

FAmily Newsletter

Issue 73 • Spring 2023

CELEBRATING FAMILIES THIS FA MONTH





UPDATE FROM HQ

The FARE Annual Leadership Meeting in Scottsdale, Arizona in February focused heavily on strategic planning. This meeting brings together our four leadership groups at FARE: the Board of Directors, the Scientific Advisory Board, the FA Adult Council, and the staff.

Strategic planning clarifies the direction and prioritization of the organization. It allows FARE leadership to define more clearly what success looks like for us. This process provides us with a strategic decision-making structure that will narrow our scope of work, focus on priorities, and identify boundaries on our path toward success.

For FARE to achieve its vision and create meaningful impacts in years rather than decades, we need to focus on three critical issues: increasing funding, driving cancer research, and structuring the organization's staffing and programs to ensure the most significant impact. We will continue this work through the spring and complete the plan in May.

As we plan for the future, we continue to move forward and look at where we can improve. In February, we completed our search for a new Philanthropy Director

by hiring Lauren Kennedy to fill this position. Lauren lives in and will be working from Atlanta. Her work history includes fundraising for 10 years at the Leukemia and Lymphoma Society and, most recently, spending seven years as a Development Director for the Juvenile Diabetes Research Foundation. This experience gives her the strategic thinking skills and major gift experience necessary to be successful as a fundraiser for FARE.

Now that Lauren is on board, we will further strengthen our fundraising this spring by adding a new Development Officer. This position is supported by a grant received from the Murdock Charitable Trust. This funding is a capacity-building grant that provides funding to help support the position over three years. This position will focus on strengthening our community fundraisers and mid-level



*Welcome Lauren Kennedy,
FARE Philanthropy Director*

donor population.

2022 was a record-breaking year for FA research, with FARE awarding \$2,874,852 to nine projects! Most of these projects focus on FA cancers. We also funded projects focused on FA neurological syndrome and the psychosocial experiences of adults with FA. Read more about our research progress on page 7.

We continue to fund exciting research in 2023. We awarded a grant to support a clinical trial of Afatinib, a promising cancer drug. This trial, led by Dr. Jordi Surrallés, will accrue patients at centers in Spain and in Germany. We also awarded a grant

to Stanford University to study in-
utero gene therapy for FA patients.
More information on these newly
funded grants is available on our
website, Fanconi.org.

Finally, I thank Rachel Altmann and
Andre Hessels, who finished their
terms on our Board of Directors in
December. Both served for six years
and made countless contributions
in their leadership positions. Andre’s
tenure included a two-year stint as
our Board president, and Rachel was
a steady advocate for the needs of
FA families. We filled their vacancies
on the Board with Dr. John Wagner
from the University of Minnesota,
who also serves on our Scientific
Advisory Board, and Dr. Hanneke
Takkenberg, co-founder of FA
Europe, professor, and an FA parent
who lives in the Netherlands.

We at FARF remain committed
to creating a better future for
individuals with FA. We will
not waiver in our dedication
to advancing FA research, and
educating and supporting
FA families. Our energy and
commitment come from all of you
who support our efforts. You are
what makes our community great
and inspires us to serve.

Mark Quinlan



Executive Director



"Even with all the challenges and difficulties I've
faced in my life, I don't let them get the best of
me. Life is too short to focus on the negatives
and frustrations. It's important to have fun, take
advantage of new opportunities, and remember
what matters in life." — Andie Kalembe

See more on page 16.



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Cover photo: Naomi with her brother and donor.



Fanconi Anemia Month Kicks off May 1!

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

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, 2023

2023
#THISISHOWIFA

Here's how it works:

Get ready...



Share your story OR choose your activity or challenge:

Do something you love!
Whether you want to do an activity for all 31 days or one event, join the cause!

Get set...



Your page is automatically created. Take a look and personalize it!

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 celebrate FA Month!

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 social media, write a letter to your community, 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, 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 your friends and tell them about your drive to help those with FA.

 <p>Share your story \$150</p> <p>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 people to give \$50.</p> <p>FUNDRAISE</p>	 <p>Get outside \$250</p> <p>Got a race coming up? Have your family/friends sponsor you in a run or do a physical activity 31 days to appreciate your body and support FARR!</p> <p>FUNDRAISE</p>	 <p>Be Creative \$500</p> <p>Artist? Baker? Crafter? Create something impressive, fun, or delicious this month and ask your community to join along!</p> <p>FUNDRAISE</p>	 <p>Get together \$1,000</p> <p>Social butterfly? Have a dinner party, host a BBQ or garden party, and ask your closest friends to come and support the cause!</p> <p>FUNDRAISE</p>
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Sign up at <https://fundraise.fanconi.org/FAMonth>



GET INSPIRED BY THESE FA MONTH FUNDRAISERS FROM LAST YEAR

2023

#THISISHOWIFA



KEVIN GATZLAFF

Kevin hosted his May Concert Series live on Facebook. He took song requests from his supporters, and listeners had a blast listening to him play and sing to support FA Month!



RACHEL ALTMANN

Rachel drew all throughout May. Inspired by memories, the FA community, funny stories, and current events in the world, her pictures and words were truly moving.

"This armadillo here, its strong armour is on the outside. Some people with FA are like that, too. Tough on the outside, tender on the inside. Don't you dare mess with them!"



LAURA AND BRIAN SCOTT

Laura and Brian formed Team Silly Socks as they spent May preparing for a 10k fun run. As a donor to FARF, Laura was inspired to join FA Month in memory of her friend, Kirsten Frohmayer.



EGIL DENNERLINE

Egil told his story to inspire and support the FA community. Our hearts were warmed when he said, "I would not be here and would not have the courage to tell my story, if not for FARF." It is our goal to empower and support all of the FA community!



JENNIFER AGGABAO

Jennifer ran the OC Half Marathon to remember her daughter, Katrina, and raise funds for a bright future for her son, Jared. Her family cheered her across that well deserved finish line!



MARY FINN

Mary asked her friends and family not only to donate, but to consider joining her team to honor her son Abe. Thank you for raising awareness by asking others to support FA Month!



AMANDA NOWAK

Amanda joined her family in walking 45 miles in the month of May to honor and remember her brother, Shaun.



HEIDI SCHMITZ

Heidi went on the move last May! "The miles I have put in didn't always feel good, but I knew I could do anything for Zach and Sydney."

2022 RESEARCH YEAR IN REVIEW

In 2022, the Fanconi Anemia Research Fund moved full steam ahead with research priorities. Notably, we invested over \$3 million into new and ongoing research efforts, with a major focus on cancer through the development of the FA Cancer Consortium. In addition, we held three focus meetings and returned to our in-person Scientific Symposium. Finally, we continued to develop the FA Research Materials repository and support clinical programs like the FA Patient Registry and Virtual Tumor Board.

Below is a recap on the research initiatives made possible in 2022 thanks to our incredible donors, fundraisers, dedicated researchers, and of course, the FA community. You will read about newly funded projects, scientific events, and clinical programs and initiatives.

NEW PROJECTS AWARDED IN 2022



FANCONI ANEMIA CANCER CONSORTIUM (FACC)

The mission of the Fanconi Anemia Cancer Consortium is to drive scientific research on FA cancers and enable all people with FA to have access to accurate cancer diagnosis and therapy. To accomplish this mission, the FACC will:

- Provide the infrastructure and resources needed to drive cancer research.
- Offer the best practice care to prevent and treat FA cancers.
- Make resources and data freely accessible to the FA research, patient, and cancer research communities.

