FANCONI™ CANCER FOUNDATION

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FAmily Newsletter

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Read about the fun at the Family Retreat on page 12

ADVANCING RESEARCH TO HELP PEOPLE WITH FA LIVE FULL LIVES

FANCONI™ CANCER FOUNDATION

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Letter from the CEO

DEAR FA FAMILIES,

As I step into my role as CEO of the Fanconi Cancer Foundation, I am deeply honored to continue this vital work alongside you. Every day, I am inspired by the resilience and commitment of our community—our incredible families, dedicated donors, passionate staff, esteemed Board of Directors, Scientific Advisory Board (SAB), and the FAdult Council. Together, we are making tremendous strides in addressing this disease and I'd like to share some of these with you in this letter.

ADVANCING RESEARCH

Over the past five years, we have achieved significant advancements in FA research thanks to this shared commitment. We funded interdisciplinary teams that are driving forward cancer research, and hosted meetings that laid the groundwork for developing new models and systems for data sharing. These efforts have brought us closer to much-needed discoveries and, ultimately, life-saving treatments.

In the spring of 2023, we focused on propelling basic and translational research through initiatives led by our previously funded Stand Up To Cancer (SU2C) and Joel Walker Ideas Lab teams. Their work is paving the way for a future cancer prevention clinical trial—an exciting development that holds great promise for our community.

The early detection screening study at the NIH continues to make significant progress, recruiting individuals with FA from across the United States. This study offers critical access to comprehensive cancer screening for all, and, importantly, includes those who may face barriers, such as distance from major FA centers or insurance issues.

We are also immensely proud of our partnership with Data for the Common Good, which has led to the creation of the first-ever international FA clinical database. This database will open new avenues for research built on trust and camaraderie between the research and patient communities. Advocates and major international FA research groups have played a pivotal role in this effort, and we are grateful for their partnership.

Looking ahead, we are focusing on important initiatives to bring researchers and FA families together, harnessing the power of the patient voice through our advocacy program. Our patient partners are at the forefront of research, fundraising, education, empowerment, and awareness. Key partnerships with leading cancer research organizations like SU2C and the American Association of Cancer Research are helping to elevate FA's visibility worldwide and acknowledge it as a cancer predisposition disease.

STRENGTHENING OUR COMMUNITY

Our commitment to the FA community goes beyond research. We are also focused on addressing the mental health needs of people with FA and their caregivers. Our psychosocial initiatives have created a global consortium of researchers dedicated to understanding and improving the quality of life for our community. This is a key component of our strategic plan.

This year, we hosted our family retreat at a new location, which has had a profoundly positive impact on our community (more about this on page 12). We have also continued our educational efforts, are working on updating guidelines chapters, offering FA Connect webinars, and creating educational content that can be utilized globally.

Our international grant program is another source of growth, as it has paved the way for the independence and sustainability of patient support groups around the world. We have fostered connections by participating in meetings hosted by FA Europe and Fanconi Brazil this past year, strengthening our global network.

LOOKING AHEAD

As we move forward, our focus remains on expanding research opportunities by leveraging shared data systems and supporting the next generation of researchers. At the same time, we look forward to the game-changing results of the team-based effort to advance a technology that would change the course of the disease: gene editing. More on this initiative to come! We are committed to driving innovation in cancer prevention and treatment, while strengthening collaborations that expedite research and bring hope to our community.

Above all, we will continue to work hand in hand with those living with FA and their caregivers toward our shared mission. By encouraging collaboration and resource sharing among researchers, we are confident that together, we can achieve the breakthroughs we need to change lives.

Thank you for your unwavering support and partnership. Together, we are stronger—and together, we will continue to make a difference.

With gratitude,

Isis Sroka, PhD
CEO, Fanconi Cancer Foundation

Progress Takes a Village: Join Us in Making a Difference This Holiday Season

At the Fanconi Cancer Foundation, we know that progress is a collective effort – it takes a village. In our case, it takes a dedicated community of FA families, donors, researchers, volunteers, and supporters all working together to improve outcomes and quality of life for those with Fanconi anemia.

Over 70% of FCF's income is generated through holiday giving, and this united effort drives the research and the support the FA families depend on. This holiday season, we're calling on our village to come together in a powerful way. Share your story, ask your community for support, and become a vital part of the progress we strive for.

You might be surprised at how many of your friends and family are ready to step up when given the chance to support someone they care about. Every simple ask with your participation, every donation, and every act of generosity contributes to the strides we're making toward a cure. Together we can continue making a difference – one gift at a time.

Share your story this holiday season

OPTION 1

Make a personal fundraising page

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

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

OPTION 2

Send a letter to your community

Prefer to send a hard copy letter to your community? We've got a template ready for you on the next page! Just send us your family update, mailing list, and photos. We'll do the rest and send them with your OK.

Bonus: Letters are great additions to your annual holiday postcard.

Pros of this choice: Most personal, people like receiving mail, and FCF covers postage costs.

OPTION 3

Send an email and/or share via social media

Looking for the most streamlined way to share updates and raise funds? We've got email and social media templates for you to copy, paste, edit, and send (they'll be in your inbox soon).

Bonus: Sending on Giving Tuesday (12/3) makes a major impact.

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

Add your page here:

SCAN ME

OTHER WAYS TO MAKE AN IMPACT:

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

Email rosie@fanconi.org to get started!

Dear Friends and Family,

[Insert greeting and personal family update here.]

As you may know, our family continues to face the challenges of Fanconi anemia (FA), a rare and relentless DNA-repair disease that leads to bone marrow failure, leukemia, and cancer. This year, we find ourselves reaching out with renewed determination to make a difference, fueled by the progress being made in research and treatment.

The holiday season is upon us, a time when we turn to our cherished friends and family, seeking your support for the **Fanconi Cancer Foundation**. Why? Because this organization has provided us with something priceless—hope. Amid the uncertainty and fear that come with an FA diagnosis, the Fanconi Cancer Foundation has been our steadfast guide, driving research forward and offering critical support to families like ours.

Here is some of the incredible progress made by FCF this year:

- **FA Cancer Screening Study:** Over 70 people have now joined the FA Cancer Screening Study at the National Institutes of Health. Thanks to this study, many FA patients have been able to detect and address cancer diagnoses early, leading to better outcomes.
- **Mental Health Study:** The first phase of a previously funded study into mental health in people with FA has yielded important findings. Researchers have identified key interventions that can significantly improve the quality of life for people with FA, offering hope for better mental health support moving forward.
- **Gene Editing Project:** Progress continues in the gene editing project, with researchers working to fine-tune gene editing tools that can effectively correct FA cells. This groundbreaking effort brings us one step closer to addressing the root cause of the disease at a cellular level.

Since its founding in 1989, the Fanconi Cancer Foundation has remained relentless in its mission: to discover effective treatments, ultimately find a cure for FA, and provide crucial education and support to affected families worldwide. But this important work is not possible without your help.

We humbly ask for your support in our ongoing quest to find a cure for FA—not just for [child's name] but for all those affected by this devastating disease. Your tax-deductible donation can be returned using the enclosed envelope or made securely online at [Insert Donation Link Here].

Thank you for helping us spread hope and love within our community. As you celebrate the holiday season with your family, please know that your generosity is a significant part of our journey toward a brighter future.

Wishing you and your loved ones peace, love, and joy this holiday season!

Research Updates

Every quarter, we update our website with the latest FA research news. So far in 2024, there are several updates! We've selected a few to highlight in this newsletter, and you can find the rest here: https://fanconi.org/2024-research-updates/

NEWLY FUNDED PROJECTS

SPATIAL ANALYSIS OF FA TUMORS FOR DETECTION OF THEIR IMMUNE REPERTOIRE AND POTENTIAL ACTIONABLE TARGETS

Investigator: Alfredo Rodríguez, PhD
Institution: National Autonomous University of Mexico
Amount Funded: $250,000

This newly funded research project aims to better understand the unique challenges people with Fanconi anemia (FA) face when it comes to treating squamous cell carcinoma (SCC). SCC tumors consist of various cell types, including cancer cells, immune cells, and other supportive cells. By studying how these cells interact, scientists hope to uncover new ways to treat cancer in FA patients, especially by boosting the body's immune response. Using advanced technologies, the research team will analyze archived tumor samples to identify key markers that could lead to better diagnosis, personalized treatment, and new therapies, particularly immunotherapy, for FA patients with cancer.

