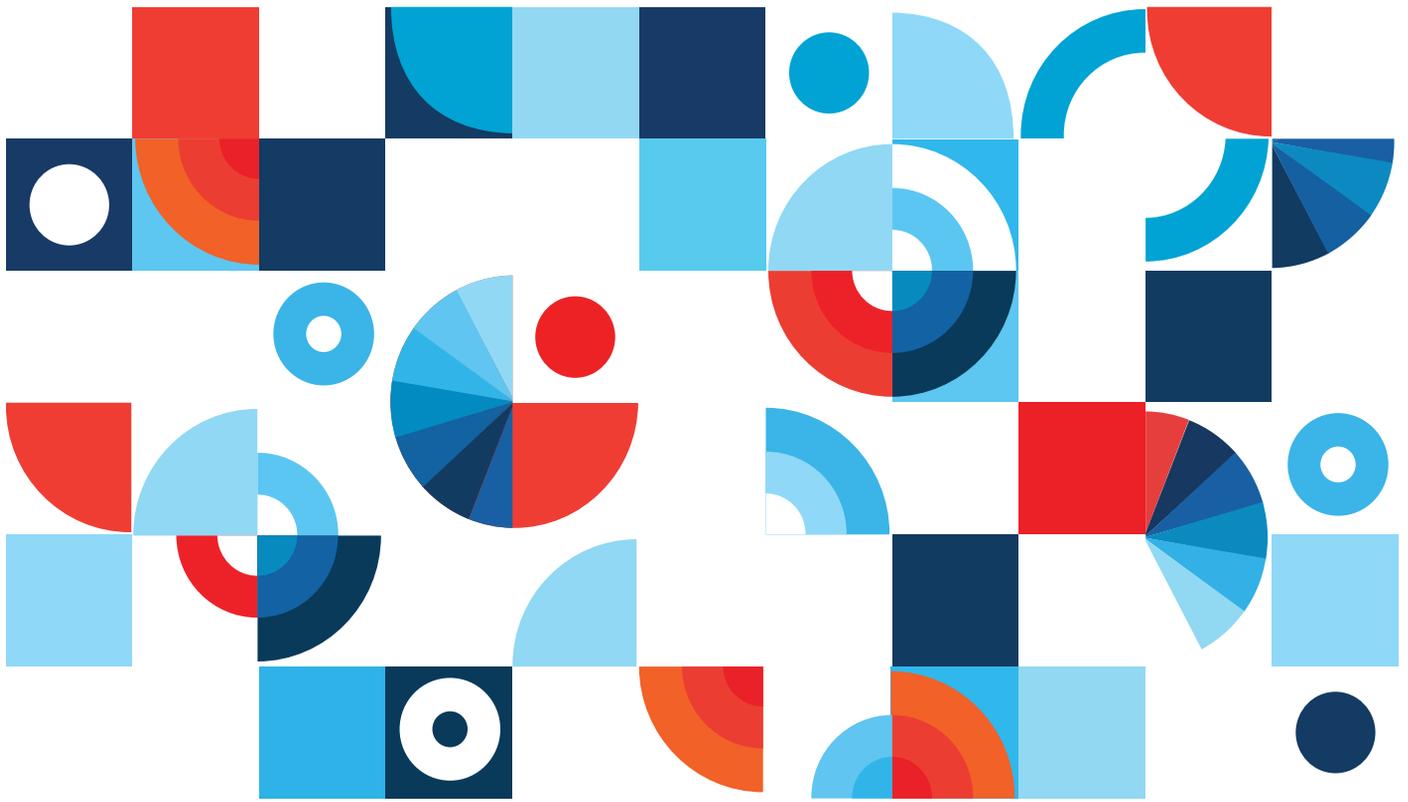
Gather

Bringing your community together allows them to be even more involved. Throw a backyard BBQ, host a game party, have a movie night, or hold a delicious dinner to share with the ones you love and tell them about your drive to help those with FA.

Share	Play	Create	Gather
Share your story \$150	Get outside \$250	Be Creative \$500	Get together \$1,000
A great place to start if you've never fundraised. Share how you're involved in FA and ask ten friends to donate \$15! Or ask three family members to give \$50.	Got a race coming up? Have your family/friends sponsor you in a run, or walk your dog for 31 days to appreciate your body and support FARR!	Artist? Baker? Maker? Create something impressive, fun, or delicious this month and ask your community to join along!	Social butterfly? Have a dinner party, host a BBQ or garden party, and ask your closest friends to come and support the cause!
FUNDRAISE	FUNDRAISE	FUNDRAISE	FUNDRAISE

Sign up at <https://fundraise.fanconi.org/FAMonth>





Research Updates: 2021-22

In recent years, much of FARF-funded research has focused on ways to prevent and detect cancer, and to develop less toxic therapies to improve and extend lives. As the research expanded, so did our approach to addressing this critical need.

In 2021, FARF focused on advancing translational and clinical approaches, while at the same time supporting basic science research projects that are foundational to the field.

In addition to our research grant award program, we now have large, collaborative research and clinical programs, including specialized focus-groups, a cancer clinical registry, a cancer early detection program, and more.

Below is a recap of the research initiatives made possible in 2021 thanks to our incredible donors, fundraisers, and dedicated researchers. You will read about grants that wrapped up in 2021 as well as newly funded projects, scientific events, and clinical programs and initiatives. You'll also read about the grants already awarded in 2022.

Grants Completed in 2021

CRISPR Transcriptional Screens for Re-Activation of HDR in FA Patient-Derived Cells

Jacob Corn, ETH Zurich

The aim of this grant was to identify potential ways to re-activate DNA repair by using a lab-based technique that activates and inactivates certain genes in FA patient cells. This work allowed researchers to determine if the overexpression of specific proteins resolved the DNA repair deficiency in FANCA and FANCD2 Fanconi anemia genotypes. Researchers found that removing a single gene from FA cells was sufficient to re-activate faulty DNA repair. These results are significant because identifying genes that play a role in DNA repair in FA cells will be useful for developing future gene editing approaches.

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 developing treatment modalities for FA head and neck cancer. In this study, whole exome and whole genome sequencing of FA cancer cell lines were used to identify relevant events associated with FA head and neck cancer. 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 overexpressed BIRC2-3 could be used as a clinically realistic treatment for FA head and neck cancers.

Pilot Study of Metformin for Patients with Fanconi Anemia

Akiko Shimamura, Dana Farber/Boston Children's Cancer and Blood Disorders Center

There were two key outcomes from this clinical research study that have important implications for people with FA. First, metformin was proven safe and well-tolerated in non-diabetic patients with FA. Second, a hematologic response was observed in 4 of the 13 evaluable patients with FA treated with metformin, suggesting the drug may improve blood counts for a subset of patients with FA. The research team is currently working on publishing results from this study and once available, FARF will provide a summary.

Modeling Hematopoietic Clonal Evolution in Fanconi Anemia

Grant Rowe, Boston Children's Hospital

The aim of this grant was to develop a new model system to study the evolutionary process of FA bone marrow failure to leukemia. Researchers plan to use this model system to understand the genetic pathways required for the development and progression of FA leukemia, and to test new therapeutic approaches.

New Grants Awarded in 2021

FARF/Stand Up to Cancer Project

In 2021, FARF developed a partnership with Stand Up to Cancer (SU2C) to facilitate collaborations and cross-pollination of ideas between the FA community and cancer experts. Stand Up to Cancer supports large integrated research teams that focus their efforts on developing treatments for cancer.

The FARF/ SU2C partnership includes three additional nonprofit

organizations: the American Head and Neck Society, the Head and Neck Cancer Alliance, and the Farrah Fawcett Foundation. This collaboration formed a head and neck cancer research team with funding from each organization.

The selected research team is led by FA researcher, Dr. Agata Smorzewska from The Rockefeller University. Joining her are over a dozen other researchers, clinicians, and patient advocates, many of whom are familiar with FARF. This team includes other FA researchers including Dr. Barbara Burtness from Yale School of Medicine and Dr. Markus Grompe from Oregon Health and Science University, and other head and neck cancer experts.

The goals for this project include (1) providing a comprehensive understanding of the biology of FA-related tumors; (2) testing new therapeutic approaches to FA-related head and neck squamous cell carcinoma (HNSCC); (3) identifying effective chemoprevention treatments, and (4) assessing the toxicity of potential cancer therapeutics. The team theorizes that by having an improved understanding of FA cancers, they can identify tumor-specific vulnerabilities.

