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# Impact Report



**Advancing Research  
To Help People With  
FA Live Full Lives**



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Members of FCF leadership:  
The Board of Directors, Scientific  
Advisory Board, and FA Adult Council

**Our shared  
problem is cancer.**

## INTRODUCING THE FANCONI CANCER FOUNDATION

# A New Name for a New Chapter

In 1989, Lynn and David Frohnmayer started the Fanconi Anemia Research Fund (FARF) in search of a cure for their three daughters, who were diagnosed with Fanconi anemia (FA). Since then, hundreds more FA families have joined their cause alongside researchers, clinicians, donors, fundraisers, staff, and volunteers.

Thanks to the collective energy and drive of the FA community, together we have made truly remarkable progress. Life expectancy of people with FA has more than doubled as cell transplant outcomes have drastically improved thanks to research supported by this organization. We have discovered 23 FA genes, including the two breast cancer genes, *BRCA1* and *BRCA2*, which connected our rare disease to cancer.

Despite the success of improving bone marrow failure, we understand, more than ever, that FA is a cancer susceptibility disease. This means that faulty DNA repair resulting from FA mutations causes an extremely high risk of cancer. Cancer is now understood to be the most significant problem that people with FA may face in their lifetimes.

As the leading foundation dedicated to supporting research on this disease, we must intensify our focus on this urgent and currently unsolved problem to discover new and better solutions.

**We are excited to announce a new name for this new era of our organization: The Fanconi Cancer Foundation (FCF).**

While the name of the disease remains unchanged, our approach must align with the most pressing challenges faced by the community living with it. That's why the Fanconi Cancer Foundation is focusing on preventing, detecting, and treating cancer in people with FA. By studying the root causes of FA cancers, FCF is helping those with FA and informing the treatment of cancer beyond the FA community.

Our expanded focus on FA cancer research does not mean a reduction in services or other research initiatives, but an evolution to better understand and address the complexities at the root of FA. FCF will continue to provide resources, education, community, and unwavering support for those affected, all while deepening our understanding of all aspects of FA. We will continue to support research in areas such as bone marrow failure, FA Neurological Syndrome, mental health, well-being, and other FA-specific issues. Our commitment to the FA community remains steadfast.

Our future research initiatives are geared towards establishing and nurturing new, innovative partnerships. We aim to collaborate with leading physician scientists, industry partners, other patient driven organizations, and funders who share the mission of advancing cancer research.

We know that community is what has enabled us to make incredible change and it is our hope that together, we will solve FA once and for all.

We deeply appreciate your ongoing support, spanning from the past to our present, and extending into our shared future.

*Mark Quinlan, MPA, Executive Director*

*Isis Sroka, PhD, Chief Scientific Officer*

*Lisa Mingo, Board President*

*Lynn Frohnmayer, MSW, Co-Founder*





## WHY CANCER AND WHY NOW?

As the leading foundation dedicated to supporting research on FA, we must intensify our focus on the most urgent and currently unsolved problem: cancer.



## HOW ARE WE TAKING ON CANCER?

- We fund innovative and collaborative research teams to tackle the root cause of FA.
- We chart a clear path for early detection, prevention, and treatment of FA cancers.
- We develop models to test new therapies.
- We fund drug discovery studies and launch clinical trials to bring therapies to people with FA.
- We empower and educate those affected.
- We provide support to those diagnosed now.



## MISSION

Our mission is to improve the lives of people affected by Fanconi anemia and associated cancers worldwide by funding exceptional research and empowering our community.



## VISION

We envision a future where we can prevent and treat the primary causes of death and disability in people with FA, enabling them to live full lives.





Adults with FA at the 2023 Retreat in Vancouver, Canada.

# Climbing one peak brought us to the base of another

RESEARCH ADVANCEMENTS SUCH AS GENE DISCOVERY AND IMPROVEMENTS IN BONE MARROW FAILURE TREATMENT HAVE INCREASED LIFESPANS. NOW WE ARE TAKING ON OUR NEW CHALLENGE: FA CANCERS.

Founded in 1989, the Fanconi Cancer Foundation celebrates 35 years of funding Fanconi anemia (FA) research, investing \$33 million in understanding the disease, pioneering therapies, and getting to the core of the problem: DNA repair.

Now, the Fanconi Cancer Foundation is the leading FA organization in the world, driving research to solve FA and associated cancers, impacting everyone affected by FA.

