



Impact Report

2024



Advancing Research
To Help People With
FA Live Full Lives



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Letter from the CEO



We began 2024 by changing our name to the Fanconi Cancer Foundation to reflect our commitment to addressing the biggest issue our community faces: cancer. To that end, we saw significant advancements in FA cancer research. The cancer detection trial at the National Institutes of Health (NIH) continues to grow, offering hope for earlier interventions and, ultimately, better outcomes for FA patients. This year we launched our Fanconi Research Initiative for Education, Networking, and Data Sharing project, creating a collaborative space for FA clinicians and researchers to connect and accelerate discoveries. We also partnered with the American Association for Cancer Research (AACR) to fund an innovative cancer research grant to an early-stage investigator.

We've seen exciting progress in gene therapy—progress that feels like a light at the end of the tunnel for so many families. Likewise, the gene editing consortium completed the first year of their project, addressing DNA issues at the core of this disease.

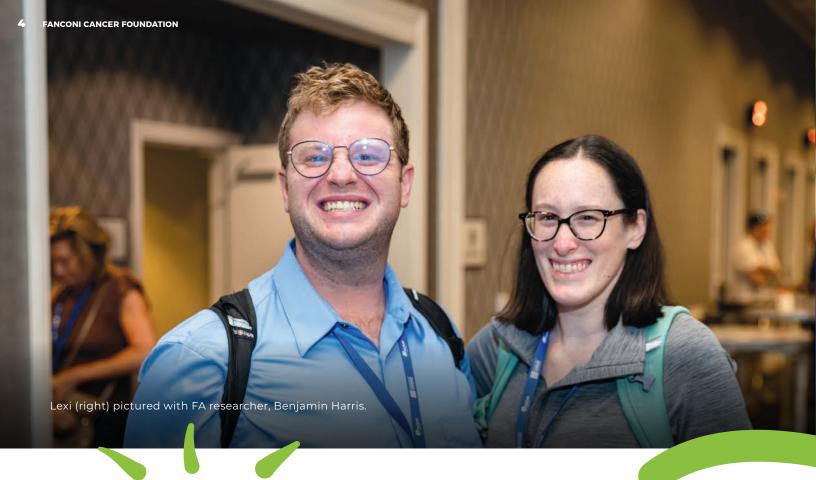
But it's not just the science that has given us hope. This year we expanded our advocacy efforts, making sure that FA voices are heard where they matter most—at every level of decision-making, from research design to awareness and fundraising. Researchers completed a comprehensive study on the psychosocial impact of FA on adults with the disease and provided much-needed intervention suggestions for navigating the day-to-day challenges of this disease.

We know this work is deeply personal—it touches every aspect of life for those living with FA and their families. While we all wish that research could move faster and a cure could be found tomorrow. It's the moments of connection, discovery, and hope that drive us and remind us why this work is so important. We aim to share and celebrate some of these moments throughout this report.

With your continued support, we will keep pushing forward. You are part of a community that lifts one another up, supports groundbreaking research, and ensures that no one faces FA alone. Together, we can take on whatever comes next and make an even bigger impact in 2025.

Thank you for standing with us. You make this work possible.

With warmth and gratitude, Isis Sroka, PhD CEO, Fanconi Cancer Foundation



The Power of Your Support

Finding Strength in Science and Community: Lexi's Story

When Lexi Marshall was diagnosed with Fanconi anemia (FA) as an adult in 2020, she attended her first FA Adult Retreat feeling isolated and nervous. What she found was far beyond her expectations. "The welcome I received was so warm it nearly lit me on fire," Lexi recalls, remembering the friendships she immediately formed with fellow patients, Fanconi Cancer Foundation board members, and researchers.

Over the years, Lexi has seen firsthand how advancements in FA research have given hope to patients like her. From breakthroughs in bone marrow transplants to emerging gene therapy trials and cancer prevention research, the strides have been monumental. "Learning about the integration of psychosocial research into future clinical studies fills me with hope—as it should for every family affected by FA," she says.

Beyond the science, Lexi has formed deep connections with researchers and clinicians who dedicate their lives to changing the course of FA. She's also giving back by helping fellow adults manage their care as a member of the FA Adult Council. "The accomplishments of the past 40 years in bone marrow transplants have been astounding, and I can see the future is in good hands as scientists tackle the next set of challenges that we, as patients, face: cancer," Lexi reflects.