TRANSFORMING TREATMENT OF INHERITED BONE MARROW FAILURE IN FANCONI ANEMIA BY PRECISE IN VIVO GENOME EDITING

Investigators: Paula Rio, Jacob Corn, Andrew Deans, Hans-Peter Kiem, Branden Moriarity, David Liu, Toni Cathomen
Institutions: Instituto De Investigación Sanitaria Fundación Jiménez Díaz; Harvard University; ETH Zurich; St. Vincent's Institute Fitzroy; Fred Hutchinson Cancer Center; University Of Minnesota; Medical Center – University Of Freiburg, Institute For Transfusion Medicine And Gene Therapy
Amount Funded: $1,258,190

Fanconi anemia (FA) is a genetic condition that leads to bone marrow failure, leukemia, and a higher risk of cancer. Right now, the only treatment for bone marrow failure in FA patients is a bone marrow transplant and this can have serious side effects. This study will use advanced gene editing techniques to fix the common genetic mutations in FA. By combining these techniques with improved delivery methods, researchers hope to directly repair blood stem cells in the body, offering a new and potentially safer treatment option for people with FA.

In the first phase of their work, researchers have fine-tuned various gene editing tools to effectively correct FA cells. They have also created the necessary models to test these gene editing and delivery methods.

UPDATES FROM ONGOING PROJECTS

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

Investigators: Kathleen Bogart, PhD, and Megan Voss, DNP
Institutions: Oregon State University and University of Minnesota
Funded in 2022

Dr. Bogart and Dr. Voss focus on understanding mental health outcomes in individuals with FA, revealing high rates of post-traumatic stress disorder, anxiety, and depression, alongside common challenges such as stigma and fertility issues. Their research emphasizes the importance of accessible mental health support and community connections, particularly for marginalized groups.

NATIONAL INSTITUTES OF HEALTH (NIH) CENTER COMPREHENSIVE PROGRAM FOR NATURAL HISTORY OF DEVELOPMENT OF SQUAMOUS CELL CARCINOMA IN FANCONI ANEMIA

Investigators: Neelam Giri, MD, and Sharon Savage, MD
Institution: National Institutes of Health
Funded in 2022

Dr. Giri and Dr. Savage's study aims to establish a central facility for comprehensive screening of individuals with FA, tracking cancer development through detailed evaluations and biospecimen collection. With more than 70 enrolled participants, the study collaborates with other FA investigators to uncover genetic and immunological mechanisms underlying cancer susceptibility in FA, ultimately aiding in early detection and treatment strategies for this high-risk population.

TRIAL TO INVESTIGATE THE SAFETY AND EFFICACY OF AFATINIB WHEN ADMINISTERED AS THERAPY IN FANCONI ANEMIA PATIENTS WITH ADVANCED SQUAMOUS CELL CARCINOMA OF THE ORAL CAVITY, OROPHARYNX, HYPOPHARYNX, OR LARYNX

Investigators: Ramon Garcia-Escudero, PhD and Jordi Surrallés, PhD
Institution: Institut de Recerca de l'Hospital de Sant Pau
Funded in 2023

Dr. Garcia-Escudero and Dr. Surrallés are launching a clinical trial to test the safety and effectiveness of a drug called Afatinib for people with FA who have advanced squamous cell carcinoma (SCC) in the mouth or throat. This trial could be a big step forward because it aims to develop the first treatment specifically for head and neck cancers in people with FA, offering a new option that avoids toxic medications and could improve the quality of life for those affected. The trial is expected to begin this fall in Spain and Germany, thanks to a partnership with the company that makes Afatinib, Boehringer Ingelheim.

REDUCING THE BURDEN OF SCC IN FA/ HEALTH LITERACY INITIATIVE: CANCER AWARENESS TEAM

Investigators: Christine Krieg and Eunike Velleuer-Carlberg, MD
Institutions: Heinrich-Heine-University and German Fanconi Anemia Family Support Group and Research Fund
Funded in 2023

The Cancer Awareness Team is dedicated to improving cancer prevention, detection, and treatment for people with FA. Their work focuses on providing education and resources to help individuals with FA make informed decisions about their health. Dr. Velleuer-Carlberg and Ms. Krieg have created oral care programs for people with FA and their healthcare providers, translated important oral screening materials, and worked directly with individuals with FA to enhance their medical care. They've also helped build international partnerships through the Fanconi Research Initiative for Education, Networking, and Data Sharing (FRIENDS). This work empowers individuals with FA to regularly check their mouths for early signs of cancer and stay on top of cancer screenings. You might see them at the next FCF meeting, and in the meantime, download the app "FA Exam" from your app store!

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

Investigators: Hiroshi Nakagawa, MD, PhD and Kenneth Weinberg, MD
Institutions: Columbia University and Stanford University
Funded in 2022

Dr. Nakagawa and Dr. Weinberg's research focuses on understanding how squamous cell carcinomas (SCCs) develop from FA stem and progenitor cells, using both mouse models and lab-grown cell models. Their studies have confirmed abnormal cell development in mice with FA and, through advanced testing, they've identified two important groups of cells: one

that includes cancer stem cells and another with cancerous epithelial cells in the early stages of disease. This research is a breakthrough for the FA community because it creates new models to explore cancer prevention strategies. Early findings suggest it may be possible to delay cancer in people with FA, opening the door to new drug therapies aimed at preventing SCC.

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

Investigators: Prashanth Ramachandran, MBBS, BMedSci and Michael Wilson, MD, MAS
Institutions: University of Melbourne and University of California, San Francisco
Funded in 2022

Dr. Ramachandran and Dr. Wilson's study focuses on better understanding Fanconi Associated Neurological Syndrome (FANS), a condition that causes brain lesions and, in some cases, large pseudo-tumors. They are working to identify the signs of FANS, study the immune response in blood and spinal fluid, and uncover possible triggers of inflammation. So far, they have recruited six individuals with FANS, all of whom agreed to detailed testing, and three of whom also provided blood and spinal fluid samples for analysis. Their findings suggest that FANS is linked to thickening and leakage in blood vessels, which can also affect the eyes. All six individuals in the study showed signs of retinal vasculopathy, which can lead to vision loss. This research is important because, until now, the causes of FANS have been unclear. Understanding what drives FANS could lead to better screening and treatments for those affected.

PROJECTS THAT WRAPPED UP THIS YEAR

SYNTHETIC LETHAL APPROACHES TO TREATMENT OF FANCONI ANEMIA (FA) GENE MUTANT HEAD AND NECK CANCER

Investigators: Barbara Burtness, MD, and Gary Kupfer, MD
Institutions: Yale University and Georgetown University
Funded in 2020

Dr. Burtness and Dr. Kupfer's study aimed to achieve several objectives: first, they sought to pinpoint and confirm specific genetic mutations in a type of head and neck squamous cell carcinoma. Next, they aimed to create models of this cancer using samples that had the identified mutations. Finally, they tested different drugs to see if they could effectively target the vulnerabilities in these mutated cells.

Their research revealed two promising approaches for treating head and neck cancer with Fanconi gene defects. One approach involves using existing drugs, which are ready for immediate testing and could soon be used in clinical trials. The other approach focuses on developing a new drug that targets a previously unexplored biological pathway. Both strategies hold potential for improving treatment outcomes for individuals with Fanconi anemia who are at risk of developing head and neck cancer.

A SMALL MOLECULE APPROACH TO OVERCOME REPLICATION DYSFUNCTION IN FA

Investigators: Sharon Cantor, PhD, and Peter Kurre, MD
Institutions: University of Massachusetts Medical School and Children's Hospital of Philadelphia
Funded in 2020

Dr. Cantor and Dr. Kurre's research is focused on addressing bone marrow failure in individuals with FA by targeting the DNA replication problems that cause the condition. They developed a reliable method to measure DNA replication gaps, which are higher in cells that lack the FA pathway. By working with bone marrow from mice with FA-related gene deficiencies, they successfully expanded blood stem cells in the lab, showing that these cells could potentially be used for future transplants. This discovery is important because the loss of blood stem cells is a major cause of health complications and early death in people with FA.