We focus on early detection, prevention, and novel therapies for FA cancers. We invest in preclinical models, clinical trials, and empowering our community.



## 1989

The FA Research Fund is founded by parents Lynn and David Frohnmayer.

## 2000s

Treatment outcomes for bone marrow failure skyrocket, the connection to cancer is made, and FA is redefined as a DNA repair disorder, not just a blood disease.

## 2020s

We enhance our comprehensive approach to prevent, detect and treat cancer, and initiate novel methods to prevent all manifestations of FA.

## 1990s

Our focus is on understanding the disease, identifying FA genes, and addressing bone marrow failure.

## 2010s

The first FA gene therapy trials begin. FCF makes a significant investment in understanding FA cancer, and for the first time ever, we have more adults living with FA than children, marking a major win as more kids are surviving.





# Wins You Made Possible



**Transplant outcomes improve:** Bone marrow transplant success rates went from less than 10% to over 95% today.



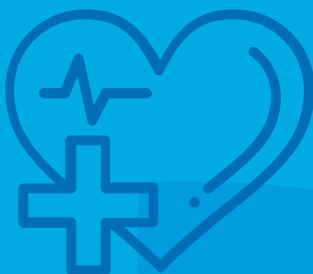
**Life expectancy increases:** When the organization was founded, life expectancy was once thought to be in the teens. Today, we have adults with FA living into their 30s, 40s, and beyond.



**Funds are multiplied:** Since this organization started, we have funded more than \$33 million in research grants. Several FA researchers funded by FCF have received major grants from larger institutions, including \$164,000,000 from the National Institutes of Health to work on FA!



**Cancer connection is made:** 23 FA genes have been discovered, including the breast cancer susceptibility genes, *BRCA1* and *BRCA2*, that play a role in the FA/BRCA DNA repair pathway.



**Cancer screening tool is successful:** Non-invasive oral cancer screenings are proven to detect pre-cancer and cancer in people with FA with high accuracy, providing an early detection method that can save lives.

FEDERAL GRANTS FUEL EXPANSION OF FA RESEARCH SUPPORTED BY FCF

# \$164,000,000

# Research You Made Possible in 2023

## YEAR AT A GLANCE

### HIGHLIGHTS:

- First ever clinical trial for FA head and neck cancer drug is funded.
- First ever FA gene editing consortium is funded, led by the top gene therapy and gene editing experts in the world.
- Comprehensive FA Cancer Screening Study is open at the NIH; more than 50 people with FA enrolled.
- 14 patients diagnosed with cancer received expert treatment counsel from our FA Virtual Tumor Board.

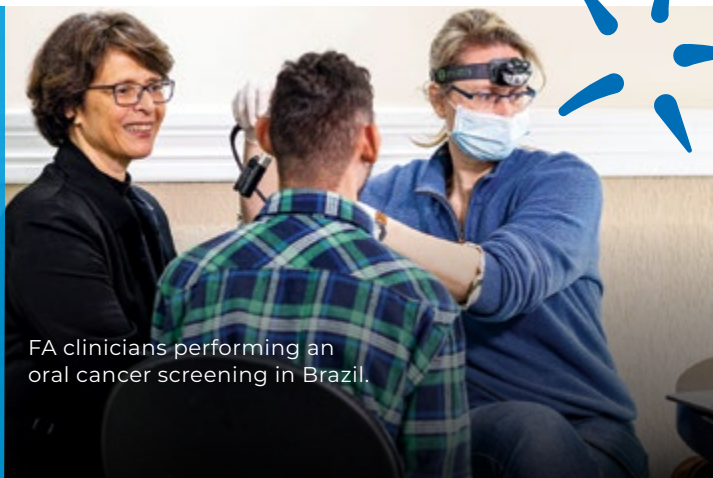
### OUR FOCUS:

#### *Early Cancer Detection and Prevention*

We know our biggest issue to tackle is cancer. The best way to do that is to prevent it altogether, or at least detect it early when outcomes are better.

Thanks to previously funded studies, we have tested the utility of using painless brush biopsies in the mouth, which accurately diagnose oral cancers in people with FA 100% of the time. This was a major milestone!

We are now globalizing this early detection approach in countries such as Brazil, France, Australia, Canada



FA clinicians performing an oral cancer screening in Brazil.

and others through our FA Cancer Consortium and in the US with a study funded at the National Institutes of Health. These efforts will enable us to prevent a significant number of cancers in people with FA, including head and neck, skin, esophageal, and anogenital cancers.