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. This coalition will involve international collaborators working to establish a comprehensive patient care strategy for FA cancer.



**FANCONI ANEMIA
CANCER CONSORTIUM**

SEVEN NEW PROJECTS WERE FUNDED IN 2022 WITHIN 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 ages 20s to 30s. Oral cavity cancers arise in areas of changes visible as white or red spots. Researchers plan to screen teens and adults with FA for cancers at regular intervals and study the visible spots in the mouth 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.

**THIS STUDY IS NOW OPEN FOR ENROLLMENT!
READ MORE ON PAGE 11.**

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.

BUILDING COLLABORATIVE PARTNERSHIPS TO UNDERSTAND FANCONI ANEMIA TUMOR PATHOGENESIS, PREVENTION, AND TREATMENT

*Agata Smogorzewska, MD, PhD
The Rockefeller University*

This team will facilitate collaborations between all current and future participants of the 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.

DEVELOPMENT AND CHARACTERIZATION OF FA-HNSCC PDX MODELS

*Jennifer Grandis, MD, and Daniel Johnson, PhD
University of California, San Francisco*

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

ORAL MUCOSAL GENE THERAPY AS A PREVENTION FOR FA-ASSOCIATED CANCERS

*Ray Monnat, MD, and Markus Grompe, MD
University of Washington and Oregon Health and Science University*

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

MODELING ENVIRONMENTAL RESPONSES OF FANCONI ANEMIA EPITHELIAL STEM AND PROGENITOR CELLS TO PREVENT SQUAMOUS CELL CARCINOMA

*Ken Weinberg, MD, Frank Ondrey, MD, and Hiro Nakagawa, MD, PhD
Stanford University, University of Minnesota, and Columbia University*

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

EXTENDED FUNDING

SYNTHETIC LETHAL APPROACHES TO TREATMENT OF FA GENE MUTANT HEAD AND NECK CANCER

*Barbara Burtness, MD, and Gary Kupfer, MD
Yale University, Georgetown University*

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

ADDITIONALLY, WE FUNDED TWO OTHER GRANTS SUPPORTING MENTAL HEALTH AND INVESTIGATING FA NEUROLOGICAL SYNDROME

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

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

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

FANCONI ANEMIA ASSOCIATED NEUROLOGICAL SYNDROME – A SEARCH FOR A CAUSE WITH ADVANCED TECHNOLOGIES

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

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

RESEARCH EVENTS IN 2022

WORKSHOP ON THE INTERNATIONAL BRUSH BIOPSY STUDY

In June, we co-hosted the FA Brush Biopsy International workshop with Dr. Eunike Velleuer and Christine Krieg from FA Germany. The purpose of this meeting was to determine the role of international organizations in implementing the global brush biopsy study with their constituents. This study has proven that oral brush biopsies are 100% accurate in identifying pre-cancerous lesions. Implementation of this study thus leads to earlier diagnoses of cancer, which results in better outcomes for patients.

WORKSHOP ON DATA STANDARDIZATION

The FA Cancer Data Standardization workshop was held in October with over 30 attendees, representing 8 countries. The overall goals of this workshop were to discuss creating standards for data collection across the international data landscape, provide information on platforms available to connect the data and build consensus on implementing a global unique identifier for all FA research participants. The information shared will inform ongoing efforts to standardize data in the FA research field. This helps to reduce redundancy and ensure data is shared to help advance research.

SCIENTIFIC SYMPOSIUM

The 2022 Annual Scientific Symposium returned to an in-person event, held September 8 to September 11 in Austin, Texas. The purpose of the symposium was to gather prominent and aspiring FA researchers and clinicians together to share the latest updates in research and treatment and to form new collaborations. This year, the event was once again held in tandem with the FA Adult Retreat, giving adults with FA the opportunity to speak with scientists and be more empowered in managing their health.

JOEL WALKER CANCER SERIES MEETING

To provide the most effective care for people with FA who have cancer, we need to ensure that therapeutic choices are non-toxic and match each person's unique tumor characteristics (precision therapy). The 5th annual Joel Walker Cancer Series meeting focused on developing strategies for best practices for precision therapy and creating the infrastructure for a molecular tumor board for FA cancer. Outcomes from the meeting established that FARF will continue to advance and support molecular studies on FA tumors so that we can develop a deeper understanding of FA head and neck cancers. In tandem to that, we will implement the necessary processes for molecular characterization of FA tumors into FARF virtual tumor board evaluations to provide people with FA precision medicine-based recommendations for treatment.

CLINICAL SUPPORT

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 FARF VTB meets virtually with patients' treating physician(s) to review cases and provide input for treatment from an FA-centric viewpoint.

In 2022, FARF convened 11 tumor boards for FA patients diagnosed with cancer.

Participate in the NCI FANCONI ANEMIA CANCER SCREENING STUDY

and help improve early detection of cancer and clinical care

The National Cancer Institute (NCI) investigators Dr. Neelam Giri and Dr. Sharon Savage have teamed up with the Fanconi Anemia Research Fund (FARF) as part of the FA Cancer Consortium to develop a comprehensive program to screen people with Fanconi anemia (FA) for early diagnosis of squamous cell cancers (SCC).

People with FA have an increased risk of developing cancer at young ages. SCCs usually appear first in the mouth, esophagus, and genital and anal areas. Visible changes that might progress to cancer often begin appearing in the teen years or in adulthood. The purpose of this study is to systematically study the use of non-invasive brushing of visible changes as well as regular screening of the esophagus and anal and genital areas. **Early diagnosis of cancer is important to allow for early treatment and improving the health and survival of people with FA.**

WHO CAN PARTICIPATE?

We invite you to participate in this study if you are an individual with FA AND 12 years of age or older. Children aged 8 to 11 years are eligible if they have areas of concern in the mouth or the anal/genital areas, or new-onset symptom such as swallowing difficulty.

You may participate in this study if you already participate in other studies at the NCI or elsewhere.

WHAT DOES THE STUDY INVOLVE?

1. completing an online screening questionnaire that should take no more than 20 minutes
2. consent for the study team to obtain and review your medical records, and
3. completing online personal and medical history questionnaires requiring about 60-90 minutes.

You will be invited (but not required) to come to the NIH Clinical Center in Bethesda, Maryland, for cancer screening studies to include:

- Physical examination including dentistry, ear, nose, and throat (otorhinolaryngology), dermatology, and gastroenterology
- Specimen collection such as a saliva, oral rinse, and oral brush biopsy and blood tests.
- Photographs of the affected areas will be obtained
- Liver ultrasound and upper endoscopy
- Other procedures may be obtained if clinically indicated and after a separate consent is obtained.

LEARN MORE

**MARROWFAILURE
.CANCER.GOV**

1-800-518-8474



Your NIH visit will last for 2-3 days. Travel-related costs to and from NIH such as transportation, meals, lodging will be covered by the study and there is no charge for any of the medical visits or tests done at the NIH.

You will be invited to return to NIH approximately once per year for up to 10 years for cancer screening.

We will discuss the results with you at each visit and, if needed, make recommendations for clinical follow-up. If cancer or other medical conditions are found during your participation in this study, we will assist you with finding appropriate care by working closely with your doctor/s.