Announcing the Fanconi Anemia Patient Advocacy Program

We're excited to announce the launch of the FA Patient Advocacy Program, designed to empower leaders within our community to become effective advocates. By sharing their lived experiences, FA advocates will play a key role in shaping FA research, policy, and initiatives that promote holistic well-being for those impacted by the disease.

WHY FA ADVOCATES ARE SO IMPORTANT

In the rare disease space, advocates can be caregivers, family members, friends, or patients themselves. Their perspectives allow for deeper discussions and decisions that directly affect their lives. This helps ensure that the FA community's voices are heard and valued, leading to better research outcomes and policies that truly reflect patient needs.

The FA Patient Advocacy Program will foster partnerships between advocates, researchers, clinicians, institutions, industry, and government agencies to advance the mission of improving the lives of those affected by FA and related cancers.

OUR ADVOCACY GOALS

1. Amplify the Voices of the FA Community: Establish a platform for the FA community's voices to be heard by stakeholders in research, healthcare, and policy.
2. Empower Advocates: Provide training and resources to equip individuals to influence research and policy decisions.
3. Ensure Patient-Centered Research and Initiatives: Use the lived experience of those with FA and their caregivers to guide patient-centered research, education, and global initiatives.
4. Promote Respectful Partnerships: Build strong, respectful relationships between people with FA, their families, and external stakeholders.
5. Improve Research Experiences: Engage advocates in research design, implementation, recruitment, and dissemination, enhancing the experience for participants and caregivers.

WHAT ADVOCATES DO

Advocates in the FA Patient Advocacy Program:

- Collaborate with Researchers and Industry: Offer input on clinical trial design, logistics, and participant experience.
- Serve as Ambassadors: Connect the research and FA communities, supporting recruitment and sharing research findings.
- Influence Policy: Work with legislators and rare disease organizations to shape state and federal policy.
- Engage with Regulatory Agencies: Represent the FA community's needs and experiences to federal agencies.
- Share Lived Experiences: Bring the patient perspective to scientific meetings, educational events, and fundraisers.

Our advocates have already been actively involved in various initiatives, including peer reviewing bone marrow failure research for the Department of Defense, offering valuable patient and caregiver perspectives on study materials for FA Quality of Life research, and sharing their personal experiences as speakers and panelists at FCF meetings and events.

INTERESTED?

The program is open to adults living with FA, caregivers, and bereaved family members. By becoming an FA advocate, you can help ensure that the voices of those affected by Fanconi anemia are at the forefront of research and policy decisions. The next round of training is planned for early 2025. Please submit your applications (available on our website) by the end of the year to be included in this session. Join us—your voice matters!

The Painted Turtle Brings Family Fun to Full Color!

Since 1991, the FA Family Retreat has been a tradition that surprises, supports, and uplifts FA families worldwide. Whether families travel from within the United States or across the globe, the retreat offers connection, educational sessions, resources, expert consultations, and psychosocial support—all during a fun-packed long weekend.

As we continue this long-standing tradition, we are excited to celebrate and reflect on the memories made at the 2024 FA Family Retreat this August!

This year, we held camp at The Painted Turtle in Lake Hughes, California. Finding the right venue to meet our community's unique needs took careful thought, planning, and searching. Given how important and rare this opportunity is for our families, we wanted to ensure it was the perfect fit—and The Painted Turtle exceeded our expectations.

The incredible energy, diverse activities, and amazing volunteers and staff made this experience unforgettable.

Each family was paired with a "family pal" whose mission was to maximize fun while ensuring everyone's safety (the countless sunscreen reminders and hydration breaks were proof!). By the end of camp, these volunteers became beloved members of each family.

From creative arts to accessible-friendly zip lining, the fun was endless. Alongside their family pals, children with FA and their siblings enjoyed a busy weekend of archery, horseback riding, science projects, making s'mores, boating, and fishing.

While parents were busy gaining knowledge, gathering resources, and attending support sessions with long-time FCF partner and psychosocial expert Nancy Cincotta, there were daily activities to engage the entire family as well. Parents strutted down the runway with their

children in a crazy fashion show, competed in egg drop challenges, and many even joined the stage for the grand finale talent show.

The crowd favorite? The Silly Olympics! The field was scattered with stations, each offering an excuse for families to splatter each other with paint and shaving cream as they played games and took on challenges. The ultimate showstopper was the surprise arrival of a firetruck on the hillside, which doused the campers with water straight from the hose. This quickly turned into a slip-and-slide party that was a welcome break from the heat, leaving everyone smiling.

The Painted Turtle made having fun, being goofy, and forming lifelong friendships among campers easier than ever. Families who initially hesitated to let loose during the abundant group songs were dancing out the door by the end of camp. Even with a packed agenda, The Painted Turtle had an incredible ability for knowing when to balance downtime with activities that recharged everyone. The accepting and magical environment that they created was felt by all and we are very grateful for their thoughtful efforts.

While educational opportunities during the FA Family Retreat are critical in helping parents care for and advocate for their loved ones with FA, we also recognize the ongoing challenges of living with FA. This year, the most heartwarming feedback came from a common perspective of both parents and children: a shared sense of belonging and a rare chance to let go of their daily stresses.

Parents connected over shared experiences, while children and teens expressed that camp was a place where they finally didn't feel different.

At FCF, these feelings of belonging, support and respite are the ultimate success stories. Whether or not you could attend camp this year, know that the well-being of this community remains at the heart of our mission.

We want to extend a huge thank you to The Painted Turtle for partnering with us and providing our families with an exceptional and well-deserved experience. We can't wait to see what The Painted Turtle has in store for 2025!

ARE YOU READY TO JOIN US NEXT SUMMER?

How do I apply? Applications for the FA Family Retreat will open in early 2025, with invitations and details shared via email and FCF's social media platforms. Apply early, as spots are filled on a first-come, first-served basis.

Who can go? Families with children with FA aged 18 and under are welcome to apply. Priority will be given to newly diagnosed families and first-time attendees. Travel scholarships are available through FCF to assist with expenses. Individuals with FA 18+ are welcome to join as volunteers!

Supporting Mental Health and Wellbeing for Individuals with Fanconi Anemia and Caregivers: Key Insights and Recommendations

At the Fanconi Cancer Foundation (FCF), we understand the critical importance of addressing mental health alongside physical health for individuals with Fanconi anemia (FA) and their family caregivers. Recent research on the mental health challenges faced by adults with FA has revealed significant insights that guide us in supporting the well-being of our community.

OVERVIEW OF PSYCHOSOCIAL EXPERIENCES IN ADULTS WITH FANCONI ANEMIA

The *Psychosocial Experiences of Adults with Fanconi Anemia: A Participatory Mixed-Methods Research Study* offers valuable insights into the mental health of adults with FA. The study, led by Drs. Megan Voss and Kathleen Bogart with an advisory council of FA adults, was funded by FCF in 2022. The study highlights that adults with FA report significantly poorer health-related quality of life compared to the general population. This includes higher rates of anxiety, depression, fatigue, sleep disturbance, and pain, as well as challenges related to cognitive function, physical function, and social participation.

One of the study's key findings is that half of the participants screened positive for symptoms of post-traumatic stress disorder, with 33% screening positive for anxiety and 25% for depression. Additionally, 44% reported a known mental health disorder at some point in their lives, and half of those were currently experiencing active symptoms. Finally, 15% believed they were experiencing symptoms of a mental health disorder but had not been diagnosed with one. These findings highlight the high prevalence of mental health concerns within our community and the critical need for increased mental health support and screening by licensed professionals.

UNDERSTANDING THE EXPERIENCES OF FAMILY CAREGIVERS

While this study focused on adults with FA, it is essential to acknowledge the experiences of family caregivers as well. Research on cancer caregivers shows that their mental health is closely linked to the health of the person they care for. When their loved ones receive mental health care, caregivers are three times more likely to access mental health support themselves (Litzelman, et al., 2021).

Caregiving is an immense responsibility. The burden of caregiving can lead to significant

"While there are many competing priorities for FA funding, the findings presented here support the need for ongoing research in the areas of mental health, wellbeing, and quality of life."

mental health challenges, with caregivers reporting higher rates of anxiety and depression than non-caregivers (Cleveland Clinic, 2022). Although we lack specific data on FA caregivers, we can infer from our community that they face similar challenges and need mental health support just as much as those they care for. Additional research focused specifically on caregivers is needed.