### WHAT'S NEXT:

- Developing education and empowerment programs so adults with FA and parents of children with FA know how to screen for oral cancer at home and educate their providers.
- Forming collaborations to develop early diagnostics using liquid biopsies, which involves testing blood, urine, or other bodily fluids to detect cancer in the body.

#### *Harnessing the Power of Data*

Studying a rare disease like FA is challenging because data is spread all over the world. Breakthroughs are much more likely to occur when researchers have access to data on as many individuals as possible.

That's why we've partnered with Data for the Common Good (D4CG), a group that has been leading international efforts to improve pediatric cancer and rare disease research through better data collection and storage since 2015.

Together, we will establish an FA data commons. This will be the world's first database with clinical data from people with FA from across the globe.

### WHAT'S NEXT:

- Working with international partners from over 15 countries to establish data standards and governance strategies for data sharing.



The Surralles Lab working on a new FA head and neck cancer trial.



FA researchers and clinicians in Spain are working on gene therapy and gene editing.

### *Increasing Knowledge with Model Systems*

Research models allow scientists to develop a deeper understanding of FA cancers and provide avenues for the rapid testing of drug therapies.

In addition to funding the development of models at the University of California San Francisco, Oregon Health and Science University (OHSU), Stanford, and University of Washington, we also continued to expand our FA Materials Resource at OHSU, which allows investigators from all over the world to access FA research resource at no cost to them.

#### **WHAT'S NEXT:**

- Creating model systems for a wide range of FA cancers to complement head and neck cancer model systems.

### *Shifting the Paradigm with Novel Therapies and Gene Correction*

Thanks to preclinical work that helped identify potential drugs to target FA cancer, in 2023 we funded the first-ever clinical trial for a potential non-toxic therapy for FA-related head and neck cancer.

The research team, based out of Spain, is investigating the efficacy and safety of the drug Afatinib when administered to people with FA who are diagnosed with advanced head and neck cancer.

One curative approach to FA is to correct mutations in the genes that cause the disease. We have supported recruitment and patient advocacy efforts for ongoing gene therapy clinical trials funded by Rocket Pharma in Spain and the US.

These trials use a gene therapy technology that leads to the expression of normal Fanconi proteins in bone marrow cells. Results from these trials so far show this type of gene therapy can be used to correct hematopoietic issues in children with one specific FA gene mutation, without adverse effects.

#### **WHAT'S NEXT:**

- Investigating new types of gene therapy, including base and prime editing, which offer the opportunity to correct the mutations in all 23 FA genes.

TOTAL RESEARCH DOLLARS AWARDED IN 2023

**\$2,305,083**

## Funded Projects in 2023

### CANCER THERAPEUTICS

#### **Clinical Trial to Investigate the Safety and Efficacy of Afatinib When Administered as Therapy in FA Patients**

Investigators: Jordi Surrallés, PhD; Ramon Garcia Escudero, PhD

Institutions: Santa Creu and Sant Pau Hospital Research Institute and Research Institute of the Hospital 12 de Octubre, Spain

**Amount awarded: \$324,733**

### CANCER AWARENESS AND EDUCATION

#### **FA Cancer Awareness Team Health Literacy Initiative**

Investigators: Eunike Velleuer, MD; Christine Krieg

Institutions: University of Dusseldorf, German FA Support Group

**Amount awarded: \$156,198**

### DATA INTEROPERABILITY

#### **Building a Fanconi Anemia Data Commons**

Investigator: Sam Volchenbom, MD, PhD, MS

Institution: University of Chicago

**Amount awarded: \$315,962**

### GENE THERAPY AND GENE EDITING

#### **Transforming Treatment of Inherited Bone Marrow Failure in Fanconi Anemia by Precise In Vivo Genome Editing**

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

Institutions: Instituto de Investigación Sanitaria Fundación Jiménez Díaz; Harvard University; ETH Zurich; St. Vincent's Institute Fitzroy; Fred Hutchinson Cancer Center; University of Minnesota; and Medical Center - University of Freiburg, Institute for Transfusion Medicine and Gene Therapy