Living with FA means you are a part of a vast community of interconnected people: from researchers, doctors, donors, and fellow families. Thanks to donors like you, people like Lexi find strength in research and relationships that go far beyond the lab.



Connection and Healing at the Annual FA Family Retreat

Since 1991, the FA Family Retreat has been a cornerstone for families affected by Fanconi anemia (FA). This year's retreat, held for the first time at The Painted Turtle in Lake Hughes, California, was a reminder of the profound impact your support has on the lives of those living with this all-encompassing disease.

For families facing the constant challenges, fear, and heartbreak of FA, the retreat offers more than just a fun weekend. It's a chance to connect with others who truly understand, experience moments of relief, and find solace in shared experiences. Each family was paired with a "family pal" whose focus was ensuring both fun and safety, creating a space where families could just be. Children with FA and their siblings took part in activities like horseback riding, archery, and fishing, while parents gained valuable insights and support through educational and psychosocial sessions.

One of the retreat's highlights was the Silly Olympics, where families let go of their worries, getting splattered with paint and shaving cream. The surprise visit from a firetruck turned into a joyous water fight, offering a refreshing break from the heat and leaving everyone laughing. The Painted Turtle's thoughtful balance of fun and relaxation created an environment where families could recharge and truly be themselves.

For many, this weekend was more than a break from the daily challenges of FA. It was a time to connect deeply with others, share stories of courage and hope, and feel that sense of belonging that is so rare. Your generosity made this possible, offering families a moment of respite from the overwhelming weight of FA. Thank you for making such an important difference in their lives.

Key Breakthroughs in FA Research

A YEAR OF PROGRESS

ADVANCING FA-SPECIFIC CANCER TREATMENT: THE AFATINIB CLINICAL TRIAL

The Impact: This pioneering clinical trial marks a significant step toward targeted therapy for FA-associated head and neck cancer. Researchers in Germany and Spain are recruiting patients to evaluate the efficacy and safety of Afatinib—a cancer treatment that could offer fewer toxic side effects than current options.

If successful, this trial could redefine cancer care for people with FA, providing a much-needed, specialized treatment approach.

Lead Investigators: Ramon Garcia-Escudero, PhD and Jordi Surrallés, PhD

NONTOXIC TRANSPLANTS: THE PROMISE OF ANTIBODY CONDITIONING

This clinical trial aims to develop a safer cell therapy for Fanconi anemia by using an experimental antibody instead of chemotherapy to prepare for transplant. This approach may reduce toxicity while supporting donor stem cell and immune system recovery. The study also demonstrates that haploidentical donor transplants are feasible with excellent outcomes. This advancement significantly broadens donor availability, ensuring that nearly every child in need has the opportunity to receive a life-saving transplant—even from a half-matched family member!

Lead Investigator: Rajni Argarwal, MD



Katherine De Los Santos: 2024 Winn/Byrd Award Winner

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.

FA CANCER SCREENING STUDY: A PIONEERING EFFORT IN EARLY DETECTION

The Impact: This groundbreaking longitudinal study is transforming cancer detection in individuals with FA.

With 70+ participants already enrolled, this study establishes a centralized cancer screening approach and lays the foundation for a sustainable resource-sharing network, which will drive future research and improve treatment outcomes.

Lead Investigators: Neelam Giri, MD; Sharon Savage, MD

THE STAND UP TO CANCER TEAM: ADVANCING PREVENTION FOR FA-RELATED CANCERS

The Impact: In collaboration with Stand Up to Cancer and three other cancer organizations, a research team worked to find new ways to prevent and treat Fanconi anemia head and neck cancers. Their work led to major discoveries that brought us closer to a prevention strategy. This team:

- Discovered that inflammation plays a key role in how FA cancers start and grow.
- Identified that common anti-inflammatory drugs (NSAIDs) may help prevent FA-related cancers.
- Found specific genetic changes in cells collected from FA patients' mouths, even before visible cancer appeared.
- Created a new computer-based tool to analyze tissue samples, which will be available to FA researchers worldwide.
- Took the first steps toward launching a clinical trial to test cancer prevention strategies for people with FA.