You will also be asked to complete follow up questionnaires and send your medical records for review approximately every six months as long as you are willing to do so.

If you cannot travel to NIH, you can choose to have cancer screening done at your local institution along with your other FA-related follow-ups; NIH cannot cover the costs of studies and evaluations done outside of NIH. We will follow you on the study remotely using follow-up questionnaires and medical record review approximately every six months for as long as you are willing to do so. We will also arrange with your providers to obtain oral brush biopsy samples for testing and reporting at the NIH as well as for the transfer of tissue (biopsy or surgery) for

special molecular studies at the NIH at no cost to you or your provider/insurance.

Your participation in this study is completely voluntary and you may withdraw from the study at any time. The information you share through the study questionnaires, and your medical records will be kept confidential.

HOW DO I SIGN UP?

If you are interested in joining the study, please visit the Fanconi Anemia Cancer Screening Study enrollment website by using the QR code or call 1-800-518-8474 for more information.

We greatly appreciate your consideration of participating in this study. Your participation will help the researchers improve cancer screening practices in people with FA. If you have any questions about the study, please contact the study team by phone at 1-800-518-8474 or by email at Fanconi@nih.gov.

STUDY INVESTIGATORS

Neelam Giri, MD

Staff Clinician and Principal Investigator on this Study
Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, NIH



Neelam Giri, MD

Sharon A. Savage, MD

Chief, Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, NIH



Sharon A. Savage, MD

SCIENTIST SPOTLIGHT

Name: **Sharon A. Savage, MD**

Institution: Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, National Institutes of Health, Bethesda, MD, USA.

Area of expertise: Pediatric hematology-oncology, genetics, cancer predisposition syndromes, inherited bone marrow failure syndromes



Sharon A. Savage, MD



MY WORK

I want to understand why people get cancer, because if we know why it happens, we have a much better chance of preventing it. Over the last two decades, my work has focused on understanding the contribution of genetics to our risk of cancer. My team and I built a long-term cancer screening study of Li-Fraumeni syndrome (LFS), a rare disorder that increases cancer risk. This study of more than 900 individuals has quantified the risk and types of cancer, identified new associations between variant type and age at cancer onset, and is currently developing a cancer prevention study for people with LFS.

When I joined the Clinical Genetics Branch in 2006, I helped build a research program in telomere biology disorders (TBDs) within the Inherited Bone Marrow Failure Syndromes program initiated by Dr. Blanche Alter. The TBDs are a spectrum of cancer-prone inherited bone marrow failure syndromes. Our detailed clinical studies of TBDs have led to improvements in diagnosis and characterized the complications and progression of the complex medical problems faced by this community.

A key part of our family studies research in the Clinical Genetics Branch is to help support patients and families by improving our understanding of the psychological and social challenges of living with rare cancer-prone disorders like Fanconi anemia (FA).

WHAT MOTIVATES ME TO WORK ON FA

My strongest motivation to work on FA is the urgent need for cancer screening and prevention strategies. The amazing success of bone marrow transplant over the last two decades means that people with FA are living and thriving well into adulthood. The scientific community has made important advances in understanding the types of cancer occurring in FA and many of the biologic

mechanisms underlying its development, but we don't yet know the best methods or utility of early cancer detection or prevention. I'm looking forward to applying my expertise in cancer-prone illnesses, genomics, epidemiology, and cancer screening to FA and to working with this vibrant community.

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

Outside with my husband, two kids, our dogs, and my camera. An amateur wildlife photographer, my camera goes with me almost everywhere. My dogs, who also count as wildlife, have their own Instagram account. You might also find me reading science fiction, knitting, or at the gym.

ANYTHING ELSE YOU WANT FA FAMILIES TO KNOW?

My most important accomplishments, have been facilitating the development of family support groups for TBDs (Team Telomere, Inc.) and the LFS Association, Inc. For each disorder, I organized the first meetings to bring patients and families together with clinicians and scientists. I am incredibly proud of the progress each of these groups has made in the 12-14 years since their inception and am honored to continue to serve on their medical board. Developing collaborative networks of scientists is the best way to move science and medicine forward. I co-created and co-lead the Clinical Care Consortium of Telomere-Associated Ailments and the Li-Fraumeni Syndrome Exploration consortium, both of which bring together dozens of investigators from around the world to advance understanding of these complex disorders. I look forward to working similarly with the FA Cancer Consortium.

BRANDON'S FANCONI ANEMIA JOURNEY

By Stephanie Febles



THE EARLY YEARS

Hi, my name is Stephanie and my 13-year-old son, Brandon, was diagnosed with Fanconi anemia (FA) at age four. After learning more about the signs and symptoms of FA, we knew Brandon had symptoms even before he was officially diagnosed. When I was 36 weeks pregnant, Brandon stopped growing and gaining weight. We were not sure if I would be able to carry full term. Fortunately, I did. When Brandon was born, he had an extra digit on his right hand. At the time, we did not think anything of it and had it removed when he was a year old.

Brandon was always full of energy and rarely sick when he was younger. When he was a little over three years old, we took him to an ear-nose-throat (ENT) doctor because we noticed he snored while sleeping. The ENT did all the pre-operation testing to have a tonsillectomy (surgical removal of the tonsils) and an adenoidectomy (surgical removal of the adenoid – tissue in the back of the throat). That's when they discovered Brandon's platelet count was low and we could not move forward with surgery. After waiting two months to have another complete blood count done, we found his platelet counts were still low. This led to several follow up tests that ultimately diagnosed him with Fanconi anemia.

With the new diagnosis came a lot of time learning since we knew nothing about FA. We quickly learned that Brandon would have frequent doctor visits where they would continue to monitor his blood counts. He didn't have any lifestyle restrictions other than not being able to play contact sports. He was still our outgoing boy.

DECLINING BLOOD COUNTS

When he was around nine years old, his counts slowly started to decline, and we had to decide if we wanted to move forward with a bone marrow transplant. He was put on the bone marrow registry right away. Since Brandon is biracial, finding a match was difficult.

I went through two rounds of unsuccessful in vitro fertilization (IVF) with hopes a sibling would be a match. In 2009, when Brandon was 10 years old, we participated in the metformin study. We hoped this would help improve his platelet counts, and thus buy us more time to find the perfect match for transplant. Unfortunately, that did not work, and Brandon started experiencing frequent nose bleeds due to his low counts. We knew we needed to come up with a new plan to help him.

GOING THROUGH TRANSPLANT

On February 25, 2022, Brandon's Dad, Raymond, was able to be his donor and Brandon underwent a stem cell transplant at Children's Hospital of Philadelphia. We spent several weeks in the hospital. On March 30, 2022, Brandon rang the Bell of Bravery and was released from the hospital. After a week back home, he endured the BK virus for a little over three weeks. Since then, all his levels have continued improving and in October that year, he was off all medications and ready to start his immunizations.

THE FUTURE IS BRIGHT

Brandon is looking forward to going back to school soon. We still struggle with eating and weight gain but are trying different things to help. We stay positive and try to live a normal life. We know we will still have good and bad days, but for now we are focused on the good.

We have a great support group from all our friends, family, doctors, and the Fanconi Anemia Research Fund. Not everyone's story is or will be the same, but if we share our stories and experiences to help one another, we can get through it. Research has come such a long way and because of that, I'm not giving up hope that will have a cure for FA one day.