**Amount awarded: \$1,258,190**

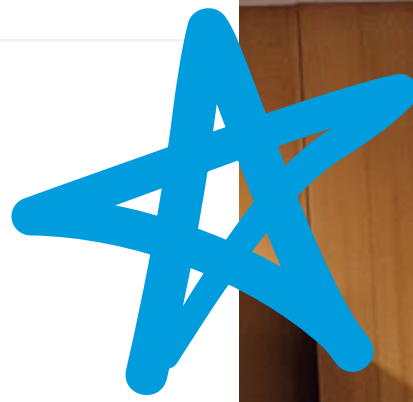
#### **Development of in Utero Therapies for Fanconi Anemia**

Investigator: Agnieszka Czechowicz, MD, PhD

Institution: Stanford University

**Amount awarded: \$250,000**

# The Genetic Revolution for Fanconi Anemia Begins Now



## WORLD-RENOWNED EXPERTS TAKE ON THE ROOT OF THE PROBLEM

The long-awaited genetic revolution for rare genetic diseases has arrived and with it, the potential to cure diseases like FA within our lifetimes using state-of-the-art gene therapy (gene replacement) and gene editing (gene correction).

Addressing the root cause of FA will require correction of each one of the 23 genes that may be mutated in individuals with FA. The replacement, or therapy of FA genes, aims to prevent bone marrow failure early in life and reduce the high risk of squamous cell cancers seen in young adults with FA.

While significant progress has improved bone marrow transplants, the treatment can increase the risk of cancer due to the use of DNA damaging agents during transplant.

Gene therapy and gene editing would bypass the need for a transplant because an individual's own stem cells would express the dysfunctional genes. Ongoing gene therapy trials for FA have shown great promise in replacing FA genes to correct hematopoietic stem cells and prevent bone marrow failure. These technologies, however, can be costly and introduce complications due to the nature of removing cells from the body to replace the FA genes.

**This is why the Fanconi Cancer Foundation is proud to develop and fund a 'Dream Team' that will advance in vivo (inside the body) gene editing technologies for FA.**

The Dream Team, recruited by FCF in 2023, is comprised of seven world-renowned gene editing experts, and an industry partner, Nanovation Therapeutics. The researchers will work together to investigate new types of gene editing, called base and prime editing, which offer the opportunity to safely correct mutations in all 23 FA genes. The team is expected to leverage their expertise and rapidly translate preclinical research into clinical trials. This represents the beginning of a very promising genetic revolution that will pave the way for a potential cure for FA.

*Thank you to the Kendall and Taylor Atkinson Foundation for the generous contribution to help fund this project.*



Researchers, clinicians, and pharmaceutical representatives working on gene therapy in FA.





# Year at a Glance: How You Empowered Our Community in 2023

## AND WHAT'S NEXT

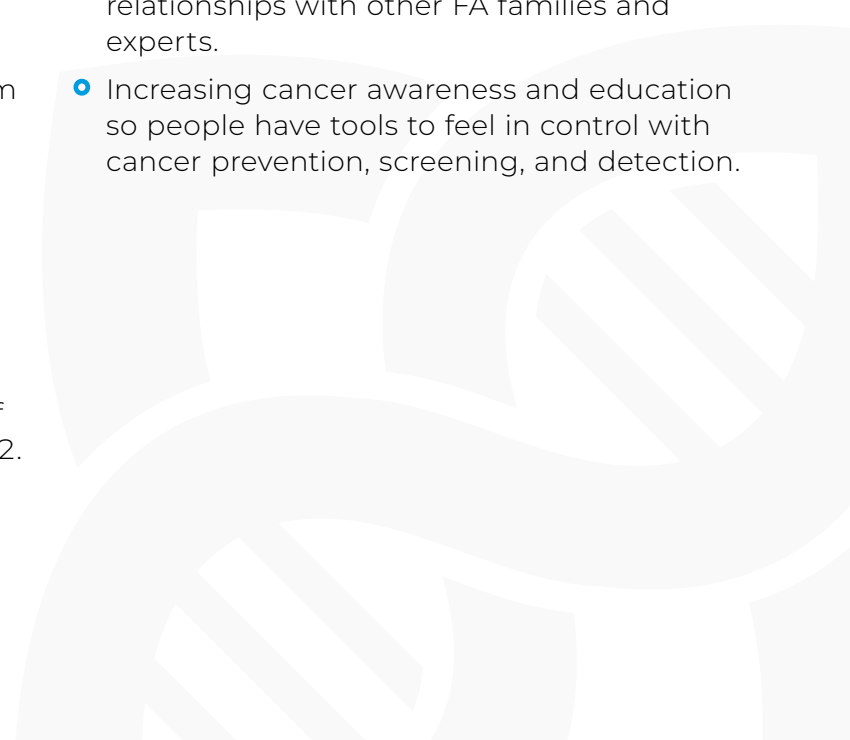
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### HIGHLIGHTS:

- 68 newly diagnosed individuals with FA and their families joined the FCF family.
- Families returned to FA Family Camp for the first time since 2019 for time together and with the experts.
- Adults with FA and their families gathered in Vancouver, Canada for the annual FA Adult Retreat to connect and learn.
- Families experiencing grief were supported through our bereavement group program “In This Together.”
- 664 volunteer-made cards were sent to 30 FA recipients around the world for an extra boost of support in rough times.
- Representatives from FA patient support groups in 15 countries joined the International FA Summit in Vancouver, Canada to exchange best practices and form collaborations.
- Groups from Brazil, Tanzania, and Latin America received \$10,000 grants to pioneer support projects in their local FA communities.
- Caregivers participated in support groups and mental health sessions.
- 115 adults with FA were surveyed as part of the mental health study FCF funded in 2022.

### WHAT'S NEXT:

- Continuing psychosocial research to help address the mental health concerns felt by individuals with FA.
- Launching a brand-new advocacy program to amplify the voices of the FA community in the development of clinical trials and research.
- Growing support programs for bereaved families, caregivers, and international FA communities.
- Developing age-appropriate educational materials to help individuals understand and feel empowered about living with FA.
- Continuing opportunities to connect in person and cultivate meaningful relationships with other FA families and experts.
- Increasing cancer awareness and education so people have tools to feel in control with cancer prevention, screening, and detection.







An FA family attends the Brazilian Family Meeting in January 2024.

**"As devastating as FA is, this community of FAmily is invaluable and means the world to us."**

-FA parent

# You're Helping Mary-Beth Defy the Odds

LIVING BEYOND EXPECTATIONS AND BECOMING A MOTHER

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**Mary-Beth has had many dreams in her life, but if you ask her, there is no question as to which one tops them all.**

It's the one that became a reality nearly two years ago: the arrival of her son, Daniel-Andrés.

Living with Fanconi anemia makes everything in life that much more difficult, so it's no surprise that FA added layers of complexity to her path to parenthood. Mary-Beth and her husband Ben endured six years, 12 fertility cycles, and countless moments of uncertainty. Yet, a year later, they got pregnant naturally, surprising them both with the greatest gift. And giving Mary-Beth an even greater reason to live and thrive:

"If I were to be gone tomorrow, I know I've lived a full life, pouring all my love into this world and the people around me. Yet, I am so not ready to die. I have a remarkable husband, a fireball of a son, and so many friends whom I love. I want to watch my son reach his milestones. Whether my FA friends dream of having families like mine, pursuing careers, seeing the world, or even learning to paint, I want to see every one of them fulfilled as well."

Mary-Beth and FA grew up together. With each passing year, donor-funded research improved life expectancy, from just seven years old when she was a child, to the 30s and beyond as she reaches that milestone herself.

Now, Mary-Beth and others in this 'new' group of FA adults navigate their 20s and 30s facing the everyday challenges of FA, alongside the very real risk of cancer. It's research that will allow Mary-Beth to see her son grow up.

Our shared cause has always been urgent, and that urgency is only increasing as more and more children with FA become adults with FA.





Mary-Beth with her husband Ben and son Daniel-Andrés.

# From Research to Reality: How You Helped Save Ryan

## RYAN'S TRANSPLANT SUCCESS STORY

Every single research study we fund impacts treatment and outcomes for the people we know and love affected by Fanconi anemia (and those who are not yet diagnosed!).

Back in 2018, donor funds supported a study to investigate a safe, non-toxic transplant protocol for stem cell transplants. The study team at Stanford used these FCF funds to test their regimen in mice. After seeing positive results, they went on to receive a grant from the Department of Defense Bone Marrow Failure Research Program in September 2021 as well as a \$4 million gift from an individual donor with the help of FCF to continue this work. They then initiated a clinical trial in 2022.