SUMMARY OF EVIDENCE-BASED INTERVENTIONS TO SUPPORT MENTAL HEALTH & WELLBEING

While there is much more to learn about the mental health challenges faced by the FA community, there are strategies that can be helpful. By addressing psychosocial factors, managing physical symptoms, and utilizing mental health interventions, the hope is to reduce the risk of individuals with FA developing mental health diagnoses.

Taking a whole-person approach to caring for individuals with FA and their caregivers is the most effective way to both modify risk and enhance overall well-being. This approach is best understood in the context of a broad definition of well-being, such as the one depicted in the model from the University of Minnesota. Well-being includes being happy and healthy in the broadest sense—not just physically, but also mentally, emotionally, and spiritually. It is possible for a person to experience significant physical health challenges yet still maintain high levels of well-being. Well-being is a state of being in balance or alignment, encompassing feelings of contentment, peace, purpose, harmony, and safety (University of Minnesota, 2024).

This model of well-being identifies six domains that impact mental health: health, purpose, relationships, community, security, and environment. The strategies recommended below can help enhance well-being by focusing on these domains.

At FCF, we are committed to prioritizing mental health as we continue to foster a supportive and resilient community.

We encourage you to explore the full report on our website, where you can find detailed evidence-based recommendations and insights to support mental health and well-being within the FA community. The report breaks down strategies into three practical levels, including those that can be done at the individual level, with the support of the local community, and with the support of one's healthcare team. Individuals with FA and their family caregivers can advocate for themselves by providing their local providers with this information.

Furthermore, five key themes emerged from the research, which provide deeper insights into the mental health experiences of adults with FA:

1. Living with FA is a Full-Time Job: Managing FA is a constant, all-encompassing task that requires ongoing attention and effort.
2. Struggling to Find and Access Mental Health Care: Many adults with FA experience difficulties in finding mental health professionals who understand their unique needs, let alone their chronic illness.
3. Facing Stigma and Isolation: Stigma and trauma take a toll on mental health. Discrimination, body image issues, gender norm violations, isolation, and healthcare trauma can lead to mental health symptoms.
4. Grief, Loss, and Community Connections: Connecting with the FA community has many benefits, but it can also involve grief when friends encounter serious medical problems.
5. Finding Ways to Cope and Stay Optimistic: Despite the challenges, many individuals with FA use various strategies to cope, such as staying occupied, cultivating optimism, and embracing their uniqueness.

These findings emphasize the need for tailored mental health care and the importance of trauma-informed support. Because individuals with FA often live far from FA Centers of Excellence, these findings also underscore the need for collaboration with local primary care providers, oncology teams, and mental health professionals.

FA Support Around The World

UPDATES FROM 2024

In 2024, Fanconi anemia (FA) communities across the globe have seen great progress, thanks to the dedication of support groups committed to improving the lives of individuals affected by FA. From empowering clinicians with new cancer prevention protocols in Portugal to developing psychological care services in Spain, these initiatives are making a tangible difference. This article highlights recently awarded grant-funded projects, alongside updates from key meetings in Brazil and Europe, where FA families and experts came together to advance knowledge, strengthen support networks, and drive global collaboration.

2024 GRANT RECIPIENTS

FANCONI ANEMIA SUPPORT VIETNAM

Vietnam | $10,000

Building a Comprehensive FA Support Network and Enhancing Medical Expertise in Vietnam

Fanconi Anemia Support Vietnam (FASV) is using their grant to establish a support group and enhance FA knowledge within Vietnam's medical infrastructure. Their project aims to create a network connecting FA patients with experienced doctors through an online database and social media. They plan to integrate FA treatment protocols into the Ministry of Health's program, and support genetic testing and clinical trials. By building a digital toolkit and collaborating with a tele-nurse, FASV will improve access to care and empower patients, especially those in rural areas, to manage their condition effectively.

FUNDACIÓN ANEMIA DE FANCONI

Spain | $10,000

Establishing a Psychological Care Unit for FA Patients and Families

The Fanconi Anemia Foundation is launching a Psychological Care Service Unit to provide essential support for FA patients and their families in Spain. This initiative addresses the critical shortage of psychological professionals and long wait times within the Spanish healthcare system. The service aims to create a safe, supportive space where individuals can receive psychological care to manage stress, anxiety, depression, and other emotional challenges associated with FA. By offering personalized support and self-care tools, the project seeks to enhance emotional well-being, improve quality of life, and assist with social adaptation throughout the disease process.

PORTUGUESE FANCONI ANEMIA RESEARCH NETWORK

Portugal | $10,000

Enhancing FA Clinician Training and Advancing Medical Procedures and Cancer Prevention

PFARN is advancing FA care in Portugal by implementing the comprehensive "Add-on Screening" program for cancer prevention developed by our partners in Germany (Eunike Velleuer-Carlberg and Christine Krieg). The project focuses on training Portuguese clinicians, organizing collaborative screening sessions, and establishing a robust follow-up process. Key activities include virtual training, practical screening sessions, and introducing the "Power 2U/Oral Self-Screening" program to empower FA patients with tools for early detection. This initiative aims to improve cancer prevention practices and ensure consistent, high-quality follow-up care for FA patients across Portugal.

Attendees at the first FA Europe Meeting in May 2024 in Paris

FANCONI ANAEMIA SUPPORT AUSTRALASIA

Australia and New Zealand | $10,000

Exploring the Experiences of FA Patients and Families in Australia and New Zealand

This project aims to gain a deeper understanding of the experiences of individuals with Fanconi anemia (FA) and their families in Australia and New Zealand. By examining the issues encountered before, during, and after diagnosis, the project seeks to identify patterns of missed diagnosis and their impact. This research will provide valuable insights for medical specialists, leading to improved diagnostic practices and earlier intervention. This group plans to interview study participants, publish findings in a peer-reviewed journal, and disseminate results to medical professionals and networks to enhance understanding and care for FA patients in the region.

BRAZIL AND EUROPE HOST FA GATHERINGS

In January, 75 families impacted by Fanconi anemia gathered in Curitiba, Brazil, for a transformative meeting supported by a grant from FCF last year. The event showcased the profound impact of community support, highlighted by the contributions of our Cancer Awareness Team, including Dr. Eunike Velleuer-Carlberg and Christine Krieg, who traveled from Germany to train local physicians and dentists in cancer screening for FA patients. The dedication of local clinicians such as Dr. Carmem Bonfim, Dr. Cassius Torres-Pereira, and Dr. Daniela Pillonetto was evident in the enthusiastic turnout and the strong sense of camaraderie among attendees. This gathering underscored our commitment to fostering a collaborative environment and making a meaningful difference in the lives of those affected by Fanconi anemia.

In May, the FA Europe Network held its inaugural pan-European scientific meeting at the historic Saint-Louis Hospital in Paris. This landmark event marked a significant milestone in the global collaboration for FA research. The venue, known for its historical achievement of the world's first successful umbilical cord blood transplant, set the stage for an inspiring gathering. Keynote speaker Professor Eliane Gluckman and Dr. Isis Sroka, CEO at FCF, provided valuable insights into the progress of FA treatment and research. The meeting, attended by 92 participants from 12 countries, highlighted the expanding interest and commitment to FA research, including the involvement of new and younger clinicians and scientists. The event fostered valuable connections and generated strong momentum for future collaborative efforts, reinforcing the power of international teamwork in advancing the care and understanding of Fanconi anemia.

From Shock to Strength: Our FA Diagnosis

BY ALEX TAYLOR

Hi! My name is Alex, and I am a single mom to my almost 4-year-old daughter, Tinslee. We discovered Tinslee has Fanconi anemia (FA) the same day we first learned about the condition. At her two-year check-up, her pediatrician recommended blood work because Tinslee hadn't been growing as expected. This led to a referral to the Hematology Oncology department at Children's Mercy Kansas City. After months of testing, we received the diagnosis.

Initially, we had no warning signs apart from her being very petite. The diagnosis brought an overwhelming mix of shock, disbelief, and heartbreak. I made the mistake of Googling FA, and what I found shattered me. I spent the first two days in tears, questioning why this was happening to my daughter. I wondered why children get sick and turned to prayer, hoping to find solace in a bigger picture. Although I had never been very religious, I needed something to hold onto.