Lead Investigators: Agata Smogorzewska, MD, PhD; Barbara Burtness, MD; Markus Grompe, MD; Silvio Gutkind, PhD; Amanda Paulovich, MD, PhD; Alexander Pearson, MD, PhD; and Bing Zhang, PhD

A NEW ERA IN FA TREATMENT: THE PROMISE OF GENE THERAPY

The Impact: Bone marrow transplants have been the main treatment for bone marrow failure for people with Fanconi anemia (FA), but they come with risks, including complications and a higher chance of developing cancer later in life. Now, outcomes from a groundbreaking clinical trial funded by Rocket Pharma are offering hope for a safer alternative. The trial has shown that patient's bone marrow successfully accepted the corrected cells (a process called engraftment), and led to lasting improvements in blood counts. Most importantly, this approach does not require chemotherapy, avoiding many of the harsh side effects of traditional transplants. This exciting progress moves us closer to a future where people with FA will have a safer, more effective treatment option.

Lead Investigators: Paula Río, PhD; Julián Sevilla, MD PhD; Juan Bueren, PhD

A BOLD MISSION: CORRECTING ALL 23 FA GENES

The Impact: To fully treat FA, scientists must find a way to correct the root cause of FA, or mutations in the 23 FA genes. The Fanconi Cancer Foundation recently funded a "Dream Team" comprised of seven top gene-editing experts and Nanovation Therapeutics to pave the way with this pioneering work. Over the past year the team has been successful in developing animal models to test gene correction, fixing FA mutations in lab-grown cells, and exploring new ways to deliver gene therapy inside the body. Genetic correction of mutations offers the promise of preventing the need for bone marrow transplants and the onset of cancer in people with FA

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

These breakthroughs mark major progress in the fight against FA-related cancers, from early detection to targeted treatments that minimize harm.



Expanding Collaboration



RESEARCH INITIATIVES MAKING AN IMPACT WORLDWIDE

THE FANCONI RESEARCH INITIATIVE FOR EDUCATION, NETWORKING, AND DATA SHARING (FRIENDS)

The Impact: Studying FA is challenging due to barriers in data sharing. The FRIENDS Consortium unites researchers and clinicians worldwide through a first-of-its-kind data commons, centralizing global clinical data to accelerate advances in FA research.

Major Milestones in 2024

- Global Collaboration: 29 representatives from 13 countries formally committed to this initiative by signing a Memorandum of Understanding to establish a governance structure for the data commons.
- Standardizing FA Research: International participants convened to define best practices for data sharing and collection on FA disease manifestations and cancer.

MENTAL HEALTH STUDY: UNDERSTANDING PSYCHOLOGICAL WELL-BEING IN ADULTS WITH FA

Dr. Kathleen Bogart and Dr. Megan Voss led a large-scale study on mental health in adults with Fanconi anemia, uncovering significant findings about psychological well-being in this community and an urgent need for accessible mental health care for adults with FA.

Key Insights:

 High rates of Post-Traumatic Stress Disorder, anxiety, and depression

- Challenges with stigma, fertility concerns, and transplant experiences
- Strengths found in FA community support and resilience

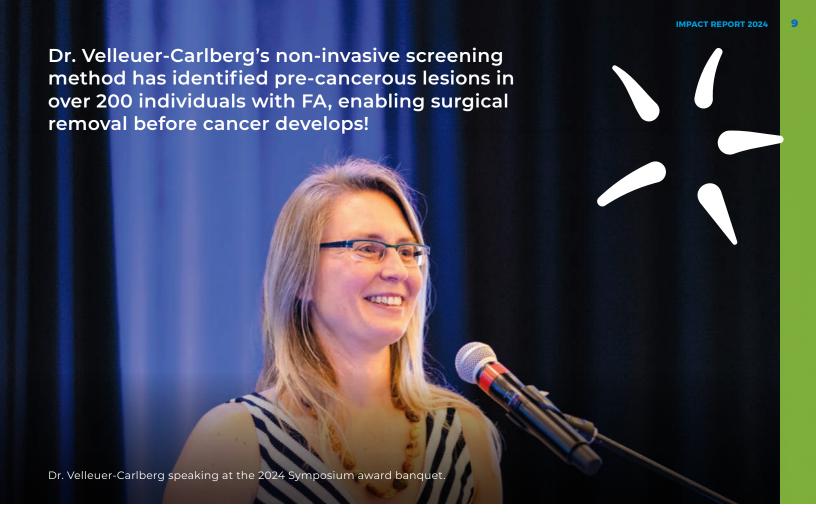
FUELING INNOVATION: 2024 FCF-AACR NEXTGEN GRANT FOR TRANSFORMATIVE CANCER RESEARCH