A year later, seven-year-old Ryan Adel from Arizona traveled to California for her transplant using this very protocol! **That is how you, as an FCF donor, are helping save lives.**

So, we want to say thank you for helping make treatment like this possible. But, we know someone who can say it even better than we can. Here's a message from Carly, Ryan's mom:

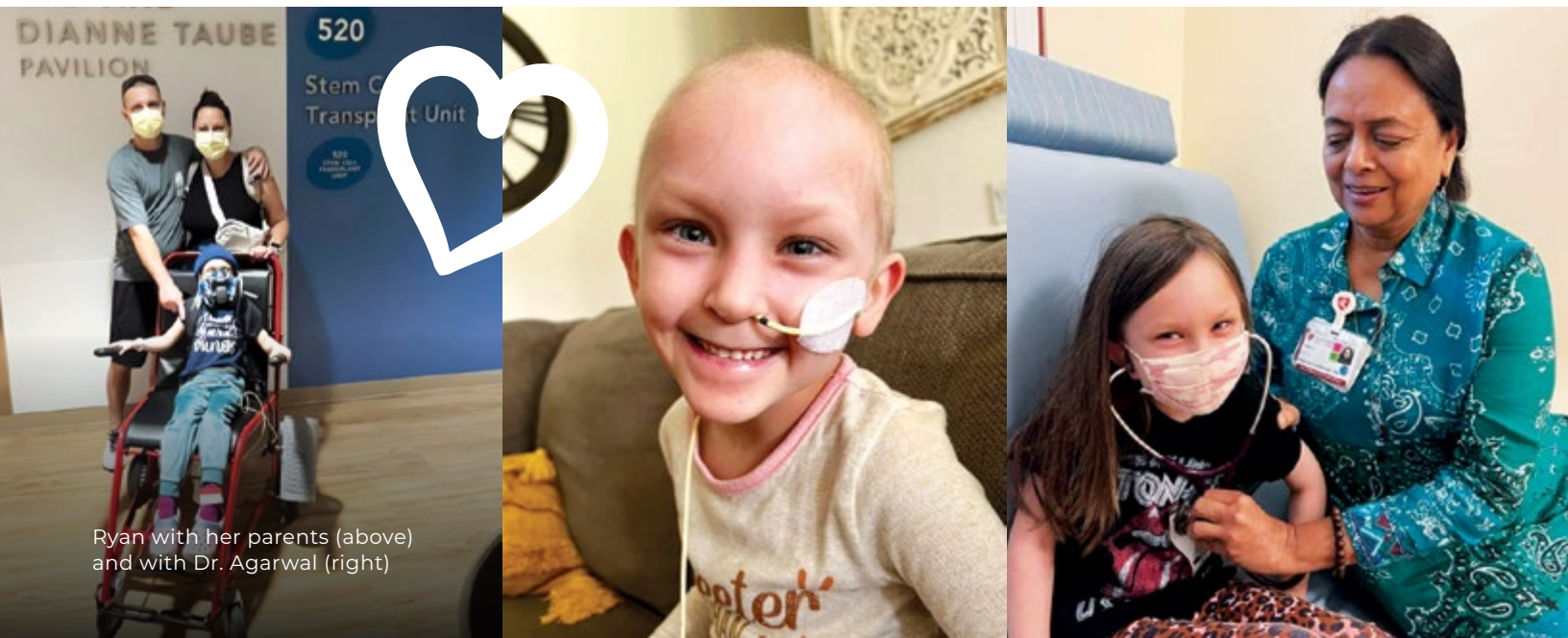
"FA clinicians and research have impacted Ryan's care beyond measure — she was fortunate enough to participate in a clinical trial which proposed a newer, less toxic approach to conditioning stem cell transplants for FA patients in bone marrow failure.

The trial was a combination of research from Dr. Rajni Agarwal in coordination with Dr. Agnieszka Czechowicz and Dr. Alice Bertaina, all of whom are incredibly talented in their work.

We want more research to help us navigate early detection of adulthood cancers, find ways to eradicate tumors without toxicity and provide an even lower toxicity conditioning for the generations of patients to come."

We couldn't have said it better ourselves.

Ryan is now back home and recovering well. She's back on her bicycle and is excited to return to school this spring!