This project will provide a pathway for developing safer and more effective prevention and treatment strategies for HNSCC in the FA population.

Understanding Clonal Hematopoiesis in Fanconi Anemia to Improve Patient Surveillance Strategies

Grant Rowe, Boston Children's Hospital

Individuals with FA experience accelerated clonal hematopoiesis, with onset as soon as the first few years of life. This results in a very high risk of FA patients developing myelodysplastic syndrome (MDS) and acute myeloid leukemia (AML). This project aims to understand the consequences of mutations recurrently found in FA patient blood stem cells, with the long-term goal of informing surveillance approaches and the decision to use bone marrow transplantation.

Research events in 2021

Workshop on Fanconi-Associated Neurological Syndrome (FANS)

Fanconi Associated Neurological Syndrome (FANS) refers to a set of central nervous system abnormalities that affect some patients with FA. The causes of FANS are ill-defined, and limited treatment options exist for patients with FA who experience this condition. The FARF Sparks workshop on FANS was held in late October and provided an overview of the current clinical state of the field for FANS and an avenue for new collaborative research

focused on this topic. FARF staff is working to develop a chapter on current clinical guidelines on FANS to publish in the Fanconi Anemia Clinical Care Guidelines and is facilitating development of a FANS Clinical Board to review cases. In addition, FARF funded a grant to support FANS research in early 2022. Read about it under “New Grants Awarded in 2022.”

Workshop on FA Gene Editing

The FARF Sparks workshop on FA gene editing was held in early December. Its purpose was to outline the current state of the field for FA gene editing and develop the foundation for a collaborative Gene Editing Dream Team that will apply for grant funding from FARF. During the meeting, researchers from across the world presented on topics such as base editing strategies, correcting FA mutations using digital genome engineering, safety studies, and in vivo gene editing. Development of the Dream Team proposal is being led by Paula Río, PhD, a member of FARF’s Scientific Advisory Board.

Joel Walker Cancer Ideas Lab

The Joel Walker Cancer Ideas Lab was held over a five-day period in early November. During this event, 31 scientists brainstormed ideas on how to shift the paradigm for treating FA cancers, formed interdisciplinary research teams to create grant proposals, and pitched their ideas to a funding panel for the opportunity to win a \$500,000 grant award. The winning team consists of doctors Ken Weinberg, Daria Mochly-Rosen, Hiro Nakagawa, Frank Ondrey, and Craig Elmets. This team will develop pre-clinical models to better understand squamous cell carcinoma in individuals with FA. Read more about this grant under “New Grants Awarded in 2022”.

Scientific Symposium

In 2021, our virtual research symposium hosted an engaged group of over 500 FA scientists, clinicians, patients, and families from around the world over a four-week period in July. Topics covered during the meeting included gene therapy and gene editing, bone marrow failure, DNA repair, and cancer. The meeting was co-chaired by Juan Bueren and Paula Río from CIEMAT, Sharon Cantor from the University of Massachusetts Medical School, Peter Kurre from the Children’s Hospital of Philadelphia Research Institute, Agata Smogorzewska from the Rockefeller University, and Susanne Wells and Parinda Mehta from Cincinnati Children’s Hospital Medical Center. The FARF Symposium is a necessary catalyst for maintaining momentum in

FA research; it provides researchers and clinicians the opportunity to share progress on their work, generate new ideas, and form new collaborative research projects.

New Grants Awarded in 2022

Joel Walker Ideas Lab Research Team: Modeling the Role of Environmental Responses in Fanconi Anemia Epithelial Stem and Progenitor Cells in FA Squamous Cell Carcinoma

Institutions/Investigators: Stanford University, Columbia University, University of Minnesota, University of Alabama at Birmingham/ Kenneth Weinberg, Hiro Nakagawa, Frank Ondrey, Daria Mochly-Rosen, and Craig Elmets

This grant will develop models to better understand squamous cell carcinoma in individuals with Fanconi anemia using non-primate animal models and organoids created from FA patient cancer cells. Developing these models is significant because they will enable researchers to better understand the pathways that result in cancer and determine the best prevention and therapeutic strategies to eliminate FA cancers.

Fanconi Anemia Associated Neurological Syndrome – a Search for a Cause with Advanced Technologies

Institution/Investigators: University of California, San Francisco/ Prashanth Ramachandran and Michael Wilson

Fanconi Anemia Associated Neurological Syndrome (FANS) is a rare condition that affects a subset of people with Fanconi anemia. FANS results in brain lesions that can lead to weakness, seizures, and cognitive issues, but the cause is currently unknown. The aim of this grant is to examine the immune profiles of individuals with FA who have been diagnosed with FANS to find the underlying cause and an appropriate therapy to treat this condition.

Psychosocial Experiences of Adults with Fanconi Anemia: A Participatory Mixed-Methods Research Study

Institutions/Investigators: Oregon State University and University of Minnesota/Kathleen Bogart and Megan Voss

The aim of this grant is to partner with the Fanconi anemia community to design a quality-of-life study that considers the physical, mental, emotional, and spiritual needs of adults living with FA. The research team will administer a quantitative survey to 100 adults living with FA and conduct semi-structured follow-up interviews with 15 adults living with FA. Results from this grant will help FARF and clinicians around the world develop strategies to improve the mental health of those living with FA.

Ongoing Research Programs and Initiatives

Global Fanconi Anemia Brush Biopsy Program

The Global Fanconi Anemia Brush Biopsy (FABB) program is a grant funded by FARF to help detect and prevent oral cancer. Investigators in this study proved that oral brush biopsies are an effective and safe way to screen people with FA for head and neck cancer. Researchers have shown that people with FA who have a negative brush biopsy test result could be spared painful diagnostic incisional biopsies. Most impressively, the technique also detects a substantial number of early precursor lesions at a non-invasive stage, when surgical removal is highly successful in eliminating cancer.

FARF funded the brush biopsy study again in 2020 for an additional three years to expand the service in the United States and to other countries and to provide training for other physicians and laboratories that will analyze the brush biopsy samples. The group has produced several educational materials to this end and is currently developing an app to help patients perform self-examinations of their mouths.

In spring 2022, FARF will hold a FARF Sparks focus meeting with international partners to discuss implementation of the FABB program.

Fanconi Anemia Cancer Consortium

Founded in 2021, the Fanconi Anemia Cancer Consortium (FACC) consists of researchers from four research institutions: the University of British Columbia, the University of Düsseldorf, the National Institutes of Health (NIH), and the Rockefeller University. The goal of the consortium is to create collaborative and integrated projects that will focus on improving patient care for early detection, screening, and treatment for FA cancers. Institutions in the consortium submitted grant proposals to FARF

in 2022 to receive support for their respective projects. More information to come on these projects.

Fanconi Anemia Research Materials

The Fanconi Anemia Research Materials (FARM) repository is a collaboration between FARF and Oregon Health and Science University (OHSU) that stores FA antibodies, human and mouse FA fibroblasts, and cancer cells lines in a centralized repository on the OHSU campus. Scientists can request materials from the FARM for their research projects by completing forms on the OHSU website.

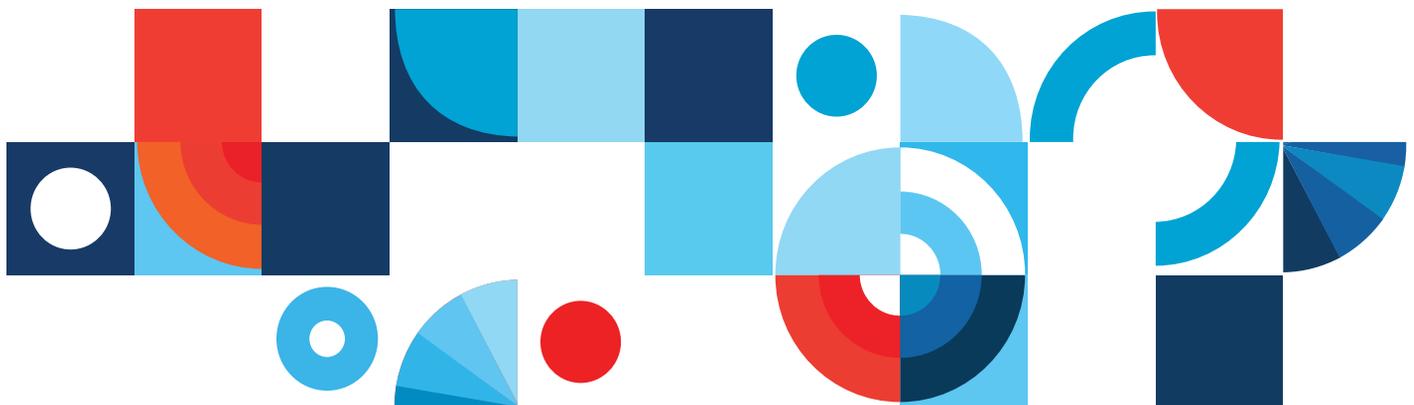
FA Patient Registry focused on FA Cancers

In 2019, FARF and the National Organization for Rare Diseases (NORD) launched a patient registry specifically on Fanconi anemia. The registry consists of patient-directed surveys that collect information about the disease progression and experiences of individuals living with FA. This free and voluntary service helps researchers direct studies that lead to better treatments for FA. We ask that every individual diagnosed with FA join the registry. You can do so online at <https://fanconiregistry.iamrare.org>.