It took me weeks to come to terms with the fact that there were no easy answers. I couldn't change the past or the diagnosis, so I focused on educating myself and becoming Tinslee's biggest advocate. We underwent all the necessary tests, scans, and procedures, and spent a year going in for lab work and check-ups.

One day, I was added to the Fanconi Cancer Foundation (FCF) support group on Facebook. Finally, I had a community of people who understood our journey. They encouraged me to seek a second opinion. Although we had been receiving care at Children's Mercy Kansas City, they didn't have an FA specialist. The closest specialist was in Cincinnati, so we drove 10 hours straight for Tinslee's appointment. We left feeling encouraged and empowered.

Tinslee is now preparing for a bone marrow transplant in Cincinnati. We don't know when it will happen, but we are confident she will receive the best care possible. While I still have moments of random tears or anger at the world for the hand my daughter was dealt, I find strength in the support of our family, friends, and community. Together, we will make it through.

Resources for Caregivers

FA CONNECT: ALL KINDS OF GRIEF

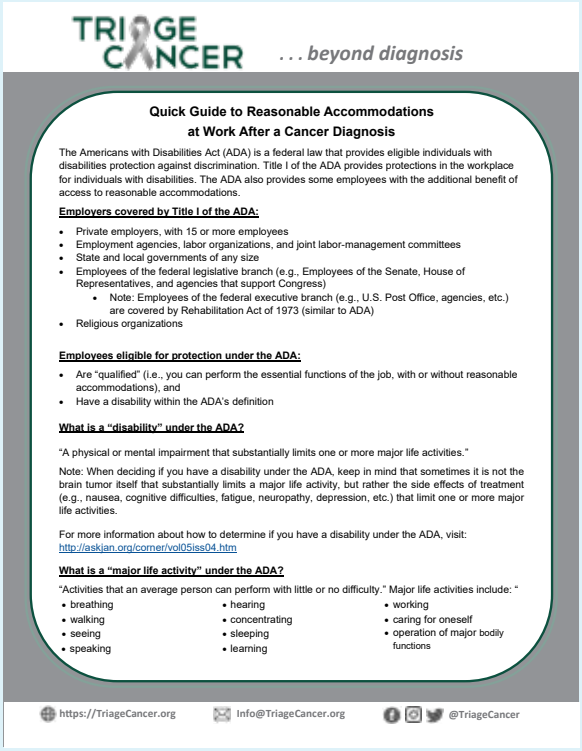
In the FA community, we experience grief at the loss of members of our FAmily, grief about parts of our lives that are different than we expected, and anticipatory grief about the losses we predict may occur. Join fellow FA caregiver, Allison Breininger, for a group discussion about how all types of grief show up in our lives on October 26th at 10am PT. To register for this session, please visit the Events page on our website.

TRIAGE CANCER: QUICK GUIDE TO CAREGIVING

What are your employment/workplace rights as a caregiver? This "**Quick Guide to Caregiving**" from Triage Cancer discusses rights and accommodations that many caregivers are unaware are available to them. From fair employment laws to leave laws, this guide provides helpful information for caregivers. See also their guide for **Reasonable Accommodations**. While employers are not required to provide reasonable accommodations to caregivers, some are willing to, and this guide answers frequently asked questions about what these accommodations are and how to ask for them. You can always find more resources similar to these in Triage Cancer's Resource Library.

COURAGEOUS PARENTS NETWORK:

Founded by a parent of a child with a rare genetic disease, Courageous Parents Network seeks to provide support and community for caregivers everywhere. They offer hundreds of educational videos, courses, guides, blog posts, virtual events and more. Their education ranges over many different topics from advocacy to clinical trial navigation to caregiver well-being and so on.



TRIAGE CANCER . . . beyond diagnosis

Quick Guide to Reasonable Accommodations at Work After a Cancer Diagnosis

The Americans with Disabilities Act (ADA) is a federal law that provides eligible individuals with disabilities protection against discrimination. Title I of the ADA provides protections in the workplace for individuals with disabilities. The ADA also provides some employees with the additional benefit of access to reasonable accommodations.

Employers covered by Title I of the ADA:

- Private employers, with 15 or more employees
- Employment agencies, labor organizations, and joint labor-management committees
- State and local governments of any size
- Employees of the federal legislative branch (e.g., Employees of the Senate, House of Representatives, and agencies that support Congress)
  - Note: Employees of the federal executive branch (e.g., U.S. Post Office, agencies, etc.) are covered by Rehabilitation Act of 1973 (similar to ADA)
- Religious organizations

Employees eligible for protection under the ADA:

- Are "qualified" (i.e., you can perform the essential functions of the job, with or without reasonable accommodations), and
- Have a disability within the ADA's definition

What is a "disability" under the ADA?

"A physical or mental impairment that substantially limits one or more major life activities."

Note: When deciding if you have a disability under the ADA, keep in mind that sometimes it is not the brain tumor itself that substantially limits a major life activity, but rather the side effects of treatment (e.g., nausea, cognitive difficulties, fatigue, neuropathy, depression, etc.) that limit one or more major life activities.

For more information about how to determine if you have a disability under the ADA, visit: http://askjan.org/corner/vol05iss04.htm

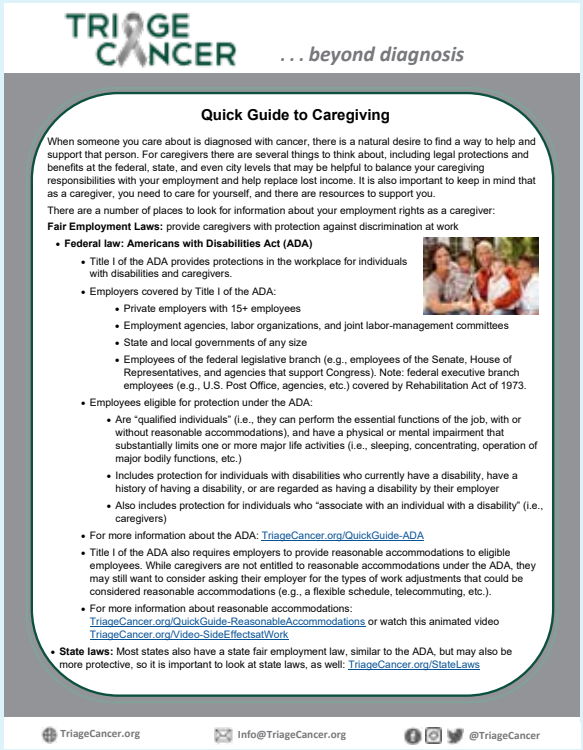
What is a "major life activity" under the ADA?

"Activities that an average person can perform with little or no difficulty." Major life activities include: "

- breathing
- walking
- seeing
- speaking
- hearing
- concentrating
- sleeping
- learning
- working
- caring for oneself
- operation of major bodily functions

https://TriageCancer.org Info@TriageCancer.org @TriageCancer

triagecancer.org/QuickGuide-ReasonableAccommodations-PDF



TRIAGE CANCER . . . beyond diagnosis

Quick Guide to Caregiving

When someone you care about is diagnosed with cancer, there is a natural desire to find a way to help and support that person. For caregivers there are several things to think about, including legal protections and benefits at the federal, state, and even city levels that may be helpful to balance your caregiving responsibilities with your employment and help replace lost income. It is also important to keep in mind that as a caregiver, you need to care for yourself, and there are resources to support you.