Ryan with her parents (above) and with Dr. Agarwal (right)



Ryan with Dr. Agnieszka Czechowicz

**FA clinicians and research have impacted Ryan's care beyond measure**

# Thank You Notes: Highlights of Donors and Fundraisers



## ORION MARX'S "TEAM BRAVERY" REACHES MILLION DOLLAR MILESTONE

Team Bravery is all about completing epic challenges and adventures to raise awareness and funds for research. Founded by FA dad (and former FCF board president) Orion Marx in honor of his daughter, Avery, the team members have once again outdone themselves.

Each of them has gone above and beyond to support the FA community. Avery's grandpa Charlie ran a triumphant 50k in Florida, her uncle Zar and friend Michael ran across the Grand Canyon, and dad Orion adventured through the Smokey Mountain National Parkway and rode across the state of Iowa. In addition, the entire team completed a run, hike, and bike adventure in Alaska last fall.

In 2023 alone, they raised more than \$100,000! This helped them reach a truly awe-inspiring milestone: Team Bravery and their community have now raised more than \$1,000,000 for FA research. Talk about EPIC.

## FA PARENTS AND FCF LEADERS "ENDURE FOR A CURE"

Last summer, FA parent Kevin McQueen assembled a team of 10 motivated supporters to take on the challenge of America's oldest bike race, RAGBRAI. This team included FCF's own Executive Director, Mark Quinlan, then board president, Orion Marx, board member, Win Gouldin, and dedicated friends and long-time supporters of the FA community, Tony Franco, Jim Popp, Chuck Frydenborg, Pete Sheldon, Rich Quinlan, and Tim Brizzolara.

Through the Endure for a Cure team's 524-mile cycle across Iowa, nine nights of sleeping in an RV, 100-degree weather forecasts, and facing headwinds that tested their teamwork, we are inspired by the Endure for a Cure team's relentless enthusiasm and enormous hearts! In the end, they exceeded their goal and raised over \$134,000 for FA research and support services, all the while connecting the community and spreading awareness of FA.





## DEVOTED AUNT AND UNCLE LEAVE A LEGACY OF HOPE

Joel Walker passed away from complications of head and neck cancer in November 2016 at the age of 33. He was a talented student, good at sports, sociable and happy. Research into treatment for FA was a high priority for Joel, along with the hope that he could help others, so he left a large part of his estate to the Fanconi Cancer Foundation.

In honor of their son, Joel's parents, Nigel and Ann Walker, created the Joel Walker Fund. The generous bequest from Joel's estate and on-going support from the Walker family made an important series of scientific meetings possible. Last year, the fund shifted to support two crucial efforts: collecting and analyzing data in the FA research field and supporting a brand-new patient advocacy program.

The Joel Walker Fund gives the Walkers and their community a dedicated way to honor Joel and his sister Joanne, who also passed from complications of FA, and a way to improve outcomes for those facing FA now.

Near the end of 2023, Joel and Joanne's late uncle Peter and aunt Lynn left an extraordinary contribution to the Joel Walker Fund. Their six-figure legacy gift will have a lasting impact on advancing FA research and supporting those affected by this devastating disease. We are immensely grateful to Peter and Lynn for their remarkable generosity and for embodying the spirit of the FCF Legacy Society. Their legacy will continue to inspire and transform lives for generations to come.

## DONOR HELPS MAKE THE GIVING SEASON OUR BIGGEST YET

Giving Tuesday is our biggest giving day of the year. It's one of the most special days because hundreds of people show up to give and share why they give. And we read every message. This year we were surprised when later that week, we received an amazing phone call from a donor who wanted to make an even greater impact.

As she explained, "My family grappled with a rare genetic disease, one that lacked any research, foundation, or support when we needed it most. Enter my neighbor, Flynn, who lives with FA. When I learned about a foundation dedicated to research and support, I was so pleased. Navigating the complexities of a rare genetic disease alone is a sad and terrifying journey."

Yvonne Baker-Hoop matched \$75,000 worth of donations during our Season of Discovery holiday campaign, bringing our total over \$320,000!

During discussions with her advisor about incorporating charities into her will, a compelling alternative emerged: a living legacy. By contributing funds now, the charity reaps immediate benefits, and Yvonne gets to see how her support helps research change lives within her lifetime.

**"My hope is that a donation to FCF now will not only impact my friend Flynn but also extend its reach to others within the FA community."**





# Celebrating 18 years of The KATA Foundation

LONGTIME FCF SUPPORTERS LOOK TOWARD THE FUTURE

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**There's nothing quite like the fierce determination of parents who have a child affected by Fanconi anemia.** Our founders had three daughters with FA and to this day, the majority of our funding comes from FA family communities. One such family community from Colorado has been working on this cause for nearly 20 years and has raised an outstanding \$3.1 million for FA research.