Brandon with his parents, Stephanie and Raymond



Brandon and his dad, Raymond, in the hospital



Brandon getting ready to ring the bell marking his departure from the hospital following transplant



LIVING LIFE TO THE FULLEST AS AN ADULT WITH FA

By Andie Kalembe

My story with Fanconi anemia (FA) began at birth. Although I was born with many anomalies and characteristics of FA, at the time, doctors deemed it impossible that I had a rare disease. Eight months later, doctors told my parents the devastating diagnosis, with the addition of the possibility that I may not live past the age of eight years old. My parents were shattered, but they were determined to give me as normal a life as possible. This was not an easy task, considering I was always sick and made frequent trips to the hospital.

TRANSPLANT AT A VERY YOUNG AGE

Preschool was an eye-opening experience for me, and the start of a lifelong love of learning. I loved my teacher and I made so many new friends. After only a few months of school, my bone marrow began to fail, and I needed a life-saving bone marrow transplant (BMT). School was put on hold until I could get better.

The beginning of my childhood was filled with countless medical appointments and long drives to find the best hospital to see me through bone marrow transplant and to provide the life-long care I needed. After visiting many hospitals and meeting numerous doctors, we found Dr. Stella Davies at Cincinnati Children's Hospital and I received my BMT at the age of five. Though my transplant is done, I still go through annual doctor appointments and cancer screenings.

LIVING WITH FA AS AN ADULT

One way I describe my life living with FA is this: it's like being picked last for a sport or a group project. It's that feeling of dread and anxiety and hurt. It's annoyance and rage that fill up inside of you. It's the wish that something would change.

Because of FA, I have a lot of noticeable characteristics such as short stature, hand anomalies, speech impairment, and a hearing impairment. Many people mistake me for being 12 years old, even though I am 20. When I go to grocery stores, the employees ask me where my mother is. When I go to my favorite restaurants, I automatically get handed the kids menu and the kids cup, and I have to explain to them that I'm a 20-year-old woman.

In addition to the comments about me being so short and looking so young, I get a lot of questions. I don't mind sharing my story at all, but sometimes the questions are asked at the most inappropriate times, such as when I'm trying to order at a restaurant, walking around in a mall, or even at a block party when I'm meeting new neighbors.

One time, I went to Lollapalooza with my best friend, and the kids my age kept teasing me as I walked through the crowds to find the perfect spot to see the artist on stage. I could hear them laughing, saying, "You're too young to be here. The kids' hours ended an hour ago."

At my own high school graduation ceremony, I heard the whispers of the kids I grew up with, commenting to



Andie at the premiere of Wicked

each other about my height to their friends. The parents gawked as I walked across the stage to receive my honors diploma.

I may have many differences compared to my peers who don't have FA, but I don't let any of them define me. Instead, I embraced them, and I became a bright and outspoken woman.

LIFE IN COLLEGE

I am currently a student at Butler University, and I truly love the college experience. I've joined many clubs and activities on campus. I am a member of the improv troupe, and I've made a lot of friends there. Despite being short and people misunderstanding me and underestimating me, I make people laugh during the improv scenes, putting my power to the test despite my differences.



I also work on campus with the University Program Council (UPC). UPC sets up activities and events for the students on campus. Some of the programs we do are plant nights, roller-skating nights, and movie nights. We even go to off-campus events such as Pacer's basketball games, concerts, and escape rooms. Working here has allowed me to prove to others that I am a responsible person, and my ideas deserve to be heard. In addition, I've established good relationships with my fellow coworkers.

I also applied to be a Residential Assistant (RA) on campus. I am very excited to see if I will get the position. I know I am a responsible person capable of being able to manage a floor of underclassmen and be a good resource and guide throughout their year.

Most recently, I joined a sorority on campus. This was extremely nerve-racking for me, as I am not what others would call "a stereotypical sorority girl". I look a lot different than the girls surrounding me, and I have very different hobbies, personalities traits and life experiences. The process was extremely challenging for me mentally because, at the time, I could not picture myself in a sorority, and I was afraid of the judgments I would receive. Despite my concerns, I found my perfect sorority, and I love them: Tri Delta!

I am proud to say I am a part of the Fanconi Anemia Research Fund's FA Adult Council. Being on this council makes me feel validated and seen, and that's a big lesson that I take away from life. I love hearing the diverse ideas to improve outcomes for those with FA, and I enjoy the feeling of being a part of something bigger than myself.

MY HOPE FOR THE FUTURE

I am 14 years post bone marrow transplant, and I'm wishing for many more years of a healthy life. I've accomplished a lot in my life through academics, clubs, having fun with my friends and family, and enjoying my interests such as theatre, movies, art, music, traveling, and dogs.

Even with all of the challenges and difficulties I've faced in my life, I don't let them get the best of me. I just let all of that allow me to be a positive person and a good influence on those around me. Life is too short to focus on the negatives and frustrations. It's important to have fun, take advantage of new opportunities, and remember what matters in life.





NAOMI, THE WARRIOR

By Amber McDougall

IT'S JUST A STOMACH VIRUS...

June 2021 was a turning point for our family that we never saw coming. Naomi had just turned seven years old. She was struggling with stomach issues for a little over a week and as far as we knew, there wasn't anything to be concerned about.

I'm not a mom who rushes to the doctor, but something about this stomach 'virus' did not sit right in my gut. Mother's intuition, I suppose. I called the doctor and they had one appointment left that morning. I asked Naomi to come in from playing so that I could take her to the doctor, even though at that moment, she looked and acted just fine.

I asked the doctor to just check her out because of the stomach issues and my gut feeling that something was going on. The doctor agreed she looked fine, but did an exam and sent her for some bloodwork just to be thorough and appease me. We left and went on with our day.

About an hour later the doctor called me because her

bloodwork didn't seem right, and the doctor wanted a redraw. We went back in and unfortunately the levels were correct. Naomi's hemoglobin was 3.1 and platelets were 6. She was in bone marrow failure, in desperate need of transfusions and a bone marrow transplant. We still didn't understand why this was happening though. We were rushed by ambulance to Walter Reed Medical Center. About two weeks later and after tons of testing we discovered Naomi has Fanconi anemia (FA).

GETTING CONNECTED TO FARF AND THE FA COMMUNITY

We had never heard of FA. It's such a heartbreaking diagnosis to get for your child, who just a few weeks before, was a 'super healthy' kid who rarely got sick. It was overwhelming to try to play catch-up on such a rare and unknown disease. There were several people in the FA community and at the Fanconi Anemia Research Fund (FARF) that reached out to us to help bridge the



Naomi with her parents



Naomi surrounded by family



Naomi, post-transplant

knowledge gap and calm the grief of a diagnosis that had just uprooted the trajectory of our family as we knew it. Those people who embraced us with love and knowledge were invaluable during that time.

BONE MARROW TRANSPLANTS AND BEYOND

We quickly moved to transplant. Naomi received her first bone marrow transplant October 2021 at Cincinnati Children's Hospital. No donors were available, so her brother, a half match, was her first donor. Any transplant is a tough process, and this transplant went as expected for the first 50 days or so. Then the BK virus caused a takeover of the donor cells and the transplant began to fail. Even after some attempts to save this transplant, it failed and the search for another donor began.