In collaboration with the American Association for Cancer Research (AACR)—a global leader in cancer research—the Fanconi Cancer Foundation is proud to fund Dr. Meng Wang's groundbreaking work as he explores how nutritional and metabolic pathways can be harnessed to reduce the risk of cancer in people with FA.

What's on the Horizon?

This trailblazing project has the potential to unlock game-changing insights into cancer prevention for the FA community. By investing in bold, next-generation science, we are fueling discoveries that could rewrite the playbook on FA cancer risk!





Dedication that Changes Lives

DR. EUNIKE VELLEUER-CARLBERG: RECIPIENT OF THE 2024 PIONEER AWARD FOR THERAPEUTIC ADVANCEMENT

At the forefront of Fanconi anemia (FA) research, Dr. Eunike Velleuer-Carlberg has dedicated her career to transforming the way we detect and treat cancer in individuals with FA. A senior physician and research associate at both Helios Klinikum Krefeld and Heinrich-Heine-University Düsseldorf, she specializes in pediatric hematology-oncology, cancer prevention, and early detection strategies.

Direct Impact: Her groundbreaking work has tackled one of the greatest challenges for adults with FA—squamous cell carcinoma (SCC), the leading cause of mortality in this population. Historically, SCC in FA was diagnosed too late, when treatment was no longer curative. Screening methods were invasive and difficult, and little was known about early cancer precursors. But thanks to Dr. Velleuer-Carlberg's 14 years of research, we now have

a non-invasive screening method that allows for early detection and successful treatment of oral cancer in FA patients—a life-changing breakthrough.

Looking Ahead: Dr. Velleuer-Carlberg envisions a future where non-invasive cancer screening becomes standard worldwide, drastically improving both the quality and length of life for those with FA. She also hopes to see increased health literacy within the FA community, empowering individuals to take an active role in their health and well-being.

Her work represents the very best of what dedicated research, collaboration, and community-driven progress can achieve. Thanks to supporters like you, we can continue making these breakthroughs possible.

OPPORTUNITIES MADE POSSIBLE IN 2024

Your Support Empowers the FA Community



Amplifying the FA Community's Voice:

THE FA PATIENT ADVOCACY PROGRAM

Since its launch in 2024, the program has empowered 22 advocate leaders in the FA community to share their lived experience and be active collaborators in shaping FA research and initiatives that promote holistic well-being for people with FA.

PROGRAM GOALS:

- Amplify the voices of the FA community.
- Provide training to empower advocates in their roles.
- Foster respectful, impactful partnerships between advocates and external stakeholders.
- Improve FA research experiences by involving advocates in research design, implementation, recruitment, and dissemination of results

Focusing on Whole-Person Health:

ADVANCING PSYCHOSOCIAL RESEARCH & COLLABORATION

Understanding and addressing the mental health challenges faced by the FA community is an ongoing effort. While much remains to be learned, a whole-person approach—one that considers all factors of an individual's health—is the most effective way to both modify risk and enhance quality of life for individuals with FA and their caregivers.

THE PSYCHOSOCIAL CONSORTIUM

Meeting regularly throughout the year, the Psychosocial Consortium plays a key role in driving mental health research in FA.

CONSORTIUM GOALS:

 To better understand the landscape of FA quality of life research, and determine the direction for future research initiatives. Share project updates to foster collaboration, innovation, and reduce redundancies among studies.

SPOTLIGHT: PSYCHOSOCIAL LUNCHEON

At the FA Symposium's psychosocial luncheon, patient advocates and researchers came together to discuss the growing focus on mental health and quality of life in FA research and the immediate needs of the FA community. Bringing these groups together allows those working in the field to learn from those they support through discussions centered on:

- Enhance participation of individuals with FA in research design and areas of study focus.
- Expand access to psychosocial support
- Develop standardized measures for future quality of life studies.