Virtual Tumor Board

The FARF Virtual Tumor Board (VTB) is a panel of physicians from various oncology fields who have experience treating patients with FA. They volunteer to discuss complex FA solid tumor cases and offer treatment guidance.

The VTB was developed to provide support to individuals with FA and their treating physicians, who may have less experience with treating cancer in individuals with FA. The VTB meets virtually with patients' treating physician(s) to review cases and provide input for treatment from an FA-centric viewpoint. ■



International Support Grants



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. To strengthen the efforts of our partners in the international FA community, FARF has established the International FA Support Grant program.

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 2022 grant cycle is now open for submissions. The deadline to submit is May 6, 2022 at 5:00 pm Pacific.

2021 recipients

Group: The Nate Foundation

Country: Zimbabwe

Project: The Nate Foundation was founded by parents of two kids with FA in Zimbabwe. They recently received an FA support grant to address the lack of information about FA in their country and improve access to support and information for patients. First, they will create a support group for individuals with FA and their families. Next, they will prepare educational information and give seminars to medical institutions. Finally, they will partner with healthcare practitioners and local government to host an educational campaign to spread awareness about FA among the public and within the medical community.

Amount awarded: \$10,000

Group: Latin-American FA group (Un corazón por Fanconi Dominican Republic, Laboratorio de Citogenética INP México, Hospital Civil Nuevo Guadalajara México, Asociación Mexicana de Anemia Aplásica - AMAA, Instituto de Investigaciones Biomédicas UNAM)

Region: Latin America

Project: *Fanconi anemia Spanish-speaking Latin-American education project.* The mission of this collaborative group is to enhance FA community-building in Latin America to improve the diagnosis and treatment of patients with FA and advance their quality of life. Following a grant in 2019 to “Un Corazon por

Fanconi”, researchers, clinicians, individuals with FA and family members began to form connections and develop educational materials for Spanish-speakers. This new grant will continue to build those efforts: (1) strengthen the communication platform available to Spanish-speakers in the FA community; (2) develop educational materials specifically for the Latin American FA population; and (3) connect patients and family members to FA researcher and doctors through virtual meetings and conferences.

Amount awarded: \$10,000

Group: Nicolaus Copernicus University in Torun, Ludwik Rydygier Collegium Medicum in Bydgoszcz

Country: Poland

Project: *The first meeting of patients with FA in Poland.* The two aims of this project are (1) to organize the first meeting of patients with FA and their families and (2) to provide education and support services to families with FA in Poland. Researchers and clinicians at this institution in Poland have been seeing FA patients for years and will use this grant to gather all patients together so they may connect, share, and learn from experts. In addition, they will use this meeting as an opportunity to begin developing an FA support group in Poland and to create The Polish FA Patient Registry.

Amount awarded: \$10,000 ■

Scientist Spotlight

Name: **Alfredo Rodríguez, PhD**

Institution: **Biomedical Research Institute, National Autonomous University of Mexico (UNAM)/ National Institute of Pediatrics (INP), Mexico**

Area of expertise: **Biology of the hematopoietic stem cells, cytogenetics**



My work:

I am a biologist born and raised in Mexico. I was trained by Dr. Sara Frias at INP/UNAM and by Dr. Alan D'Andrea at Dana-Farber Cancer Institute/Harvard Medical School. I have studied Fanconi anemia (FA) for the past 13 years from several perspectives. Additionally, I have performed diagnosis and used computational modeling to understand the behavior of FA cells. During my postdoctoral training I explored the potential of TGF β pathway inhibitors to improve Fanconi anemia's bone marrow failure and used single-cell resolution technologies to study hematopoietic stem cells from patients with FA.

Recently I became a principal investigator at UNAM, the leading University of Mexico. I maintain a strong interest in studying FA using new technologies, including single cell DNA sequencing, single cell proteomics and single cell imaging. My research group is also enthusiastically performing computational and mathematical modeling of FA cells in the face of DNA damage. This is important because in FA, excessive apoptosis (programmed cell death) can lead to tissue atrophy, and cells with unrepaired DNA damage can lead to cancer.

In addition, with my colleagues from Mexico and Ana Tabar, an adult with FA from the Dominican Republic, we started a series of patient-oriented talks delivered in Spanish and directed to Latin-American patients with FA to provide information about the disease, how it is treated, and what follow-up is needed.

What motivates me to work on FA:

Through studying FA both in Mexico and in the USA, I have met so many new people and made new friends. Some of these new friends have Fanconi anemia. Although I am still a young scientist, my academic contributions to the FA field allowed me to competitively apply for a position at the University of Mexico and start my own laboratory. Therefore, I feel in debt to patients with FA and want to give back to them focusing my energy and expertise to learn more about the threats that they face daily, and potentially contribute to finding treatments and a cure for this disease.

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

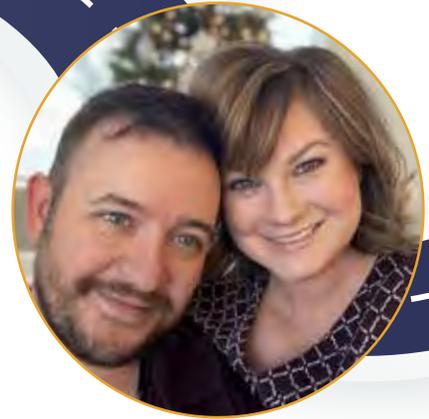
I love visiting my hometown where my mother and most of my siblings live. I enjoy lap swimming, spending time with my friends and traveling with my partner across Mexico.

Anything else you want FA families to know?

Engaging with the FA community has given me a new perspective on how I understand science and how knowledge is generated. Now I feel that when we study FA, we become more empathic. We understand that FA is not just samples or cells; it's people, it's friends, it's Family. ■



Alfredo with Anne and Jason, two adults living with FA who worked in Alan D'Andrea's lab



Our unwavering pursuit and the long road

By Katherine DiCamillo

Hello, FAmily! We are Katherine and Tony DiCamillo. I am the proud mother of four boys, one of whom is diagnosed with Fanconi anemia (FA). Our road to discovering Levi was a boy with FA felt so long and winding. Each time we pursued medical answers, we felt hopeful. Then, each appointment or test typically ended with fear or more questions.

During my pregnancy with Levi, we chose prenatal genetic testing, and got the call that our baby may have a genetic disorder called Edwards Syndrome. We were devastated. Most babies with Edwards don't survive past birth. We were naive enough to never expect a child with any diagnosis and to take this initial scare as gospel.

Because of this, Levi's pregnancy was labeled high risk. While Edwards was soon ruled out, the consensus was the same: something is wrong, we just don't know what. We can't even count how many

doctors told us that. Levi experienced intrauterine growth restriction, so he was monitored closely several times a week. Eventually, at 37 weeks, he stopped growing and labor was induced. Levi was strong, healthy, and very engaged with the world around him. He was also tiny, at 5 lbs 4 oz. I had never held a baby so small! He never spent any time in the newborn intensive care unit, and was treated for jaundice at home. We were so happy to go home and proceed with a normal life.

Slowly, as Levi grew, we noticed he was different than our other boys. It was tricky to tell if his sounds were happy or sad, he never slept very long, and his affect was somewhat flat. Our pediatrician recommended we engage with an early intervention program through our county, and Levi was soon receiving weekly speech, feeding, and occupational therapy. These supports were vital in discovering a tongue tie and they taught us about Levi's sensory

processing disorder. He continued to be small, labeled "failure to thrive."