The best match we could find was a 6 out of 10, but that was our only choice. We had to move forward. In February 2022, Naomi received her second bone marrow transplant. The workup for this transplant was tough and the recovery hit her hard with lots of complications. She really didn't start feeling normal again until end of January 2023. The one year mark was February 2, 2023 and her counts are looking great!

As parents, watching Naomi go through all she went through from June 2021 until recently was no easy task. It was heartbreaking. Naomi is a warrior.

We are just now feeling like the dust is settling on a whirlwind that hit our family out of nowhere. Looking back, this journey has taught our family so much. The amount of love and support our family received during this season has opened our eyes in ways we couldn't have expected from our local community, family and friends, the FA community, the kindness of strangers and the selflessness of a donor.

Our faith has given us a river of peace through this storm. Naomi has inspired us with her grit and strength. Our 10-year-old hero son stepped up twice to donate bravely, without hesitation, for his sister. Our other kids have made us so proud with their endurance and sacrifice throughout this process. We've witnessed beauty from ashes throughout all of this.

Looking forward, we have hope. We are not naïve to the potential cancers that may be in Naomi's future, but the amount of dedication to research and progress that keeps being made is encouraging. No matter where this diagnosis takes us in the future, we know we have a very big FAmily out there supporting us.

**Adults with
FA Retreat**
Sept. 28 - Oct. 1
Vancouver BC,
Canada



We are so excited about our upcoming Adults with FA Retreat from September 28th – October 1st in Vancouver BC, Canada! It's an opportunity for individuals with FA ages 18+ and their loved ones to meet other adults with FA, learn about medical and research updates, attend support sessions, and participate in voluntary research studies. We will have some new educational topics, support sessions and a chance to get to know each other better. Registration will open on June 15th and we hope to see you there!



5 THINGS I'M MOST LOOKING FORWARD TO AT THE UPCOMING FA ADULT RETREAT

By Fatma Issak, FA Adult Council Member

1. Meeting up with FA adults! I hope to meet new friends, gain more insight into their unique lives, as well as catching up with old friends.
2. As a council member I am excited to introduce myself to families, ask about their experiences with FA and learn about how we can better provide for patients with FA and their families.
3. I am also very excited to potentially go on an outing in Canada. I would love to spend time with families outside of the world of FA and relax for a bit.
4. As a person who loves science, I am excited to learn about any new technology and research that has been done for Fanconi Anemia. I am interested to see how far research has come and what is to come in the future.
5. Chatting with researchers is always fun and I believe it gives both parties a chance to learn more about FA experiences and research.

TRAVEL SCHOLARSHIPS ARE OFFERED TO ATTEND THIS MEETING

Thanks to the generous Norris family, FARF is able to offer travel scholarships to adults with FA who would like to attend this meeting, but for whom cost may be prohibitive.

The Alex B. Norris Memorial Fund was set up in honor of Alex Norris, who passed away from complications of FA in 1994 at the age of 17. The memorial fund started in approximately 2011. Alex's parents still make annual donations to the fund in honor of their son. We are so grateful for their ongoing generosity, which allows for adults with FA and families to connect with one another, learn, and network with researchers at FARF meetings.

Travel Scholarship Due Date for the Adult Meeting: July 21.
More information at www.fanconi.org



HOW CAREGIVER COACHING HAS HELPED ME



By Sarah Borden

Sarah and Allison

Caregiver coaching is essential to my wellbeing. Having a child with Fanconi anemia can be isolating, even with a large and steadfast support system and a loving partner. As much as our family, friends, neighbors, and coworkers try to understand, they simply can't comprehend what it's truly like. That's where Allison from The Negative Space comes in. She genuinely knows what it's like to love and care for someone with a rare disease.

I reached out to FARF and Allison when my son's counts were low. I felt overwhelmed with loneliness and the fear of what was to come. My 9-year-old-son was on the verge of his bone marrow transplant. We had spent the past 2+ years in isolation due to the pandemic, and the thought of enduring this monumental challenge and more isolation was daunting to say the least. I'm forever grateful that Allison was with me every step of the way – before, during, and after my son's transplant – offering guidance and useful tools when needed, but also just being there to listen and make me feel seen, heard, and validated.

Allison and I connect virtually for the most part, but she was also there for me in person while I was in Minneapolis with my son. She braved

the cold Minnesota winter to walk with me, help me process my feelings, and provide some respite from the long, demanding days in the hospital.

Allison's presence is calm and refreshing. She's a bright ray of light who guides me through the maze of emotions that comes with navigating this disease. I look forward to our conversations and leave feeling lighter and ready to take on the next challenge that will inevitably come my way. Caregiver coaching has changed my life (and my family's lives) for the better. I'm thankful I have another person to lean on. I'm thankful my family doesn't have to take on this disease alone. And I'm thankful that FARF recognizes the importance of supporting caregivers like me, so that we can fully and wholeheartedly support our loved ones in return.

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 who 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.



MY (CONTINUED) JOURNEY WITH FANCONI ANEMIA FAMILIES

By Nancy Cincotta, Psychosocial Consultant (nancycincotta@gmail.com)

Nancy Cincotta, LCSW, MPhil

HOW IT ALL STARTED

One day, while I was working at Mount Sinai, Dr. Jeffrey Lipton asked me to do him a favor. He asked me to run a support group for families of children with Fanconi anemia (along with Drs. Blanche Alter and Arleen Auerbach). More than thirty-five years later, I now suspect that he unknowingly asked me for a lifetime commitment. That was in 1987.

Since that time, I have had the privilege of running groups, doing research, presenting, writing, and developing projects and programs for individuals with FA, their siblings, parents, and partners, at all the FA Family Meetings, all the Adult Meetings, and at regional FARF meetings. I've also been part of a Family Meeting in Denmark, virtual meetings in Australia and Norway, and FARF virtual events.

I introduced FARF to Camp Sunshine, bringing two organizations I was connected to together. For several decades, I have worked with the Master of Science Degree in Genetics Counseling program at Mount Sinai, inviting twelve students to the Family Meeting each year, where they have learned much more about what it is to live with FA than in a traditional classroom. More recently, I have engaged individuals with FA in mentoring Genetics Counseling students in several formats.

THE PATH FORWARD WITHOUT CAMP SUNSHINE

Although my relationship to Camp Sunshine changed in February, my professional path remains constant. Modelled on the efforts of clinicians and other researchers, I have made populations impacted by inherited bone marrow failures syndromes an ongoing commitment and it is my plan to spend more time in these pursuits.

I am currently working on projects that involve individuals with FA, as well with other rare disease communities. I hope

to launch a series of focus groups and engage in more psychosocial research and group work. It is my sense that individuals and families in all the inherited bone marrow failure groups can learn from each other, and it is my hope to create a forum to facilitate that communication.

Many of you also know that FA has become a prominent part of our household, with both my son, AJ Cincotta-Eichenfield growing up sharing his artistic talents and friendships with many people with FA, and my husband, Dr. Andrew Eichenfield serving as the onsite physician at the Family Meetings. We have all grown in this connection together and made FA a family affair.

I included a piece of one of the many art activities we have shared. You will find the "FA Skyline" (above), a favorite collaborative project with people with FA, the Mount Sinai Genetic Counseling class, AJ, and me. Each person with FA had a body tracing done, and then we photographed the tracings and created a unique FA landscape with them — a true work of FA-art!