There are a number of places to look for information about your employment rights as a caregiver:

Fair Employment Laws: provide caregivers with protection against discrimination at work

- **Federal law: Americans with Disabilities Act (ADA)**
  - Title I of the ADA provides protections in the workplace for individuals with disabilities and caregivers.
  - Employers covered by Title I of the ADA:
    - Private employers with 15+ employees
    - Employment agencies, labor organizations, and joint labor-management committees
    - State and local governments of any size
    - Employees of the federal legislative branch (e.g., employees of the Senate, House of Representatives, and agencies that support Congress). Note: federal executive branch employees (e.g., U.S. Post Office, agencies, etc.) covered by Rehabilitation Act of 1973.
  - Employees eligible for protection under the ADA:
    - Are "qualified individuals" (i.e., they can perform the essential functions of the job, with or without reasonable accommodations), and have a physical or mental impairment that substantially limits one or more major life activities (i.e., sleeping, concentrating, operation of major bodily functions, etc.)
    - Includes protection for individuals with disabilities who currently have a disability, have a history of having a disability, or are regarded as having a disability by their employer
    - Also includes protection for individuals who "associate with an individual with a disability" (i.e., caregivers)
  - For more information about the ADA: TriageCancer.org/QuickGuide-ADA
  - Title I of the ADA also requires employers to provide reasonable accommodations to eligible employees. While caregivers are not entitled to reasonable accommodations under the ADA, they may still want to consider asking their employer for the types of work adjustments that could be considered reasonable accommodations (e.g., a flexible schedule, telecommuting, etc.).
  - For more information about reasonable accommodations: TriageCancer.org/QuickGuide-ReasonableAccommodations or watch this animated video TriageCancer.org/Video-SideEffectsatWork
- **State laws:** Most states also have a state fair employment law, similar to the ADA, but may also be more protective, so it is important to look at state laws, as well: TriageCancer.org/StateLaws

TriageCancer.org Info@TriageCancer.org @TriageCancer

triagecancer.org/quickguide-caregiving-PDF

Katherine De Los San Receives the 2024 W for Adults with FA

The De Los Santos family first experienced the complexities of Fanconi anemia as they endured the devastating loss of their daughter, Gracie, who passed away from complications following her bone marrow transplant. Later, genetic testing revealed that Katherine would be born with FA as well.

Katherine faced bone marrow failure at age eight, and thankfully her health stabilized after a successful transplant. She went on to pursue her academic dreams, earning an undergraduate degree in Biology with a minor in Chemistry. When the pandemic struck, she returned home and immersed herself in healthcare. She worked as a medical assistant in pediatrics and cardiology, all while contributing to her community through volunteer work with Be The Match, The Icla da Silva Foundation, and mission trips with her church.

Her passion for healthcare led her to pursue a master's degree at Mercer University last fall, where she began the Preclinical Sciences program with the goal of attending medical school.

However, just five days before Christmas, her path took a sudden turn when she was diagnosed with esophageal cancer during the Fanconi Anemia Cancer Screening Study, conducted at the NIH.

"Cancer may have affected my body, but it has not conquered my spirit. It has taken some strength, but never my joy or resilience. I am here today, stronger and more determined than ever." — Katherine De Los Santos

ntos
inn / Byrd Award

This cancer diagnosis changed Katherine's life. It felt like any hope to become a doctor and pursuing her passion came to a standstill.

Dr. Giri and the team at the NIH guided her through understanding her health. Their attentiveness and expertise made her feel truly seen and heard, especially after her cancer went undetected despite previous doctor visits. Though receiving this diagnosis and treatment paused her aspirations, the outstanding care she received reignited her passion to make a difference in the world of healthcare.

Now in recovery, she is back on track with her studies and is preparing to apply to medical school this year. The profound impact that compassionate, knowledgeable healthcare providers can have on a patient's life stayed with Katherine since her cancer diagnosis. Recognizing that many rural communities, including those in her home state of Georgia, lack access to high-quality healthcare, she is determined to make a difference by serving children in these underserved areas.

We are honored to support Katherine as she pursues her goals by presenting her with the 2024 Winn/Byrd Award. We are confident that Katherine will continue to make an impact within healthcare and undoubtedly become a resource to patients and children in rural communities and beyond, ensuring they have access to the care and attention they deserve.

Robin Lewis is Honorary Recipient

This year, the committee honors Robin Lewis who has made remarkable progress, alongside his wife, in establishing *Matches on the Map*. Through this initiative, they have traveled across South Africa, recruiting bone marrow donors and raising awareness about the need for lifesaving matches.

Robin's goal is to sign up 1,000 potential donors each year while creating sustainable recruitment efforts at universities and schools that will continue long after their journey. Additionally, they are integrating FA support groups within South Africa as they continue to grow their educational talks and recruitment drives. We eagerly anticipate seeing the lives they will touch. Congratulations, Robin!

As we journey through 2024, the Fanconi Cancer Foundation (FCF) is experiencing a significant leadership transition that marks both a farewell and a new beginning. We want to take a moment to celebrate the remarkable contributions of our former Executive Director, Mark Quinlan, and to warmly welcome our new CEO, Dr. Isis Sroka.

HONORING MARK QUINLAN'S LEGACY

Mark Quinlan has been a pillar of growth and innovation for FCF. His tenure saw the expansion of our international community and the creation of an international support grant program, which has significantly extended our reach and support to FA families worldwide. Mark's vision and dedication have been instrumental in recruiting and training a growing, highly competent team, establishing a solid foundation for future growth. Mark worked to professionalize our organizational infrastructure and demonstrated strong financial stewardship that allowed for impactful growth in research, programs, and fundraising.

"I want to express my deepest gratitude to everyone who has supported the organization and me personally over the years: staff, board members, and of course, FA families," said Mark. "Without you, the organization would not be as strong as it is. I am honored to have been the leader of this incredible organization and I will eagerly watch as it continues to advance research and support families affected by FA."

Celebrating Leadership Transitions at FCF: A Tribute to Mark Quinlan and Welcome to Dr. Isis Sroka

Mark's involvement went beyond administrative duties. He actively participated in family fundraising events, demonstrating his commitment to our cause. Notably, he rode across Iowa in the first Endure for a Cure ride, and participated in many a golf tournament.

Under Mark's leadership, FCF has grown stronger and more cohesive, setting a robust groundwork for the future. If you've gotten the opportunity to know Mark over the years, you know his friendly, easy-going sense of humor and his kind and generous spirit. We are deeply grateful for his unwavering dedication and the lasting impact he has made on our community.

WELCOMING DR. ISIS SROKA

As we bid farewell to Mark, we are thrilled to introduce Dr. Isis Sroka as our new CEO. Dr. Sroka joined FCF in 2018 as Director of Scientific Operations and has served as Chief Scientific Officer since 2023. Her strategic vision and ability to foster key partnerships have been pivotal in advancing our vision and mission over the past six years.

Dr. Sroka established the international Fanconi cancer and gene editing consortia, both groundbreaking initiatives that have united researchers globally to accelerate discoveries in FA and related cancers. She led the launch of the new FCF FA Patient Registry, facilitated direct support for individuals with FA diagnosed with cancer through the FA Cancer Virtual Tumor Board, and spearheaded strategic collaborative initiatives with external partners like Stand Up To Cancer and the American Association of Cancer Research. These efforts have driven transformational research efforts, resulting in significant advancements in our fight against FA cancer.

Beyond these initiatives, Dr. Sroka served as editor-in-chief of the newly updated Clinical Care Guidelines and spearheaded the FRIENDS Data Project, a first-of-its kind large-scale international collaboration that will provide the infrastructure for data-driven research solutions. Dr. Sroka's vision for FCF has also fostered significant collaborative opportunities between the FA community and FA researchers, and a heightened emphasis on enhancing well-being and empowerment for the FA community. You can read more about this vision in our strategic plan.

"I am deeply humbled and honored by the opportunity to continue my journey with the FA community and FA researchers in our shared mission to combat FA. There is no cause more meaningful to me than finding a solution to this disease, which touches the lives of so many I deeply care about," said Isis. "As we embark on this next chapter, I look forward to fostering a spirit of unity and progress as we pursue innovative solutions that inspire hope and address the challenges posed by FA."

LOOKING FORWARD

With Dr. Sroka at the helm, we are excited about the future of FCF. Her proven track record, compassionate, patient-centered approach and strategic insights will undoubtedly drive us towards new achievements in research and support for FA families.

We extend our heartfelt gratitude to Mark Quinlan for his years of dedicated service and welcome Dr. Isis Sroka as she embarks on this new journey with us. Together, we will continue to advance our mission and strive for a future where FA and associated cancers are no longer a threat.

Thank you for your continued support and trust in FCF. We look forward to working together to achieve our shared goals.