When we introduced foods to Levi, we began a painful journey with the gastrointestinal (GI) department at our local children's hospital for his severe constipation. Every test came back normal. I remember clear as day, sitting with the GI doctor with my older boys and Levi. Pointedly, she said: "Are these all your children? Levi looks nothing like his brothers. He has a genetic disorder. See his eyes? He has epicanthal folds." I felt defensive and crushed. I thought we made it through all of that already.

From there we were referred to genetics and endocrinology. Our list of specialists kept growing, and Levi's medical world felt like a part-time job. We worried we were chasing a ghost but decided to go with our guts-- we needed to find answers. As we were given Levi's symptoms, like a typical American adult, I searched the internet for everything I could think of



to answers

to help the doctors put these odd puzzle pieces together.

After two years of testing, on a whim we checked a small box on a form that screens for a BRCA2 mutation. We checked this box because several months earlier, Tony's mother was diagnosed with cancer due to a BRCA2 mutation and Tony knew he had that mutation as well. When the testing came back, the genetic team called us to let us know that most likely Levi had Fanconi anemia, and that I also had the BRCA2 mutation.

Because we had never heard of FA, we didn't know how to feel about it. Our Colorado hematology team did a great job educating us, but some doctors have never heard of FA. I remember explaining to a doctor what FA was and why we were sitting in his office - it was so disconcerting. He had never heard of FA. Once we were connected with FA specialists via the Fanconi Anemia Research Fund, we felt such a deep

release from worry, knowing it wasn't our job anymore to educate the doctor.

The year of Levi's diagnosis, we would meet with a medical expert and feel absolutely flooded. We would take the time to process our feelings and the new data, only to have the next appointment and be flooded again. Needless to say, our threshold shifted, and we found out quickly that to stay healthy as parents, we needed to be proactive in our emotional, spiritual and physical health.

We had so much feedback from family and friends during this whole journey. Some said: "you both are small people! Of course, Levi is labeled 'failure to thrive!'" Some said: "he looks happy and fine, so why keep testing him?" Some said: "Go with your gut."

This is what we tell parents now, too. You go with your gut, and don't stop pursuing answers until you feel release from it. Today we are preparing to move our family temporarily to Minnesota for Levi's second prophylactic bone marrow transplant. We received his diagnosis just in time. We are surrounded by a community and have a deep faith in Jesus. Levi's road to diagnosis was winding and confusing, but we know so many moments were orchestrated by heaven for Levi's good. With hope in our hearts, we take another step with our giggly boy, so that ideally, he never knows what it's like to have a blood cancer! ■

“ You go with your gut, and don't stop pursuing answers until you feel release from it. ”

I am a fighter and a cancer survivor

By Michelle Watkins



Michelle with her husband Jeff and son Ryan

Hi, my name is Michelle and I'm from a small town outside of Pittsburgh, Penn. Like a lot of teenagers, I had big dreams and goals for what I was going to do with my life. I knew early on that I wanted a career, to get married, and have two children. I grew up with the assumption that I would grow old with my husband and have grandchildren. I also assumed that any major medical issues that we might have would develop when we were much older. Cancer is very prevalent in my family, but all my relatives developed their cancers in their seventies and eighties. I never imagined I would get cancer in my thirties.

The start of the fight for my life

In the fall of 2010, I felt a lump on the right side of my breast. After speaking with my physician, I had a mammogram and an ultrasound. Following a recommendation from the radiologist, I then had a biopsy. Two days before Christmas, I received the news that I had triple negative breast cancer. In that moment, my life turned upside down. I remember wondering how this could be possible when I was only 32 years old with a five-year-old son just starting kindergarten. Little did I know this was only the beginning of the fight for my life.

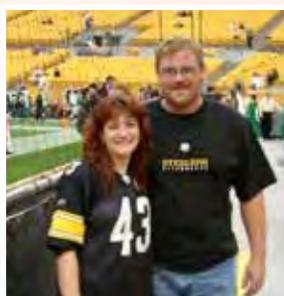
A few weeks later, I experienced the traditional breast cancer regime which included a PET scan, insertion of a port (a device

surgically implanted under the skin to deliver chemotherapy directly into the vein), and consultations with a breast cancer specialist and a breast surgeon. After many consultations and tests, the plan was to treat this cancer with aggressive chemotherapy and surgery followed by radiation.

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

Diagnosed with Fanconi anemia

After eight long weeks of waiting, I finally learned that I was now part of a rare disease population of special individuals living with Fanconi anemia. Once my doctors learned more about FA and that I would need specialized treatment for the breast cancer, they decided to consult with doctors at the Dana-Farber Cancer Institute and the University of Pittsburgh. Over the next nine months, I received a modified chemotherapy and a reduced



“ I cannot change the fact that I have Fanconi anemia and that I’m prone to cancers. Instead, I can fight, and I can share my story with doctors and researchers to help them find a cure someday. ”

radiation regimen. Despite the odds, I survived. My story is a road map for breast cancer survivors with FA and is even written about in a medical journal.

Following my treatments, I started receiving a PET scan every six months, an MRI and mammogram once a year, a blood count check every other month, and annual checkups with the dermatologist. In addition, I saw an FA head and neck specialist who used a scope to look for any lesions or potential cancer spots in my mouth due to the high risk of head and neck cancers in individuals with FA.

The battle with cancer continued

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

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

for the rest of my life.

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

How I stay strong

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





Eli Lana, teen living with FA

Navigating Depression and FA Through the Teen Years

By Mary Ann Lana

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

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

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

Noticing the changes

During those final two years of hosting the 5K for FA when Eli was 13-14 years old, our family had also suffered several losses, one after another, and we could not catch our collective breath. Eli

suffered especially. In 2019 after our last event, he was wrapping up 8th grade and preparing to start high school. He had become sullen, was engaging in risky behaviors, and withdrawing from those he loved. We sought treatment for him, and admittedly we were discouraged to find that the progress was slow. We wanted so badly to help him. By the second semester of his freshman year of high school, we were in Covid lockdown. The combination of remote learning and isolation from friends kept Eli from the human connection and day-to-day interaction he so desperately needed. He sank lower.

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

Seeking professional support

Over time, with behavioral counseling and support from our family and close friends, things improved. We learned how to talk about depression and to explore how it affects our lives, and we are still learning. We found a pediatric

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

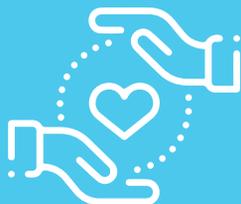
I am realizing now that parenting Eli is parenting a young man with two diagnoses that can be life-threatening. There is the Fanconi anemia that looms on the horizon and threatens cancer, and there is the depression that tricks him into thinking he has nothing to live for. I will admit, I was not prepared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

So perhaps if you are reading this as an FA parent with a soon-to-be teenager, you might not feel prepared either. And of course, your situation will be different. But in any case, I offer you this: If and when you get here, you are not alone.

To those walking alongside us, with FA teens who are struggling now: this is so unbelievably hard, isn't it? You're not alone either.

To those up ahead who helped teens who struggled to become well-adjusted adults, or perhaps you're one of those FA adults yourself: your wisdom is more valuable than you know. Please pass it on. ■

FARF Expands Resources and Programs for Caregivers



FARF provides education and support to caregivers through a variety of programs and services. We hope that through these programs, you as a caregiver feel seen, heard, and supported.

Thank you to Allison Breininger at The Negative Space, an FA caregiver herself, for helping to design and implement these programs. The Negative Space is an organization that shines light on the realities of caregiving, provides direct services to caregivers, and educates and equips those who support them with concrete tools and strategies.

“ We realize that so many of the services, support, and appointments you spend your days on are aimed at the needs of your loved one. But we also see that you, dear caregiver, are living through and with the effects of this disease as well. This space is for you. ”

– Allison Breininger, FA caregiver & founder of The Negative Space

I'm Part of the Story

We are excited to continue partnering with **The Negative Space** in 2022 to celebrate and recognize your integral role in the Fanconi anemia (FA) experience. You are part of the FA story, but you also have your own story. We hope that the items in this box remind you that YOUR story matters.

To notify FARF that a primary caregiver is currently supporting a loved one through a major medical event and could benefit from receiving a caregiver gift box, please contact Family Services Program Manager, **Rosie Holcomb** at rosie@fanconi.org.