Professional auspices may change, but our commitment to help those with FA and their families has only grown over the years. So, although we will not see you at Camp this summer, I am inspired by all the psychosocial pathways ahead. I look forward to the ongoing and new initiatives in which we will connect on the FA landscape, including partnerships with individuals with FA, their family members, and collaborative efforts with FARF and Drs. Lipton, Vlachos, and Shimamura.

I have had the distinct honor of watching many of you in the FA community grow up, embrace life, and deal with whatever FA brings. I will be back at the Adult Retreat and look forward to seeing you there. Whether I have met you in person, on Zoom, or have corresponded over email, let's continue the dialogue; there is so much more to say! I am forever grateful that Dr. Lipton asked me for that favor.

I want to express my ongoing admiration for the Frohnmayers, Dr. Alter, and everyone who comprises the FA Community.

THANK YOU, OUTGOING BOARD MEMBERS, AND WELCOME, NEW MEMBERS!

WE GIVE THANKS TO RACHEL ALTMANN AND ANDRE HESSELS, WHO COMPLETED SIX YEARS OF SERVICE ON THE FARF BOARD OF DIRECTORS.

Rachel and Andre joined the board in 2017 and have been instrumental to advancing FARF's mission in the years since.

Rachel chaired the Winn/Byrd Award Committee and served on the International Grant Review Committee, which she will continue to participate in. Additionally, she led (and continues to lead) grief support groups for the FA community. She's a champion of FARF's diversity, equity, and inclusion efforts, and remains committed to advancing FARF's efforts to better care for the entire FA community, especially those with less access to care.

Andre brought an international perspective, as well as expertise in finance to the board. He served on the Nominating Committee, Scholarship Committee, and will remain on the the Budget and Investment Committee. Andre went on to serve as board president from 2020-2021. He helped lead the organization through the challenges of the pandemic, weathering fundraising constraints and the transition to a 'virtual FARF'.

Both Rachel and Andre have been major supporters of FARF in other ways, too: they have raised funds, donated generously, attended nearly every FARF event, offered friendship and wisdom to those in the FA community, and always made themselves available to support staff members. We will miss Andre and Rachel on the board, but are grateful to continue working with them in their new volunteer roles!



Rachel Altmann



Andre Hessels



Henneke Takkenberg



John Wagner

WELCOME TO THE FARF BOARD OF DIRECTORS, DOCTORS HANNEKE TAKKENBERG AND JOHN WAGNER!

Dr. Takkenberg has been an active FA volunteer since 2010, after her third daughter was diagnosed with FA in 2008. She leads the Dutch FA working group and together with Bob Dalgleish (Fanconi Hope, UK), heads FA Europe. Dr. Takkenberg brings to the board a European perspective on FA and expertise in clinical decision making and patient engagement as a Professor of Clinical Decision Making in Cardio-thoracic Interventions in Rotterdam, Netherlands. She is a strong promotor of equal opportunities, diversity & inclusion through her work as Professor of Management Education and Executive Director of Erasmus Centre for Women and Organizations at Rotterdam School of Management at Erasmus University Rotterdam.

Dr. Wagner is a leader in the FA clinical field. His career has focused on the development of new treatment approaches for life-threatening diseases for which conventional treatments are unsatisfactory. He is recognized for pioneering the use of double umbilical cord blood transplantation in adults and embryo selection to insure an HLA matched, healthy child for another child in need of transplant. He is also a leader in the use of regulatory T cells to prevent rejection and graft versus host disease, expanded blood forming stem cells to speed blood and marrow recovery, and novel conditioning regimens to dramatically increase the chance of curing patients with FA.

We are so pleased to work with these two esteemed doctors and FA advocates to advance our mission!

FUNDRAISING SHOUTOUTS



Gerard and Cynthia Vandermeys
with Lorraine McQueen (left)

FA DOESN'T PAUSE FOR RAIN!

This October, more than 70 golfers gathered at Magnolia Greens for the 4th annual Play for FA Golf Tournament. Even with the lingering threat of rain and thunder, they all showed up (ponchos at the ready!) to support the FA community. And they showed up big time, raising nearly \$25,000! The day ended up full of friends, raffles, food and drinks, prizes, and luckily some kind weather to enjoy it all. We can't thank this community and the Vandermeys family enough for their dedication, hard work and generosity!

"We feel so loved and supported on this journey. You give us hope and you give us strength to keep pushing forward."

CHANGING LIVES SLICE BY SLICE

Nearly everyone loves pizza, right?! Emma's family put that fact to use and hosted a day of pizza and raffles at a local parlor. The turnout was even better than they expected and together they raised over \$1,100 for FARF! Amanda, Emma's mom, said it best: "We feel so loved and supported on this journey. You give us hope and you give us strength to keep pushing forward." Efforts like this make such a difference to our community and help to raise awareness of FA throughout the world. Thank you, Barber family, for making a difference, slice by slice!



Emma Barber



The Grossman Family

JOURNEY WITH JACOB

In January, the Grossmans and their family and friends gathered for an afternoon filled with laughter in honor of the deeply cherished and dearly missed Jacob Grossman. It was incredibly special to see FAMILIES unite and support each other as many FA family members from the region attended and spoke at Journey with Jacob. With dueling pianists, a huge raffle prize, and many more surprises, they raised a phenomenal \$24,000 to support FA research! We are so grateful to the Grossman family for all of the effort put into this incredible event to remember Jacob and help others affected by FA. Thank you!

FAMILIES GATHER FOR A NIGHT TO REMEMBER

The Connelly family accomplished something magical this March! Evan and Becca's Enchanting Evening thanked its generous guests with a night of entertainment, drinks, dinner, speakers, and even shopping, with 90 auction items at their fingertips. Overall, they surpassed \$90,000 to support FA research! We know how deeply the Connelly family cares about the FA community, and that shines through with this event. Thank you for your hard work, caring hearts, and dedication to bettering the lives of those with FA.



Evan and Becca's Enchanting Evening



Play for FA's Century Ride

PLAY FOR FA CYCLISTS RIDE #SEANSTRONG

The McQueen family was accompanied by Team Bravery last fall as they rode 100 miles during Play for FA's Century Ride. Their son, Sean, lives with Fanconi Anemia Neurological Syndrome (FANS) and has been working incredibly hard to adapt to associated challenges. His family and friends have responded full force in support of his journey and goals. Through their experiences with FANS, the McQueens have a newfound appreciation for ability and mobility and raised over \$50,000 during Century Ride! Thank you, Sean and the McQueen family, for being #SeanStrong and bettering the lives of those with FA.

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

TEAM BRAVERY IS ON THE MOVE FOR FA!

2022 was Team Bravery's BIGGEST year yet, both in challenges AND in funds raised. They hiked, biked, and ran all over the country, even running marathons back-to-back, all while hitting their goal of raising \$200,000! We are speechless at the hard work, drive, determination, and heart that they put into each of these challenges. Every time we celebrate one of their accomplishments, this incredible team, led by the Marx family, reminds us that they don't tackle these challenges for any glory. They push themselves for YOU, the FA community. Nothing compares to living with FA, so they are inspired to make a difference challenge by challenge as they hike, bike, and run for FA research.