The enthusiasm among participants underscores a strong commitment to advancing wellbeing initiatives—a crucial step toward a healthier future for the FA community.

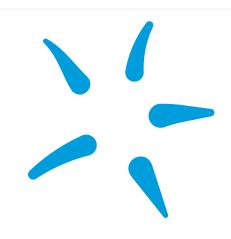
Your support and generosity makes all of this possible for our community. You enable collaborative efforts, multiplying our power of impact and propelling progress, resources, and hope for FA families.



FA adults engage with researchers at the 2024 Symposium poster session.

PROGRAMS THAT CONTINUE TO GROW

How You've Helped Meet the Community's Needs



Making Expert Advice Available to All

THE FCF VIRTUAL TUMOR BOARD (VTB)

As a rare disease, physicians worldwide are often unfamiliar with the complexities of FA. The VTB connects FA specialists with physicians nationwide to review current cases together. This program continues to expand each year, having now reviewed 53 cancer cases since its inception in 2020. This year, the VTB addressed a range of cases, including head and neck, anogenital, gastrointestinal, and brain cancers. The program is highly valued by treating physicians who may be less familiar with FA and provides significant reassurance to FA patients, knowing their cases are reviewed through an FA-focused lens.

THIS YEAR:

- 16 cases brought to the VTB
- 19 referrals from treating physicians
- 26 FA specialists participated to provide feedback on patient cases

More Voices Give More Progress

THE FA PATIENT REGISTRY'S RELAUNCH

2024 marked significant progress for the Fanconi Anemia Registry with the launch of the updated platform. The new registry includes streamlined surveys designed for easier completion, focusing on quality of life, as well as the early detection, diagnosis, and treatment of cancer. Participants also provide information about their care teams, enabling the registry to serve as a connection point to reach out to clinicians to provide resources and encourage participation in FCF programs. Additionally, an incentive program

was introduced, offering a \$50 virtual Visa gift card to any participant who completes all surveys within the year.

RELAUNCH RESULTS:

- 164 participants on the new platform
- 558 surveys submitted
- 67 participants completed all surveys

Community when Needed Most

POSTMARKED WITH LOVE (PWL)

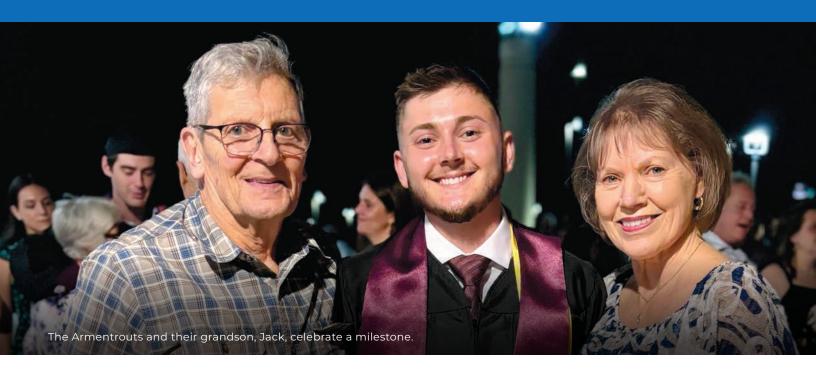
Handwritten notes filled with words of encouragement and comfort were sent to individuals with FA, caregivers, and those grieving to offer support during especially difficult times or to celebrate milestones in their FA journey.

THIS YEAR:

- 28 card recipients
- 530 cards received
- 25 active volunteers
- 6 PWL card making parties



Honoring the Generosity of Our Dedicated Donors



John and Evelyn Armentrout

When our grandson, Jack, was nine, our son shared news that changed our family forever—Jack had been diagnosed with Fanconi anemia. Like many, we had never heard of this rare disease, and what we learned was devastating: his future was uncertain, and time was not on our side.