Coaching for Caregivers

At FARF, we see and honor caregivers and all that they do each day for the person in their life living with FA. We recognize that this role is hard and can feel lonely and overwhelming. Our partner, Allison Breininger, offers one-on-one peer coaching to caregivers who are looking for someone who has been in their shoes, and that can provide a safe place to talk along with practical support. FARF is pleased to offer a limited number of scholarships for FA caregivers interested in receiving coaching but for whom cost is prohibitive. Contact Allison for more information allison@thenegativespace.life.

Anticipatory Grief Resources

We often think of grief as something that only happens after a death, but it can also be felt in *anticipation* of a death or other kind of loss. In this community, grief begins at the time of diagnosis (or as soon as the *possibility* of death occurs in one's mind), and it does not have a destination. It's natural to grieve the future you thought you'd have with your loved one, the inevitable medical crises on the horizon, the physical and emotional pain that your loved one will endure, future financial strains, relationships that may suffer, as well as all future secondary losses that accompany a diagnosis like Fanconi anemia. This feeling of grief *before* impending loss is called anticipatory grief. Anticipatory grief includes a wide range of emotions, with grief responses that fall on a very broad spectrum; there really is no right or wrong way to grieve.

Have you experienced anticipatory grief? You're not alone. Many, if not all, in the FA community share this experience.

That's why two members of our caregiving community, Allison Breininger and Rachel Altmann, have put together a list of resources for those experiencing anticipatory grief or grief from the loss of a loved one. No one should have to face grief alone. Visit this link to view the resources: <https://bit.ly/3IrtujK>.

If you are experiencing grief and would like help navigating resources, or to be connected to others in our community who have walked in your shoes, feel free to reach out to our family services team at 541-687-4658 x 301. We are here for you.

Ianacare App

Do you ever wish for an easy way to keep people updated or to ask for help when you need it? Do you want a way to connect with other caregivers? **ianacare** might be the perfect solution for you. IANA stands for I Am Not Alone. Their mission is to encourage, empower, and equip family caregivers with practical tools and supportive communities, so no caregiver does this alone. They have a free app, a podcast, and webinars as ways to support caregivers and provide practical resources. To learn more about how this app works, visit ianacare.com.

FARF Staff Support

FARF Family Services staff are available for one-on-one support as needed or desired. While we do not offer traditional counseling or case management services, we do offer support by assisting with information gathering, referrals to FA specialists and community partners, directing folks to helpful resources, providing education, establishing connection among peers, and by providing a listening and empathetic ear.

Please know our Family Services team is here to support you. You can reach the Director, Jordan Deines at Jordan@fanconi.org and the Program Manager, Rosie Holcomb at Rosie@fanconi.org.



Fanconi Anemia Fact Sheet

WHAT IS FANCONI ANEMIA?

Fanconi anemia (FA) is an inherited DNA repair disorder that may lead to bone marrow failure, leukemia, and/or solid tumors. FA can affect all systems of the body. The types and severity of symptoms can differ widely from person to person. Many people with FA undergo hematopoietic stem cell transplants to treat bone marrow failure, precancerous blood cell changes, and leukemia.

Due to the underlying DNA repair problem, people with FA are at a much higher risk of developing a variety of cancers and at a much earlier age than patients in the general population. Those who have had a successful stem cell transplant, and are therefore cured of the blood problem associated with FA, still must have regular examinations to watch for signs of cancer.

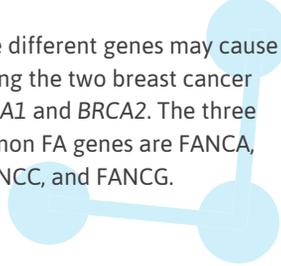
Research has resulted in better outcomes and longer lives for those with FA. There is now a growing population of adults living with FA.

WHAT CAUSES FA?

FA is a very rare genetic disorder. FA is primarily a recessive disorder: if both parents carry a defect (mutation) in the same FA gene, each of their children has a 25% chance of inheriting the defective gene from both parents. When this happens, the child will have FA.

HOW MANY FA GENES ARE THERE?

Twenty-three different genes may cause FA, including the two breast cancer genes, *BRCA1* and *BRCA2*. The three most common FA genes are *FANCA*, *FANCC*, and *FANCG*.



WHO CAN HAVE FA?

FA occurs almost equally in males and females and is found in all ethnic groups. The incidence rate, or the likelihood of a child being born with FA, is about 1 in 131,000 in the U.S., with approximately 31 babies born with FA each year in the U.S.

WHAT ARE THE SYMPTOMS OF FA?

Individuals may experience one or several of these symptoms:

- Abnormal blood cell counts
- Birth defects affecting thumbs, forearms, and other parts of the skeleton
- Bone marrow failure and/or leukemia
- Certain types of cancers (especially head and neck and gynecologic cancers)
- Kidney, urinary tract, and heart malformations
- Digestive difficulties
- Hearing loss
- Intellectual developmental delay

HOW IS FA TREATED?

At the present time, stem cell transplantation is the only long-term cure for the blood defects in FA. To prepare for transplant, the patient's own bone marrow is destroyed, making space for the new, healthy stem cells to engraft.

Even if the patient has had a successful stem cell transplant, they must still watch for signs of cancer, especially in the head and neck and anogenital regions. Early detection is key. Surgery remains the best course of treatment for those who develop cancers. Surgery may also be used to address other symptoms of FA, like missing thumbs.

THE FANCONI ANEMIA RESEARCH FUND IS HERE FOR YOU

RESEARCH

Our research focuses on cancer, bone marrow failure, FA genes and the DNA repair pathway, and other body systems affected by FA

SUPPORT

We provide 1:1 guidance to people with FA, caregivers and families. We help provide resources needed to manage FA and emotional support for those who want it.

EDUCATION

FA is a complex disease, which is why we create materials to help understand each stage, like our FA Clinical Care Guidelines and topic-specific flyers and brochures.

COMMUNITY

We hold live and virtual events for people with FA and their families to learn, connect, meet with experts, and participate in research opportunities.



Introducing POSTMARKED with love

A New Community Care Program

Postmarked with Love is an opportunity for volunteers anywhere to provide individuals with Fanconi Anemia (FA), caregivers, those grieving, and others affected by FA with words of hope, comfort, and love through handwritten notes as they are going through especially difficult times.

Anyone can participate! This is an opportunity for people from all backgrounds and walks of life to participate in sharing love with those impacted by Fanconi anemia. We welcome anyone from within the FA community and those who had never heard of FA before now, to participate in spreading the love.

There are two ways to get involved in spreading the love:

1. Nominate folks for the Postmark recipient list.
2. Make cards or notes for those on the list.

supplies to make cards during this time, or just bring a pen and paper to take notes. Feel free to invite your friends and family to register as well. The more, the merrier! Upcoming orientations are listed on our website.

Step Three: Make cards and/or write notes

Maybe even consider hosting a virtual or in-person card making party with your friends and family! Not crafty? No problem! All you need is a pen, piece of paper, envelope, and a stamp to participate. A simple and heartfelt note on a piece of paper means the world to the person receiving it. Refer to the Postmark recipient list in your email to address your cards to specific individuals. If you prefer, you may also send us general cards that may be sent to anyone on the recipient list.

Sometimes it can be difficult to know what to say to someone who is going through a challenging time for fear of



Nominate someone to receive cards:

If you know anyone impacted by FA who could use a little extra love and support as they navigate a difficult time, make sure to nominate them for the Postmark recipient list. They will receive a surprise envelope filled with handwritten cards and notes from volunteers who want to spread the love. No identifying information about the recipient will be shared with volunteers. You can nominate someone by visiting Fanconi.org or emailing rosie@fanconi.org.



Become a Postmarked with Love volunteer:

Step One: Sign up to volunteer

Once signed up to volunteer, you will automatically be added to our volunteer email list. You will receive quarterly emails that will direct you to the Postmark recipient list - those who will receive cards that quarter. You must sign up as a volunteer to access the list of recipients. These emails will also contain registration links for upcoming volunteer orientations.

Step Two: Register for a volunteer orientation

These quarterly, thirty-minute sessions are both informational and informal. You may come prepared with your crafting



saying the wrong thing. That's why we created a guide with some suggestions of what to say and what not to say.