Team Bravery members

TOGETHER, WE GAVE MORE

As we neared the end of 2022, we asked FAmilies what they wanted more of. Your answers? More support, more research, more memories with family, more birthdays, and more hope. This became our theme for the annual year-end giving season. With the most families FARF has seen participate in Giving Tuesday and the holiday season, we surpassed our Giving Tuesday goal of \$150,000! We'd like to give a heartfelt thanks to everyone who participated, donated, and spread FA awareness in 2022. YOU gave those with FA brighter and more hopeful futures. Thank you.



KATA Foundation's Old Quincy Barn Dinner

KATA CREATES A SPECTACULAR EVENING

Last September, our friends at the Kendall and Taylor Atkinson Foundation (KATA) held their Old Quincy Barn Dinner for the first time in two years. Not only were they able to gather for a magical night of top-notch food, drinks, entertainment and dancing – they also hosted a new fundraiser during the event: Hope Floats. On the night of Barn dinner, over 700 purchased lanterns were launched onto the pond with a chance for their sponsors to win a prize if chosen. Each numbered lantern was also paired with an FA Warrior, giving them a chance to win as well. The event raised more than \$140,000! We are inspired by this inventive way to both raise funds for the FA community as well as treat loved FA Warriors directly. Thank you, KATA, for your continued support and amazing events.

WINN/BYRD AWARD FOR ADULTS WITH FA

DEADLINE JULY 14

MORE DETAILS:

Tell us how you are working to make a difference in your community.

Tell us about your goals. Are they a stretch for you based upon where you are now, not in comparison to someone else?

Tell us how you demonstrate leadership in your own way.

Describe how you would use the award.

Apply online at fanconi.org or by emailing jordan@fanconi.org



Henry Fenyo, the 2022 recipient, with previous recipient Robin Lewis (left) and FARF Executive Director Mark Quinlan (right)

COMMUNITY FUNDRAISING LIST

In 2022, FA families and community members raised nearly \$2,800,000 for the Fanconi Anemia Research Fund! More than 220 families and community members raised funds through events and appeals. Each dollar donated advances research and family support, making a difference for all those affected by FA and their families. Sincere thanks to every family and individual who worked so hard to raise funds in honor or memory of loved ones.

\$1,500,000+

Lynn Frohnmayer

\$200,000+

Orion and Lisa Marx

\$140,000+

The Kendall and Taylor Atkinson Foundation with the Nash Family

\$25,000 - \$99,000

John and Martina Hartmann
Todd and Kristin Levine
Kevin and Lorraine McQueen
Gerard and Cynthia Vandermeys

\$15,000 - \$24,999

Brian Horrigan and Amy Levine
Ian and Tricia Mitchell
Peggy Padden
Rose and David Pennell
Sharon Schuman
Nigel and Ann Walker

\$10,000 - \$14,999

Tyler Morrison and Rachel Altmann
David and Mary Ann Fiaschetti
Rachel Grossman
Charles and Kathleen Hull
Keith and Jessica Loo
Mark and Diane Pearl

\$5,000 - \$9,999

Michael and Jennifer Aggabao
James and Jennifer Armentrout
Chris and Jennifer Branov
Ryan and Rebecca Brinkmann
Mauro and Kerrie Cazzari
David and Kim Chew
Joeseoph and Nancy Chou
Christopher and Susan Collins
Brittney Ferrin
Rachel and Zachary Gratz-

Lazarus
Timothy and Mary Ann Lana
Mark Ritchie and Lisa Mingo
Paul and Rena Rice
Andrea and Robert Sacks
Egil Dennerline and Nanna Storm

\$2,000 - \$4,999

Donna Behlke
Andre Hessels and Rutger Boerema
David and Sarah Borden
Sean and Allison Breininger
Elizabeth and Richard Butts
John and Kim Connelly
Rachael Alaniz and Kevin Gatzlaff
Jeff and Beth Janock
Owen Hall and Margaret Kasting
Maria and Bill Katris
John and Karilyn Kelson
Daniel and Angie McMahon
Sheila Meehan
Caroline Nguyen
Nancy Nunes
David and Stacy Ownby
Chris and Mel Payne
Peter and Janice Pless
Neil and Emily Robison
Ron and Alice Schaefer
Sean and TaLisa Sebourm
Joseph and Natalie Vitrano
Robert and Julie Williams
Jason and Joan Woodle

\$1,000 - \$1,999

Brian and Carly Adel
Jennifer and Bryan Aitkens
Mark and Linda Baumiller
Adam and Marissa Becker
Jackie Burton
Donna DellaRatta
Jeremy and Michelle DellaValle
James and Carol Dillon
Chloe Eminger

Scott and Windy Farmer
Erik Kjos-Hanssen and Turid Frislid
Andrew Coons and Valeen Gonzales
Dr. Michael Greenberg
Rachel and Kristian Guttulsrud
Gary Haftek
Stan and Michelle Kalembo
Robert and Anna Langtry
Kristina Mack
Alaina Mercer
Ronald and Fredi Norris
George and Kathryn Reardon
Richard and Marilyn Sablosky
Colleen Satterlee
Colleen Scholl
Bradley and Darlene Starner
William and Mary Underriner
Marc Weiner
Mary Eileen Cleary and Gleaves Whitney
Michael and Kimberly Williams

Up to \$999

Peter and Donna Abramov
Glen and Teresa Alessandri
Ronald and Tena Arroyo
Dr. Vicki Athens
Amanda Barber
Israel and Mary Jo Becerra
Stephanie Bell
Jasmine Bennetsen
Dan Klug and Elizabeth Bertrand-Klug
Annette and Roger Bevelhymmer
John and Elaine Beyer
Tracy Biby
Randolph and Nancy Bloxom
Domenico Bertolucci and Federica Bonati
Richard and Tena Bosen
Carole and David Boudreau
Arianna Pederson and Robert Bright
Nathalie Britt
Edward and Barbara Brookover

Donald and Danielle Burkin
Bruce and Jackie Cannon
Robert and Barbara Capone
Richard and Ashley Cobden
Larry Davis
Cleonce DiSandro
Edward and Janice Duffy
Lindsay and Sandra Dunn
James and Crystal Eubank
Curt and Crystal Fales
Carole Felmy
Nancy Finnegan
Daryn and Carol Franzen
Kim Frock
Fabio and Sune Frontani
Emmanuel and Dana Gallegos
Maria Rocha and Gabriel Gallegos
Melody Ganz
Laurie Gerhardt
Brian and Lisa Gillott
Patrick and Maria Gleason
Andrew and Jennifer Gough
Brian Anderson and Sultana Graham
Madeline and Patrick Gregg
David Guidara
Shawn and Doreen Gummoe
Jacqueline Hardy
Eric and Elisabeth Haroldsen
Robert and Victoria Hathcock
Helen and Sean Healey
Patricia and Michael Hilbert
Judith Hoffman
Stephanie and Thomas Hutter
Shane and Colleen Irvin
Nancy Jansen
Randy Jones
Ashleigh Kamsickas
Chad and Lauren Kriner
Brian Kuell
Christopher and Dana Lamb
Eugene and Renee Lemmon
Peg LeRoux
Larry and Gayle Licari
Robert and Darla Lindenmayer
Tanner and Jessica Lindsay
William and Jacquelyn Lucarell
Leighsa and Paul Makowicz
Stuart Cohen and Deane Marchbein
Daniel and Nicole McCarthy
Jeremy and Stacey Mefford
Marie Di Mercurio
Eugenio Grassi and Brittany Miller
John and Barbara Miller
Adam and Olivia Mindle
James and Holly Miranda
Kelly and Gerald Mlachak
Kate & Daniel Montgomery
Jordan, Laurie and Daryll Moore