Fundraising Shoutouts

"It seems only yesterday that Amy Frohnmayer was coming to my living room for violin lessons, and Kirsten Frohnmayer was sitting on the couch, taking in every note. I feel so fortunate for this opportunity to contribute to scientists' efforts to make FA just one more treatable condition." – Sharon Schuman

A GRAND FINALE WITH A HUGE IMPACT

Sharon Schuman is a lifelong friend and involved supporter of those with FA, as well as an outstanding violinist who has put her talent toward funding FA research through the longest-standing fundraising event with FCF. After an incredible quarter of a century, this year marked her grand finale! She hosted her 25th Annual Benefit Concert at co-founder Lynn Frohnmayer's home, where she was joined by pianist Brian Hsu of the University of Oregon School of Music to perform one of Mozart's gorgeous sonatas. Her dedication to fundraising through this beautiful event has raised nearly $500,000 over its lifetime! Thank you, Sharon, for all you have done and continue to do for those with FA!

A MILESTONE TO CELEBRATE

Julia Pless celebrated an amazing milestone this year: her 20th bone marrow transplant birthday. Even better, it fell on the day of the eclipse! She decided this was a sign to create a fundraiser, "20 Years: A Celestial Celebration," where she reached out to her friends and family and raised nearly $4,000 with their generous support. Julia, we are so thankful for your thoughtful effort in raising funds for FCF and grateful that milestone rebirthdays like yours are possible due to the significant progress made in FA research through support like this. We can't wait to celebrate the next one with you!

A CROWD FAVORITE RETURNS WITH A BANG!

This April, Play for FA reintroduced their longstanding event, Band, Brew, and BBQ in Richmond, Virginia. As one of the largest fundraising events in the history of FCF, this event engages guests to learn about FA and the impact they can make while enjoying live music, a lively auction, photo stations, great food, and more. Making a comeback after its pause during the pandemic years, this beloved event, created by FA families in Virginia, inspired donors and sponsors as they raised an astonishing $180,000! We can't thank the Vandermeys, McQueen, and Wisniewski families enough for their outstanding impact and dedication to funding FA research!

24TH CHRIS HULL MEMORIAL SIGMA PI OPEN

This June marked the 24th Chris Hull Memorial Sigma Pi Open, an annual golf tournament in memory of Chris Hull. Chris was a 1989 Penn State graduate, a member of Sigma Pi fraternity, and at age 33, he was one of the oldest FA patients when he passed away in 1999. Now, a friendly rivalry gathers between Chris' fraternity brothers and his hometown friends and family to remember him and raise funds for FCF. This year, they raised over $10,000 for FA research! We are grateful to the Hull community and the Sigma Pi fraternity for your continued support!

A FLOOD OF ORANGE SUPPORT FOR COLEY!

An orange storm took over Massachusetts this summer, all in support of those with Fanconi anemia. Once again, Coley's Cause Memorial Golf Tournament blew us away, raising over $37,000 for FA research. Coley's Cause honors Nicole "Coley" Levine, who passed away in 2004 from complications from FA. Coley's family, along with their outstanding friends, keep her memory alive as they raise funds to improve the prognosis and life expectancy of those with FA. Throughout the lifetime of the tournament, this community has met an incredible milestone and raised over $500,000 to FCF! The lives they have improved through Coley's memory are truly remarkable!

MOLLY CELEBRATES LIVING LIFE TO THE FULLEST!

Molly Nash, an individual with FA, turned 30 this year. To celebrate, she hosted a virtual fundraiser in support of FCF and raised nearly $1,500. As she asked her friends and family to donate, she shared, "When I was born, my family couldn't have imagined I would be celebrating a birthday 30 years later. I've lived through so much in my three decades, and I have so much more living to do! My friends (and me) depend on continued research so we can celebrate many more birthdays." Thank you, Molly, for thinking of the FA community during your special day and letting your supporters know the huge difference they've made and continue to make in the lives of those with FA!

Join the FAM Club

What's the FAM and why join? Here's what the Brannock family has to say:

"Jason is vigilant to the constant and ongoing threat of cancer. Being able to help fund the research on a monthly basis is one small way we can repay the community and, hopefully, help find new ways to improve the quality of life for Jason and others with FA."

— Mike Brannock, FA Parent

By joining the Fanconi Anemia Mission (FAM) Support Club, you become part of a special group of monthly supporters dedicated to finding answers that will better the lives of children and adults with FA and associated cancers.

The FAM club may be a perfect way to fit supporting research into your life by:

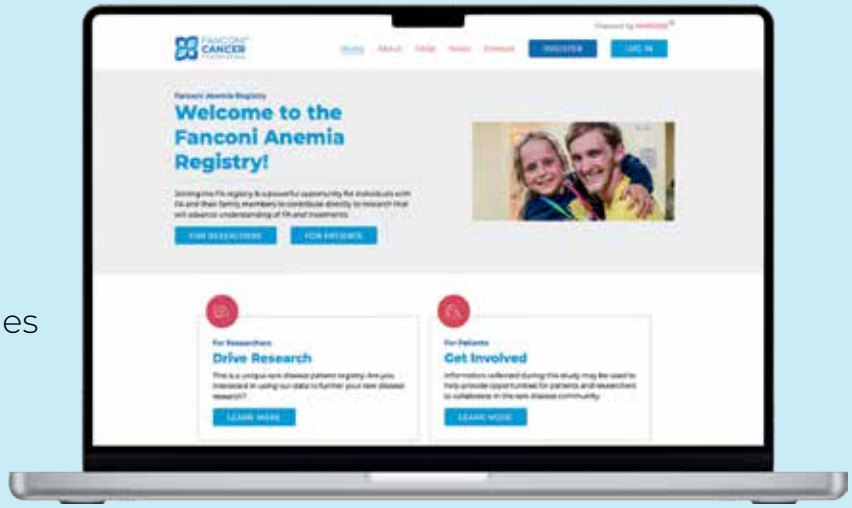
- Fitting your budget
- Giving continued support to families worldwide
- Helping FCF plan for the future and expand!

Join the FAM and check out the perks: **https://fundraise.fanconi.org/JoinTheFam**

The New FA Registry is Faster, Simpler, Better. Have you joined yet?

IMPROVEMENTS:

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



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

YEP, WE NEED YOU!

We are excited to announce the launch of our newly updated FA Patient Registry! We get it; you've probably filled out many an FA registry. And we know that you already have so much on your plate, which is why we've made our registry shorter and easier to fill out.

By joining the FA Patient Registry, you will be contributing to crucial research that drives progress and makes a real difference. We're rare, so collective momentum is key, and your participation is invaluable!

2024 GOAL:

50
new participants!

AS OF SEPTEMBER, WE ARE AT 28!

HOW TO JOIN THE REGISTRY

Visit fanconiregistry.iamrare.org to create your private account

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

Know that you're helping researchers find answers faster

JOIN THE FA REGISTRY TODAY: HTTPS://FANCONIREGISTRY.IAMRARE.ORG

In Loving Memory

JACIE SORROWS
5/20/2016 - 7/5/2024

Jacie was joyful and happy through all of life's obstacles. Her body was sick, but her spirit was not. She loved everyone she met, and she was always making new friends everywhere she went. She was diagnosed with VACTERL at birth and FA at a year old. Her body unfortunately got too sick to be able to undergo a transplant and she passed away July 5, 2024. To know her was to love her.

— Tracy Sorrows, Jacie's Mother

JOAN EUGEN MATEMU
8/19/2017 - 4/30/2024

Joan my lovely daughter, I am very proud to be your mother. Joan, you were strong, calm and very tolerant throughout your journey with Fanconi anemia. You fought for your life without complaints during transplant. You always thanked me for caring for you and gave me hope that you would be okay and back to a normal and happy life. That gave me so much strength. Thank you, Joan, for being my comfort and strength during Ivan's death and all the time we grieved together. I'll be your legacy. I'll be your voice. You live on in me. So, I have made the choice to honor your life through helping others who face the same FA journey. I love you always in my heart, Joan. I miss you, my baby.

— Winlady Boniface, Joan's Mother

AGUSTINA MILAGROS KAUCIC
10/8/2015 - 7/30/2024

Agus was a very loved, cared for, and educated girl. She was super sweet, kind, and happy, with dreams to become an actress, singer, dancer and model. She was a great warrior, always happy and with a smile on her face. She taught us to love unconditionally and that despite the pain, you can be happy. Her departure leaves an immense void and a legacy. We are proud and honored to have been her parents. Agus, we love you eternally. Agus is and will be infinite.

— Cecilia Cordoba, Agustina's Mother

BAYLOR LINDSAY
6/4/2003 - 7/25/2024

Baylor's memory will forever live on in the hearts of those who were fortunate enough to have known him. Those who knew him best knew that he showed love through humor and teasing. We hope he is continuing to laugh with us and at us from heaven.