There are a few things to keep in mind when making cards:

- Please no medical advice or treatment suggestions
- Keep notes supportive of all as recipients come from all different backgrounds and are diverse in their genders, ethnicities, and beliefs.
- Be you! It's okay to include inspiring quotes, silly jokes, or little details about yourself (nothing too personal).
- Some people are religious, some are not. Please avoid religious comments, as they may be inappropriate for those with a different belief system.

We have provided an idea list of what to say and not say at [Fanconi.org](https://www.fanconi.org).



Fanconi Anemia Research Fund
C/O Postmarked with Love
360 E. 10th, Suite 201
Eugene, OR 97401

Send cards without individual envelopes or in unsealed individual envelopes, within a packet containing all the cards.

If you make a card for a specific individual, please indicate the individual's number on a separate note for FARF staff. For more information, visit www.fanconi.org/explore/postmarked-with-love or email rosie@fanconi.org ■

New updates + features added to the FARF website



Updated navigation makes it easier to find what you need

We recently reorganized the navigation of the FARF website, making it easier for you to find the information or support you need. The section for individuals, caregivers and families is organized into three parts: disease information, support resources, and education resources. Each section features several links to relevant information. If you ever need help finding information or resources, please don't hesitate to let us know: info@fanconi.org. This website is a resource for the FA community, so we're always making improvements and we welcome your feedback.



New resource library features a catalogue of info sheets and videos

We are excited to announce a brand-new tool to the website: the FARF Resource Library. Each time we create a new infographic, fact sheet, or video, it is uploaded to the library. Every recording from the FA Connect educational sessions is also found here. The library is organized into eight main categories, is searchable, and features an extensive list of "tags" so you can find exactly what you're looking for. These resources are made for individuals with FA, caregivers, family members, and other people in your community. If you have an idea for a resource, or would like to suggest new topics to be featured, let us know at info@fanconi.org. ■

2022 Event Calendar

Events have long been a cornerstone for connection and learning for the Fanconi anemia community. Getting together is of huge value to all of us. Whether it's adults with FA, families and caregivers, researchers and clinicians, or donors – coming together in support of a shared mission is what makes us so connected and strong. We are hopeful we can provide in-person events again this year.

FARF will continue to host the virtual FA Connect support and education sessions. We received such great feedback from those who attended these events that FARF decided to continue providing them in 2022.

The FA Connect Series is a combination of stand-alone virtual events for individuals with FA, families, and caregivers to learn and receive support from those in the FA community.

What types of events are hosted?

- Educational Sessions (60-minute Q&A sessions with expert clinicians or researchers)
- Support Groups (90-minute psychosocial groups)

FA Connect events are free and hosted through Zoom. Educational sessions are recorded and posted online in case you cannot attend at that specific time. Live Spanish interpretation is also available during all FA Connect educational sessions. Note: Support sessions are not recorded or reshared.

Where can I find the event schedule?

All upcoming events have been posted on the FARF website's event calendar for easy browsing and sign-up (www.fanconi.org/calendar). Interested attendees will be able to sign-up ahead of time to prompt a calendar reminder or can easily log in on the meeting date by clicking the zoom link.

May 19 **FA Connect Q&A**
Eltrombopag Clinical Trial Update
 May 19 at 1:00 pm PT
 Dr. Andre Larochelle, National Institutes of Health (NIH)

May 21 **FA Connect Support**
Bereavement Support for FA Parents, Caregivers & Siblings
 May 21 at 10:00 am PT
 Rachel Altmann, FARF Board Member; FA Parent

June 18 **FA Connect Support**
Caregiver Support Session—You are not alone: Support Group for Caregivers
 June 18 at 10:00 am PT
 Allison Breining, FA Caregiver

July 16 **FA Connect Support**
Bereavement Support for FA Parents, Caregivers & Siblings
 July 16 at 10:00 am PT
 Rachel Altmann, FARF Board Member; FA Parent

August 20 **FA Connect Support**
Newly Diagnosed Families & Support within the FA Community
 August 20 at 10:00 am PT
 Nancy Cincotta, Psychosocial Director at Camp Sunshine

September 8-11 **Scientific Symposium & Retreat for Adults with FA**
 September 8-11
 JW Marriot Austin | Austin, Texas



September 17 **FA Connect Support**
Bereavement Support for FA Parents, Caregivers & Siblings
 September 17 at 10:00 am PT
 Rachel Altmann, FARF Board Member; FA Parent

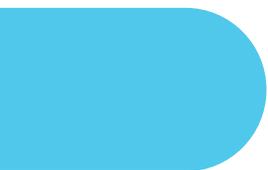
October 15 **FA Connect Support**
Caregiver Support Session- Topic TBD
 October 15 at 10:00 am PT
 Allison Breining, FA Caregiver

November 19 **FA Connect Support**
Bereavement Support for FA Parents, Caregivers & Siblings
 November 19 at 10:00 am PT
 Rachel Altmann, FARF Board Member; FA Parent

December 17 **FA Connect Support**
The Sibling Experience
 December 17 at 10:00 am PT
 Nancy Cincotta, Psychosocial Director at Camp Sunshine at Sebago Lake

For an update on the Family Retreat at Camp Sunshine, see page 29.

Our Commitment to Diversity, Equity and Inclusion



In late 2020, the Fanconi Anemia Research Fund (FARF) conducted a needs assessment with a variety of stakeholders in the community. The purpose of this assessment was to understand the gaps in our services and organization as it concerns diversity, equity, and inclusion (DEI). After dozens of interviews, the findings revealed that there are opportunities at FARF to address gaps in access to services, increase representation of the diverse community affected by Fanconi anemia (FA) and cultivate safer and more inclusive spaces for all community members to be seen, heard, and valued.

In 2021, we engaged with a consulting firm specialized in DEI. A group of about 25 FA community members participated in a series of workshops to further understand and improve access, representation, and equity. Two of the key outcomes from this process were (1) to develop an organizational policy addressing DEI and (2) to outline concrete plans to advance DEI efforts.

Below you will find the approved policy as well as our plans to advance DEI in 2022 and beyond. Updates to this document will be recorded on our website <https://www.fanconi.org/explore/diversity-equity-and-inclusion>.

Organization policy and plan

As a global nonprofit organization dedicated to finding better treatments and a cure for Fanconi anemia (FA) and providing education and support services to all affected by FA, the Fanconi Anemia Research Fund (FARF) is dedicated to building a more equitable and inclusive space for every person in the FA community. Our organization works with and serves a diverse population, including individuals affected by FA, caregivers, family members, researchers, clinicians, fundraisers, donors, staff, and volunteers. In addition, FARF interfaces with other organizations in the research, cancer, rare disease, and patient advocacy spaces.

We recognize the history of oppression in our institutions and society – including healthcare and research – that results in ongoing disparities for many. While we recognize the limitations of a small, rare disease nonprofit in resolving these large systemic issues, we embrace the opportunity to create positive change within our organization and the FA community. We believe that organizations of any size that engage diverse perspectives and evolve to be more inclusive and equitable will have a positive effect on society.

For those reasons, FARF is committed to improving our organization by acknowledging our biases and operationalizing our values.



We commit to building and nurturing a diverse, inclusive, and equitable environment in which every person in the FA community feels respected and valued regardless of race, gender, age, ethnicity, national origin, sexual orientation, ableness, or religious identity.

We commit to being nondiscriminatory and providing equal opportunities for employment, volunteering, and advancement in all areas of our work.

We commit to recognizing and addressing inequities in our policies, programs, and services.

We commit to updating and documenting our progress on diversity, equity, and inclusion practices.