Determined to support Jack, his parents, and his sisters, we turned to the Fanconi Cancer Foundation—a community committed to education, family support, and groundbreaking research. Through FCF, Jack's family found solace and connection through shared experiences at Camp Sunshine. In 2019, with the full support of FCF's resources, a dedicated medical team, a strong mother by his side, and a supportive

family back home, Jack persevered through a grueling bone marrow transplant and returned home five months later.

Jack is our miracle grandson, a testament to the power of medical research, unwavering faith, and FCF's incredible work. In 2024, we proudly watched him graduate from college and marry his high school sweetheart. This year, we will celebrate Jack's 24th birthday—an occasion we once feared he might never reach.

Supporting FCF remains one of our highest priorities. The advancements we've witnessed fuel our faith in the future, and we will continue giving as they push forward in the search for better treatments and, ultimately, a cure.



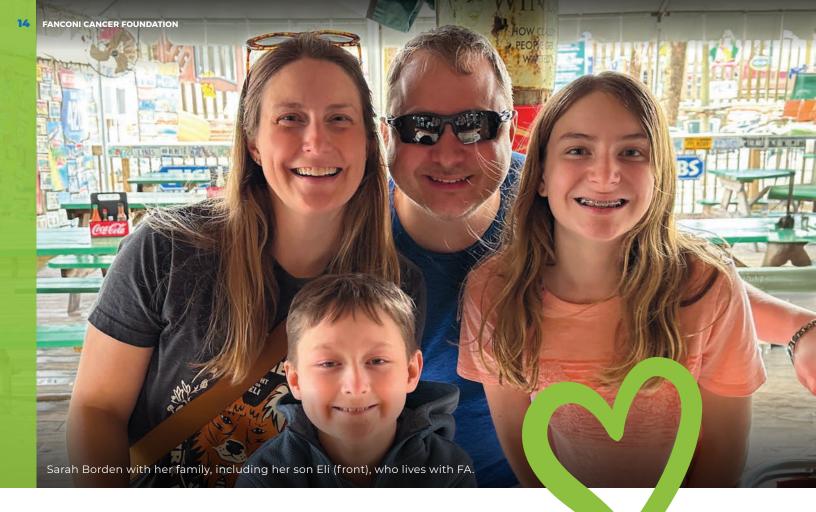
Jackie & Paul Jags

Fanconi anemia isn't just a rare disease to us it's personal. Our niece and nephew, Alex and Jacqueline Vandermeys, were both diagnosed with FA in 2012. We will never forget the day their parents, Cindy and Gerard, shared the news with us—the heartbreak and devastation in their eyes as they processed what this diagnosis meant for both of their children.

At the time, life expectancy for FA patients was grim. But today, thanks to incredible advancements in treatment and care, the outlook has improved dramatically. That progress is a direct result of the research funded by the Fanconi Cancer Foundation, and it is why we give.

Our admiration for the Vandermeys family runs deep. Their strength, resilience, and unwavering hope have been an inspiration. But beyond them, we are continually moved by the FA community—by the way families rally together, support one another, and advocate for scientific breakthroughs.

Every breakthrough brings us one step closer to a cure. Knowing that our contributions help extend and improve lives gives us purpose. It is an honor to support this important work, and we will continue to do so with hope for a future where FA is no longer a threat.



The Borden Family

As a parent and caregiver to my son, Eli, who lives with FA, it's easy to feel powerless when managing a rare disease. The endless waiting and the unknowns of the future weigh heavily on your heart. Watching your child endure grueling treatments—the chemotherapy with its harsh side effects, the struggles at school, the battle against constant fatigue and appetite loss—can make you feel like everything is out of your control

Yet, even though I can't change the diagnosis, there is immense power in deciding how to respond. Loving my son unconditionally has always been my greatest role as his caregiver, but I wanted to do more—to make a bigger impact and create meaningful change. I needed to fight for him. That's why I became an advocate for FCF.

FCF's Advocacy Program allows me to help others understand the profound challenges of FA from both the patient and caregiver perspective. I've collaborated with researchers and doctors in clinical trial programs, ensuring that family

voices are at the center of critical decisions. I've worked with companies developing treatments for FA, guiding them in crafting communications that speak directly to caregivers.