— Jessica Lindsay, Baylor's Mother

BELINDA ANGEL
11/2/1981 - 8/6/2024

Belinda was a devoted daughter, sister, wife, and mother who loved her family so much. She impacted many in her life through her career as a kindergarten teacher and a cheerleading coach. She was very creative, loved baking, and had a great appreciation for art. Belinda's faith and her daily Bible readings gave her courage and strength for the health battles she faced. Her bubbly, dynamic personality was infectious to everyone in her life, and she will be missed deeply by everyone she knew and loved.

— Shannon Angel, Belinda's Husband

HAFSA SHAHID
11/19/2014 - 4/20/2024

Hafsa was a loving child with a kind heart. Her exceptional brain with compromised genetics that were not her fault. She was inquisitive, with future dreams of becoming a professor. She was best at reciting Quran with her beautiful crisp voice. She was playful, shy, and loving, like every child in the world.

— Shahid Iqbal Awan, Azad Kashmir, Hafsa's Parents

WITH THANKS

FAmily Fundraisers 2024

From January through August 2024, the FA community has raised more than $1.3 million for the Fanconi Cancer Foundation! 184 community fundraisers raised funds with 88 raising at least $500. Each dollar donated advances research and family support, making a difference for all those affected by FA and their families. Sincere thanks to every family and individual who worked so hard to raise funds in honor or memory of loved ones.

$500,000 +
Brian Kuell

$100,000 - $150,000
Kevin and Lorraine McQueen
Gerard and Cynthia Vandermeys

$25,000 - $99,999
Jeanne Atkinson
Lynn Frohnmayer
Orion and Lisa Marx
Paul and Rena Rice
Coley's Cause Charitable Trust

$15,000 - $24,999
Mark and Linda Baumiller
Mauro and Kerrie Cazzari
Charles and Kathleen Hull
Maria and Bill Katris

$10,000 - $14,999
James and Jennifer Armentrout
Ryan and Rebecca Brinkmann
Andrea and Robert Sacks

$5,000 - $9,999
Brian Adel and Carly Eade
Adam and Marissa Becker
Scott and Windy Farmer
David and Mary Ann Fiaschetti
Tanner and Jessica Lindsay
Alaina Mercer
Ron and Alice Schaefer
Tyler Vitale
Nigel and Ann Walker

$1,000 - $4,999
Michael and Jennifer Aggabao
Rachael Alaniz
Tyler Morrison and Rachel Altmann
Darryl Blecher and Diana Fitch
David and Sarah Borden
Chris and Jennifer Branov
Sean and Allison Breininger
Matt and Jackie Burton
David Guidara
David and Kim Chew
Bill and Pat Danks
Marie Di Mercurio
James and Crystal Eubank
Britteny Ferrin
Elizabeth and Richard Butts
Andrew and Jennifer Gough
Rachel and Zachary Gratz-Lazarus
Dr. Michael Greenberg
Owen Hall and Margaret Kasting
John and Martina Hartmann
John and Karilyn Kelson

Stephen and Jennifer Klimkiewicz
Chad and Lauren Kriner
Timothy and Mary Ann Lana
Robert and Anna Langtry
Eugene and Renee Lemmon
Brian Horrigan and Amy Levine
Keith and Jessica Loo
Leighsa and Paul Makowicz
Alexandra Marshall
Kelly McKenna
Kate & Daniel Montgomery
Lisa and Jack Nash
Karen and Nicholas Nehmi
Peggy Padden
Peter and Janice Pless
Neil and Emily Robison
Bradley and Darlene Starner
Joe and Jacqueline Vona
Matt and Krissie Wisniewski

Up to $999

Peter and Donna Abramov
Yocheved Appel
Dr. Vicki Athens
Judith Hoffman and Lawrence Backman
Faith Barbe and Shane Estelle
Amanda Barber
John and Audrey Barrow
Israel and Mary Jo Becerra
Melissa Beckers
Angela Bedoya Family and Friends
Jasmine Bennetsen
Domenico Bertolucci and Federica Bonati
Richard and Tena Boson
Edward and Barbara Brookover
Donald and Danielle Burkin
Frank Cabral
Hugo Canalli
Robert and Barbara Capone
Cassie Carlson
Amy Chadburn
John and Kim Connelly
Rebekah Contri
Valeen Gonzales
Lea Ann and Jeff Stiller
Mahazareen Dastur
Jeremy and Michelle DellaValle
Egil Dennerline and Nanna Storm
Jake Dorman
Edward and Janice Duffy
Oscar Duque and Yanira Ramirez
Sharon Swanson
Seth Parelman
Chloe Eminger
Carole Felmy
Daryn and Carol Franzen
Brian and Cindy Fuller
Emmanuel and Dana Gallegos
Melody Ganz
Melissa Gonzales
Madeline and Bryn Gregg
Benjamin and Stephanie Griggs
Rachel Grossman
Young Ju Ha
Eric and Elisabeth Haroldsen
Robert and Victoria Hathcock
Donna Behlke
Eleanor and Roger Herman
Andre Hessels and Rutger Boerema
Ryan and Brenda Hinshelwood
Stephanie and Thomas Hutter
Shane and Colleen Irvin
Jeff and Beth Janock
Stan and Michelle Kalemba
Ashleigh Kamsickas
Lila Keleher
Mark Lamm and Angella Stitely-Lamm
Callie Toal and Family
Darla and Dustin Strasburg
Philip Nelson and Candy Lindsey
Col Gregory & Lt Col Lynnette Lowrimore
William and Jacquelyn Lucarell
Kristina Mack
Kirstine la Cour Rasmussen
Aaron and Nicki Marsters
Angie Keaton
Daniel and Angie McMahon
Aaron Means
John and Barbara Miller
Adam and Olivia Mindle
Ian and Tricia Mitchell
Georg and Sabine Mohr
Judi Montgomery
Griff and Cecilia Morgan
Tim and Ashleigh Pinion
Ashley Motil
Amy Murphy
Tony and Lina Nahas
Louis and Virginia Napoles
Robert and Mary Nori
Nancy Nunes
Susan Ortiz
William, Kelli and Kit Owen
David and Stacy Ownby
Caroline Nguyen
Mark and Diane Pearl
Melissa, Dave and Axel Perdue
Janice and Kenneth Sysak
Marcos and Silvana Pineschi Teixeira
P. Michael and Kay Proctor
Lynn and Shirley Quilici
George Reardon
Shelby and Kayla Richardson
Mark Ritchie and Lisa Mingo
Kevin and Katherine Rogers
Craig and Alisha Rushing
Richard and Marilyn Sablosky
Ty Sanders
Colleen Satterlee
William and Connie Schenone
Eric Schlueter
Colleen Scholl
Sean and TaLisa Sebourn
Bryan and Karen Siebenthal
Karin Staab
Adam and Jennifer Stewart
Sharla and Josh Strickland
Ana Alejandra Tabar Concha, Elvin Estevez Lopez and Violeta Tabar
Alex Taylor
Bianca Taylor
Holly and Iain Taylor
Devon and Charles R. Tessier
Bruce and Loreen Timperley
Kathy Tomalesky
Mark and Susan Trager
Michael and Beth Vangel
Theresa and Louis Viola
Joe and Wendy Vitiritto
Brie Whittler
Robert and Julie Williams
Jason and Joan Woodle
Wesley and Susan Wycoff

Upcoming Events

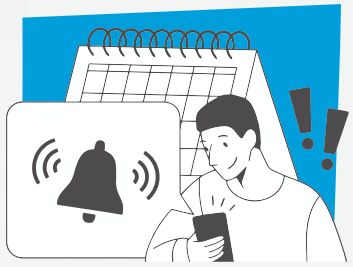
OCTOBER 2024

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

- October 10, 2024
  Vandermeys Family | Virginia

FA CONNECT | ALL KINDS OF GRIEF

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



DON'T FORGET TO DOWNLOAD THE FAEXAM APP

Step up your proactive approach to health by incorporating self-screenings for your mouth. Alongside regular dental and ENT check-ups, you can easily perform these screenings using the FAexam app, developed with our partners at the German FA Support Group. Available for free download for iPhone or Android. Just search "FAexam".

How to Help

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

Scan to donate now.

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