The Fanconi Anemia Research Fund agrees to implement the following action items to promote diversity, equity and inclusion in our work:

Organizational

- Create a DEI committee comprised of staff and board members
- Develop policy to reflect an organizational commitment to diversity, equity, inclusion
- Recruit leadership (boards and committees) that represent previously underrepresented groups
- Incentivize professional development for staff members that addresses DEI (ex. learning Spanish, attending trainings); build into employee review process
- Update staff job descriptions and requirements to reflect DEI policy

Mission programs

- Continue to translate educational materials into Spanish, including Spanish subtitles on videos
- Update and simplify the Family Services enrollment form to include more accurate and inclusive demographic information
- Create Family Advisory Committee to ensure programming is accessible and meets the needs of the community
- Launch the Postmarked with Love program to reach folks who are not very connected to FARF, to allow all stakeholders to

- participate, and to increase awareness of FA
- Encourage community members to ask state leadership to declare May FA awareness month
- Expand caregiver support packages to international caregivers
- Develop Global Resource Map of FA expertise on the FARF website
- Support and direct early detection brush biopsy project expansion
- Develop Fanconi Anemia Cancer Consortium North America in 2022 with intent to grow internationally in subsequent years
- Inform and steward graduate students, postdoctoral scholars, and new investigators to become more involved in the FA research community
- Continue to fund international research grants
- Support global initiatives via the International FA Support Grant Program

Events and communications

- Add virtual component to in-person events (via video streaming or recordings)
- Offer Spanish-speaking interpreters at virtual events and at in-person events when possible
- Simplify travel scholarship applications and remove identifying information from applications for blind review by scholarship committee to ensure equity
- Translate scholarship materials into Spanish
- Market scholarship opportunities more broadly
- Create and share more visual content such as video and infographics
- Increase social media engagement and reach by using targeted ads
- Expand communications to audiences with specific situations, starting with international patients/families and bereaved families
- Increase storytelling from varied audiences (ex. siblings, grandparents, chosen family)
- Include an option for self-identified pronouns in all event registrations
- Use non-gendered pronouns in FARF communications where appropriate
- Partner with international FA organizations to publish materials in other languages and through the cultural lens in that country

Approved by the FARF Board of Directors on February 24, 2022. ■

FAMILY FUNDRAISING SHOUTOUTS



Lucy Offers Ice Pops

Seven-year-old Lucy hosted her own fundraiser by selling ice pops to support FARF. Lucy, who lives with FA, made 25 ice pops and raised over \$500 in one afternoon! Thank you for helping other kids like you and hosting a creative at-home fundraiser, Lucy!



Play for FA Cyclists Hit the Pavement

This year, the McQueen Family was determined to continue fundraising despite the pandemic, so they hit the pavement for their Play for FA Century ride. As the McQueens stated, "Just because we have to pivot our fundraising, FA does not stop, and neither will we." They asked their supportive community to sponsor Kevin and roughly ten other cyclists who participated in a 100-mile bike ride to raise funds for FARF. Thanks to generous donors, the McQueens raised \$60,000 to make a difference in the lives of individuals with FA! Thank you, Kevin, Lorraine, and sponsors, for your generosity and determination!



Giving Tuesday Reaches Major Milestone

This December, donors from around the world came together to accomplish an amazing feat: our biggest Giving Tuesday yet! More than \$100,000 was raised for FA research and families in a single day. Two generous donors agreed to match the first \$75,000 raised, dollar-for-dollar, doubling the gifts made. Thank you to everyone who gave, raised funds, shared their story, and rallied to make this happen. We are so grateful!



Community Honors Beloved Member's Passion

Jacob Grossman loved connecting with people, swimming and 80s music. When he passed away from complications of FA in late 2020, many of his friends and community members looked for ways to honor him. In October, the Vernon Township of Illinois named the community aquatic center after Jacob Grossman, a beloved member of the Buffalo Grove community. The new name honors Jacob, a Stevenson High School graduate, who never let health challenges keep him from enjoying his love of swimming. At the unveiling, his family raised over \$5,700 for FA research and support services. Thank you for giving back to the FA community while honoring Jacob in this special way, Grossman family and friends.



Team Bravery Celebrates 50 Years with 50K

This year is a big milestone for Team Bravery and for team leader and FARF board president Orion Marx's, who is celebrating his 50th birthday. The team is determined to celebrate year-round by raising funds to support the FA community. How did Team Bravery kick off leader Orion's 50th birthday? They took on another epic challenge for the Fanconi Anemia Research Fund, of course! Huge congratulations to the team on completing the Cabin Fever 50K at New River Gorge National Park, WV. They're on the way to their goal of raising \$200,000 this year! Thank you, Team Bravery, for always looking for the next adventure!



Holiday Appeals

Every holiday season, families reach out to their loved ones to share their story, raise support for our community, and help fund grants and support programs. This past season, nearly 30 families sent out fundraising letters and emails to their family and friends around the world. Over half of FARF's income is raised in November and December, all due to dedicated families and community members. In 2021, more than \$260,000 was raised on the #SeasonOfPromise campaign page alone! Thank you for all you do and for creating a wonderful holiday season here at FARF!



Adult with FA Launches New Career and Gives Back

Ivan Ravelo, who lives with FA, recently began a career in real estate and sold his first property! As a member of the FA community, Ivan generously chose to donate a portion of his proceeds to FARF. He made his \$500 donation in memory of his dear friend Jacob Grossman, who passed away from complications of FA. Thank you so much for your kind gift, Ivan, and best of luck in your new career!



Facebook Fundraising Celebrates Birthdays and Goes #SeanStrong

Every year we have generous and thoughtful community members who host Facebook birthday fundraisers in support of FARF. This December, one of these fundraisers was in honor of Sean McQueen's 23rd birthday. The community was encouraged to remind themselves of how grateful they are for their body for at least 23 minutes on Sean's birthday. Whether that was to go on a run, hike, meditate, or even look in the mirror and tell yourself how amazing your body is for allowing it to do the things you can do, we thought this was a perfect way to celebrate Sean. By the end of the fundraiser, more than \$50,000 was raised! Thank you for thinking of the FA community on your special day! ■

FAMILY FUNDRAISING LIST

From January through December 2021, FA families have raised more than \$2,700,000 for the Fanconi Anemia Research Fund! More than 220 families raised funds with community events and appeals, a big increase compared to 2020. Each dollar donated advances research and family support, making a difference for all those affected by FA and their families. Sincere thanks to every family and individual who worked so hard to raise funds in honor or memory of loved ones.