Being part of the advocacy program is deeply meaningful and rewarding. Every time I share our story with scientists, clinicians, and industry leaders, I hope it makes their work more personal and impactful. My dream is that these collaborations lead to better outcomes for FA patients and more support for the caregivers who love them unconditionally.

To those who support FCF, whether through donations, research, advocacy, or simply showing up for families like mine, thank you. Your generosity fuels groundbreaking research, provides critical education, and creates a network of strength for families facing FA. Because of you, we can believe in a brighter future for our children. And for that, I am forever grateful.



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We appreciate you!

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Fundraising Highlights: Celebrating Our Community's Impact



Endure for a Cure: Pushing Limits, Fueling Hope

In its inaugural year, Endure for a Cure united participants from across the country, each taking on physical challenges to raise funds and awareness for Fanconi anemia. From running and cycling to hiking and swimming, every effort was a testament to the resilience of the FA community.

Participants' dedication—and your generosity— made this campaign a resounding success! Together, we raised an incredible \$50,000, fueling groundbreaking research and vital support for FA families.

We're thrilled to announce that Endure for a Cure will return this year! Whether you're a runner, cyclist, swimmer, or looking to create your own unique challenge, we invite you to join us once again in making an impact.

Katris Golf Tournament: Swinging for a Cure

The Katris family teed up for success with their first-ever Swinging for a Cure golf tournament, bringing together friends, family, and supporters for a day of golf, generosity, and giving back. Thanks to their dedication and the incredible support of their community, the event raised an astounding \$125,000 for FA research!

"We were thrilled with all the great support that we had for this event and touched by the generosity of everyone involved."

- The Katris Family





2024 Financial Summary

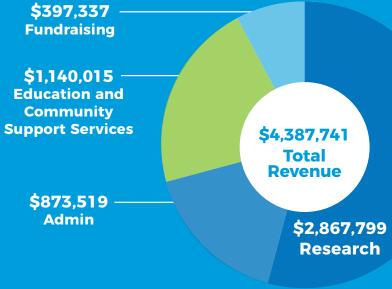


Your generosity is more than just a gift; it's the bridge between hope and science, ensuring that we don't just wish for change, we actively create it.

With your support, we empower researchers to pioneer groundbreaking approaches, develop innovative therapies, and unlock lifealtering discoveries, all aimed at transforming the lives of those impacted by FA.

We take great care to steward your generous donations. If you have any questions about how your gifts support our mission, we would love to connect with you. Please feel free to reach out to Isis Sroka, Chief Executive Officer at isis@fanconi.org or 541-687-4658. Thank you for making our mission possible.

Your Gifts at Work



Looking Ahead: 2025 and Beyond



WHAT'S NEXT?

Future Goals for the Fanconi Cancer Foundation



• Expand research initiatives, focusing on FA cancer research and gene therapy.



• Cancer prevention trial development.



• Enhance community support programs, including mental health initiatives.



• Build advocacy for researchers and internationally.



• Build international collaborations and data-sharing efforts through the FRIENDS Project.

Take Your Support to the Next Level!

JOIN THE FAM SUPPORT CLUB

By joining the Fanconi Anemia Mission Support Club, you become part of a special group of monthly supporters dedicated to finding answers. Your ongoing contributions help:

- Fit giving into your budget with affordable monthly donations
- Provide continued support to FA families worldwide
- Allow FCF to plan for the future and expand vital research

READY TO JOIN?

Contact Lauren Kennedy, Philanthropy Director at lauren@fanconi.org.

FCF introduced us to our FA family—a community that understands what we are going through because they are living it too. The support and friendships we've made through FCF have been nothing short of life-changing.

FCF isn't just a foundation—it's hope, support, and a lifeline for families like mine.

— Liz Butts. FA Parent



With Gratitude: Together We Move Forward

To our donors, families, researchers, and community members—thank you.

Your generosity fuels every breakthrough, every family connection, and every step toward a future where those with Fanconi anemia have more answers, better treatments, and greater hope.

Because of you, research is advancing. Because of you, families have a network of support. Because of you, we are building a future where FA no longer defines possibilities.

We are deeply grateful for your dedication to this mission. Together, we are making an impact that will last for generations to come

Thank you for being part of the Fanconi Cancer Foundation.

Liz Butts daughter, Allyson, who lives with FA



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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 millions, 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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