Griff and Cecelia Morgan
John and Betty Mozisek
Kenny and Lisa Myhan
Tony and Lina Nahas
Louis and Virginia Napoles
Lisa and Jack Nash
Yalitzta Negron
Alice Nicholson
Jian Yang and Jing Nie
Robert and Mary Nori
William, Kelli and Kit Owen
Seth Parelman
Michael and Joanna Peros
Leah Petsanas
Tim and Ashleigh Pinion
John and Dianne Ploetz
Lynn and Shirley Quilici
Pedro and Marina Ravelo
Shelby and Kayla Richardson
Kelsey Robinson
Kevin and Katherine Rogers
Les and Nancy Ross
Craig and Alisha Rushing
Jennifer and Brian Sadlowe
Samantha, Theo, Matthew and Owen Samson
Ty Sanders
Sharon Saunders
William and Connie Schenone
Bryan and Karen Siebenthal
Jack and Debbie Siegel
Sylvette Silverston
Jamie Slappo
Russell and Rachael Smith
Karin Staab
Tariea and Julian Stephens
Lea Ann and Jeff Stiller
Greg and Brandi Stuart
Paul and Debra Sundsvold
Sharon Swanson
Janice and Kenneth Sysak
Ana Alejandra Tabar Concha, Elvin Estevez Lopez and Violeta Tabar
Mary Tanner
James and Kerri Tilson
Bruce and Loreen Timperley
Thomas and Cathy Uno
Lucian Valor
Michael and Beth Vangel
Theresa and Louis Viola
Joe and Wendy Vitiritto
Joe and Jacqueline Vona
Ira and Terry Walker
Lorne Shelson and Annette Waxberg
Jessica and Ezekiel Werden
David and Erica Williams
Chad and Dawn Wood
Kyle and Madison Wright
Sean and Kristin Young
Thomas and Marjorie Zaborneylliams



COLLECTIVE GRIEF IN THE FA COMMUNITY

It's with a heavy heart that we recognize those in this community that we've most recently lost. Since our last publication, eleven of our dear friends have passed away (see In Loving Memory section, where some are represented). We are grateful for the bright impact that they had and will continue to have in the lives of those in this community and beyond. They will be remembered and deeply missed.

As we remember all of those we've lost, it's important to acknowledge the shockwave that is grief, which can reverberate throughout the entire community during times of loss.

Most in this community have witnessed the difficulties experienced by those with FA and their loved ones. Social media has made it easy to share and follow life updates, making it a helpful tool for gathering information and providing support; however, it also exposes us to the raw challenges that accompany this disease, including the loss of loved ones.

When members of an entire community experience extreme change or loss, collective grief may occur as a natural response, and community members may experience feeling a lack of control and powerlessness. Anticipatory grief may also accompany collective grief, compounding these feelings, as we see loss around us and anticipate future loss. When we experience grief individually, we are typically most aware of our own personal mourning processes, but with collective grief, we become bound to the grief and mourning of others

within the community.

Because this collective experience can be overwhelming, we've provided some potential ways that we might cope together, while acknowledging it is completely appropriate to process grief in your own way. There is no one way to experience or integrate grief into one's life; it's unique to each individual.

Public mourning: Virtual grief support groups, FA Facebook groups, community vigils, the "Living Memory Room" at the FA Adult Retreat. More information can be found at Fanconi.org or by emailing FARF at info@fanconi.org.

Publicly honor those who have died: Submit a photo and note about your loved one to FARF for the "In Loving Memory" section of the newsletter, submit photos and stories for the "Living Memory Room" at FA retreats, post pictures and share favorite memories on social media, plant a tree in honor, advocate for a cause in honor, participate in a memory walk/run.

Practice community care: Volunteer to make heartfelt cards for those grieving in the community, volunteer

as a virtual grief group facilitator, send a loving message or flowers to the grieving family, reach out to those that are having a difficult time.

Personal space: Public mourning isn't for everyone. We all grieve in our own ways. For some, this might look like journaling, meeting with a therapist, reading, researching, or even stepping away from FA community activities for a time, if that's what it takes to tend to yourself with compassion.

We will all experience grief in various forms throughout our lives. There's no step-by-step manual for processing grief, and there's no timeline. And while overwhelming, collective grieving can be a powerful reminder that we are not alone in this.

Poet, Mark Nepo wrote, "If we commit to loving, we will inevitably know loss and grief. If we try to avoid loss and grief, we will never truly love. Yet powerfully and mysteriously, knowing both love and loss is what brings us fully and deeply alive."

More resources:

It's OK That You're Not OK - Megan Devine, LPC, forward by Mark Nepo

Grief Recovery Center - Asma Rehman, LPC

The National Child Traumatic Stress Network (NCTSN)

IN LOVING MEMORY

Shemiah Gande

7.12.2011 – 2.25.2023



David Montenegro

5.7.1977 – 2.1.2023

“David was my life mentor, and a mentor to others. He spent his free time volunteering for his daughter’s basketball team. When the doctors told him his FA would not allow him to live past his childhood; he defied the odds. The doctors told him that he would not live past 20 or 30 years; he defied the odds. The doctors told him he would never have children; he again defied the odds and had 2 AMAZING daughters. His fighting spirit will live on in his daughters, Alani and Aliana. It will live on in our hearts and memories.” – Velea Montenegro, David’s sister



Angela Bedoya

10.20.1992 – 10.8.2022

“Angela was a strong fighter with a huge heart and was a true inspiration. She used her intelligence and her personal experiences with FA and a bone marrow transplant to help others facing similar circumstances. Angela was very loved and will be greatly missed by her family, friends, and the FA Community.” – Dan Bedoya, Angela’s brother

Thomas Silverston

3.26.1981 – 10.10.2022

“Thomas Silverston, PhD, was a Senior Lecturer at Faculty of Sciences and Technologies, Nancy, University of Lorraine and Teacher-Researcher in Tokyo. He was married to Mika. He never developed any hematologic issue, unlike his identical twin brother, Ben. But a throat cancer was detected at the end of 2020. He is terribly missed by his wife, his family, his colleagues and friends.”

Hamideh Hamzenejadi

5.22.1986 – 10.20.2022

“I come from a place where love and compassion are valued. Where do you come from?”

– Sajad, Hamideh’s brother



Zachary Evan Blecher

5.15.1986 – 3.5.2023

“With deep sorrow, we announce Zack’s death at his home in Cheswick, PA. He was diagnosed with FA-A in June 1990 and received a transplant in Paris, France in January 1991. During the last three years Zack faced throat, oral and liver cancers while maintaining his kind and gentle nature. He will always be in our hearts. – Amanda Anderson (wife), Darryl Blecher and Diana Fitch (parents), Aaron, Mishan and Nathaniel (brothers).”



SAVE THE DATE

September 28 - October 1, 2023
Vancouver, Canada

FANCONI ANEMIA SCIENTIFIC SYMPOSIUM & RETREAT FOR ADULTS WITH FA

www.fanconi.org

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

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