\$1,400,000+

Lynn Frohnmayr

\$175,000+

Orion and Lisa Marx

\$125,000+

The Kendall and Taylor Atkinson Foundation with the Nash and Griggs Families

Kevin and Lorraine McQueen

\$25,000 - 49,999

John and Kim Connelly

Rachel and Zachary Gratz-Lazarus

Alan and Rachel Grossman

John and Martina Hartmann

Todd and Kristin Levine

Mark and Diane Pearl

Rose and David Pennell

Gerard and Cynthia Vandermeys

\$15,000 - 24,999

Ryan and Rebecca Brinkmann

Mauro and Kerrie Cazzari

David and Mary Ann Fiaschetti

Ian and Tricia Mitchell

Peggy Padden

Nigel and Ann Walker

\$10,000 - 14,999

Brian and Carly Adel

Tyler Morrison and Rachel Altmann

Edward and Janice Duffy

Gary and Heidi Grassi

Charles and Kathleen Hull

Brian Horrigan and Amy Levine

Andrea and Robert Sacks

Michael and Beth Vangel

\$5,000-9,999

James and Jennifer Armentrout

Adam and Marissa Becker

Andre Hessels and Rutger

Boerema

Sean and Allison Breininger

David and Kim Chew

Joseph and Nancy Chou

Brittney Ferrin

Rachael Alaniz and Kevin Gatzlaff

Andrew and Jennifer Gough

Timothy and Mary Ann Lana

Sheila Meehan

David and Stacy Ownby

Peter and Janice Pless

Paul and Rena Rice

Neil and Emily Robison

Joe and Wendy Vitiritto

Jessica and Jonathan Young

\$2,000-4,999

Michael and Jennifer Aggabao

David and Sarah Borden

Scott and Windy Farmer

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Barbara and Chris Hawkshaw

Helen and Sean Healey

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Keith and Jessica Loo

William and Jacquelyn Lucarell

Kristina Mack

Kory and Julie MacMurray

Daniel and Angie McMahon

Mark Ritchie and Lisa Mingo

Caroline Nguyen

Ronald and Fredi Norris

Nancy Nunes

Chris and Mel Payne

Shelby and Kayla Richardson

Kevin and Katherine Rogers

Ron and Alice Schaefer

Kelly Semkiw

Joseph and Natalie Vitrano

Jessica and Ezekiel Werden

Mary Eilleen Cleary and Gleave Whitney

\$1,000-1,999

Jeffrey and Donna Boggs

Chris and Jennifer Branov

Donna DellaRatta

James and Crystal Eubank

Erik Kjos-Hanssen and Turid Frislid

Emmanuel and Dana Gallegos

Sindhuja Gangadurai

Stanley Gilbert

Jessica and Kristian Guttulrud

Gary Haftek

Jeff and Beth Janock

John and Karilyn Kelson

Robert and Anna Langtry

Emily Salo and Kenn Lonquist

Peggy McDaniel

James and Holly Mirenda

Lisa and Jack Nash

Kristine la Cour Rasmussen

George and Kathryn Reardon

Craig and Alisha Rushing

Colleen Satterlee

Colleen Scholl

Bradley and Darlene Starner

Egil Dennerline and Nanna Storm

Sharla and Josh Strickland

Janice and Kenneth Sysak

William and Mary Underriner

Ira and Terry Walker

Marc Weiner

Michael and Kimberly Williams

Up to \$999

Peter and Donna Abramov

Assila Al-Marshoudi

Marzban and Daisy Ardeshir

Amanda Barber

John and Audrey Barrow

Mark and Linda Baumiller

Israel and Mary Jo Becerra

Chris and Karen Bentley

John and Elaine Beyer

Tracy Biby

Rodrigo and Junia Bires

Randolph and Nancy Bloxom

Domenico Bertolucci and Federica Bonati

Richard and Tena Boson

David Boudreaux

Arianna Pederson and Robert Bright

Donald and Danielle Burkin

Elizabeth and Richard Butts

Christina Cachero

Hugo Canalli

Robert and Barbara Capone

Darrel and Kalani DeHaan

Jeremy and Michelle DellaValle

Scottie and Jessica Dill

James and Carol Dillon

Brian and Jennifer Dorman

Delbert and Linda Dotson

Lindsay and Sandra Dunn

Chloe Eminger

Curt and Crystal Fales

Carole Felmy

Daryn and Carol Franzen

Fabio and Sune Frontani

Maria Rocha and Gabriel Gallegos

Melody Ganz

Brian Anderson and Sultana Graham

Madeline and Patrick Gregg

Benjamin and Stephanie Griggs

David Guidara

Shawn and Doreen Gummoe

Eric and Elisabeth Haroldsen

Robert and Victoria Hathcock

Patricia and Michael Hilbert

Judith Hoffman

Shane and Colleen Irvin

Nancy Jansen

Ashleigh Kamsickas

Lila Keleher

Randy and Christie Kelley

Daniel and Aeileeng Kold

Verena Konig

Chad and Lauren Kriner

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Eugene and Renee Lemmon

Peg LeRoux

Tanner and Jessica Lindsay

Philip Nelson and Candy Lindsey

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Ana Alejandra Tabar Concha and Elvin Estevez Lopez
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 William and Connie Schenone
 David and Karen Sheppard
 Bryan and Karen Siebenthal
 Sylvette Silverston
 Julia, Wilhelm and Lorelei Skakandy
 Jamie Slappo
 Karin Staab
 Adam and Jennifer Stewart
 Lea Ann and Jeff Stiller
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Mary Tanner
 Holly and Iain Taylor
 Marcos and Silvana Pineschi Teixeira
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Update on Camp Sunshine

As of March 2022, Camp Sunshine is working to determine what their 2022 schedule will look like.

Traditionally, the Fanconi anemia week takes places in late June. Because of the time needed to plan logistics of this event (coordinating speakers, inviting doctors, etc.), **it is with sadness that FARF has determined we are unable to hold our regular session at Camp Sunshine this year.**

Camp may still host an FA meeting; however, it would look different from years past. Should Camp Sunshine host an FA week, it is our hope that our Family Services team (Jordan and Rosie) could attend to connect with FA families.

While our friends at Camp are determining the scope of their programs, FARF will continue with our virtual FA Connect series to provide opportunities for connection and learning.

We look forward to returning to our regular in-person gathering in 2023! ■

USE OF LOGO

A reminder to our families with FA: Please use our logo or letterhead only after you have consulted staff at the Fanconi Anemia Research Fund and received approval. This step is necessary to be sure our messages are accurate and consistent, and it helps avoid legal complications. We are happy to collaborate on fundraisers and mailings.

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.*

FARF Leadership Updates

Thank you, Departing FA Adult Council Members!

Duncan Nunes

Duncan Nunes joined the Fanconi Anemia Adult Council in 2019 as an inaugural member and served until March 2022. Duncan is a scientist who has devoted his career to advancing the science to treat and cure FA. He works at the Novartis Institute for Medical Research and most recently served on the funding panel for the 2021 Joel Walker Ideas Lab at FARF. His ability to be acutely observant, curious, and intentional with his insight has been invaluable to the FA Adult Council, to FARF staff, and to the many FA researchers whom he has come to know well as a fellow scientist.

While Duncan's presence on the FA Adult Council will be greatly missed, he has graciously volunteered his valuable expertise to FARF's Award Review Committee (ARC), where he will assist with reviewing and critiquing FA research grant proposals. Through his service on the FA Adult Council and the Joel Walker Ideas Lab, it became clear that Duncan is not only a scientist, but a passionate advocate for the people behind the science. We are so grateful for his service on the Council and look forward to working with him in his new role on the ARC. Thank you, Duncan!



Duncan Nunes

Amelia Hawkshaw

Amelia joined the FA Adult Council in 2019 as an inaugural member and served until December 2021. Amelia has become a strong leader and advocate in the global FA community.

In 2019, Amelia played an integral role in the conception of Fanconi Anemia Support Australasia (FASA), an FA support organization for those living in Australia, New Zealand, and surrounding areas. She now serves on the FASA board and is very involved in planning community events and developing opportunities for education and support.

Amelia is wise beyond her years and has been kind enough to share her wisdom with FARF and the FA Adult Council over the last couple of years. Her thoughtful and creative input has led to the development of successful FARF-hosted events, and increased accessibility of education and support to the international community.

Amelia has a passion for bringing awareness to the needs of those impacted by FA all around the world. We will greatly miss the witty, fun, and positive energy that Amelia brought to the FA Adult Council. Nonetheless, we are happy for her as she embarks on new and exciting endeavors! No doubt, her impact on the FA Adult Council and within the global FA community will be long-lasting. ■



Amelia Hawkshaw



Applications will be open from May 1st, 2022 – June 30th, 2022. Applicants will be selected in July 2022. The mission of the FA Adult Council is to provide ongoing support to FARF staff and the Board of Directors by providing informed input as FARF plans new activities or develops policies and procedures related to FA adults.

Learn more and apply here:
www.surveymonkey.com/r/7PJRYZ5

In Loving Memory



Emma Routh

2.3.2005 to 11.17.2021

“Emma was pure joy to be around. She loved everyone. The Bible says you never know when you entertain angels. This small community had an angel living in it.”
– Lisa, Emma’s grandmother



Elijah Woods

10.23.2003 to 3.5.2022

“He was a true carrier of light to all those who came in contact with him.”
– Sharonda, Elijah’s mom



Spencer Shearer

6.6.1987 to 11.26.2021

“Spencer fought through bone marrow transplant with courage and grit, and didn’t complain once. His mother and I were in awe at his strength and kindness to all who cared for him. Spencer’s spirit will continue to live through his 1-year-old son, Kai.”
– Kelley, Spencer’s wife



Kylin Akins

7.9.2013 to 12.7.2021

“Kylin loved playing outside, riding horses, playing video games with his older brother and riding his four-wheeler. Kylin dreamed of being a fire fighter on a horse. His motto was “built different.”
– Victoria, Kylin’s mom

Support for those who have lost loved ones

FARF holds free virtual bereavement support sessions every other month. These are interactive sessions for adults and older teens whose loved one has died. Connect with other bereaved members of the FA family, learn about resources, and share strategies that have supported you in your grief work. These sessions are facilitated by Rachel Altmann who has been active in the Fanconi anemia community for many years, as an FA parent, a member of the

FARF Board of Directors, a contributor to FARF newsletters, and a fundraiser. Her daughter, Nina, died of complications from Fanconi anemia in 2006 at age three and a half. Rachel continues to honor Nina’s legacy by working to advance FA research and support other families who face FA.

You can register for these sessions on the FARF website or email Rosie Holcomb at rosie@fanconi.org to assist you in getting registered. ■



360 E. 10th Ave, Suite 201
Eugene, Oregon 97401

RETURN SERVICE REQUESTED

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 the Fund's website (www.fanconi.org)

Donations by Phone:

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

Donations by Mail:

360 E. 10th Ave., Suite 201, Eugene, OR 97401

Donate While Shopping on Amazon:

www.smile.amazon.com. Choose Fanconi Anemia Research Fund.

Donations of Appreciated Stock:

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

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