The Kendall and Taylor Atkinson Foundation (KATA) was founded in 2006 in memory of Kendall and Taylor, a brother and sister diagnosed with FA in 1990 at the ages of three and seven. Their mom and KATA co-founder Jeanne Atkinson shares, "Their diagnosis was an agonizing blow which led to a whirlwind of uncertainty, information gathering, and decision-making. We were told that without a bone marrow transplant they would not likely live to adulthood. Our lives were forever changed."

Kendall was in college in 2004 when she received her transplant with an unrelated, mismatched donor. Tragically, the transplant protocol proved too toxic, and Kendall died four weeks later.

Just a year later, high school senior Taylor received his transplant. 106 days later, Taylor presented with graft-versus-host disease, where the donor cells were attacking his own cells. Taylor died nine months later.

To honor their children's memory and help others with FA live longer and better lives, Ken and Jeanne Atkinson began the KATA Foundation. Surrounded by an incredible team of dedicated volunteers, they have consistently raised hundreds of thousands of dollars to support research every year. Their signature event, a country-western gala appropriately dubbed "Hoot N Holler" brought hundreds together in support of the cause, and other events like the Art Howe Golf Scramble, Barn Dinner, and Hope Floats Wish Boat Launch, showcased the fun-loving creativity of the community and its spirit of generosity.

After Ken's unexpected and tragic death in 2016, the community continued to rally around the family and their mission to better the lives of those with FA. The impact of this Colorado group on the FA community is undeniable.







Since Kendall and Taylor underwent transplant 20 years ago, outcomes have significantly improved thanks to research funded by FCF and the KATA Foundation. KATA has supported cancer prevention studies, the development of preclinical models, the head and neck cancer trial, and most recently, the gene editing project, among many other projects.

This year, after decades of volunteer-driven fundraising and support, the KATA Foundation will hang up its proverbial hat and officially 'call it a night'. While KATA will no longer host their events, their legacy and impact will carry on with the establishment of the KATA Fund within the Fanconi Cancer Foundation, a dedicated fund to advance FA research.

We are endlessly grateful to the Atkinson family and the entire KATA community, whose years of effort and support have made a true, lasting difference. Thank you.



# 2023 Financials

**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 life-altering discoveries, all aimed at transforming the lives of those impacted by FA.



We take great care to steward your generous donations. That's why we continue to have the coveted 4-star rating from Charity Navigator. 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 Mark Quinlan, Executive Director at [mark@fanconi.org](mailto:mark@fanconi.org) or 541-687-4658. Thank you for making our mission possible.

	2023	2022	2021
Individual Contributions	\$ 1,152,361	\$ 2,376,690	\$ 2,349,121
Corporate Contributions	\$ 252,104	\$ 79,974	\$ 85,864
Nonprofit and Foundation Contributions	\$ 1,666,496	\$ 522,831	\$ 544,577
Grants, Sponsorships, Misc. Income	\$ 158,558	\$ 28,694	\$ 7,863
<b>Total Income:</b>	<b>\$ 3,229,519</b>	<b>\$ 3,008,189</b>	<b>\$ 2,987,425</b>
Investment Revenue Gain or (Loss)	\$ 696,687	\$ (1,109,202)	\$ 697,606
<b>Total Revenue:</b>	<b>\$ 3,926,206</b>	<b>\$ 1,898,987</b>	<b>\$ 3,685,031</b>
Research Grants	\$ 1,639,245	\$ 1,590,085	\$ 1,718,289
International Support Grants	\$ 35,392	\$ 53,975	\$ 30,000
Education and Program Support Services	\$ 1,321,392	\$ 1,230,694	\$ 647,915
<b>Total Program Expenses:</b>	<b>\$ 2,996,029</b>	<b>\$ 2,874,754</b>	<b>\$ 2,396,204</b>
Administrative Expenses	\$ 569,462	\$ 599,038	\$ 622,128
Fundraising Expenses	\$ 398,389	\$ 333,957	\$ 232,937
<b>All Expenses:</b>	<b>\$ 3,963,880</b>	<b>\$ 3,807,749</b>	<b>\$ 3,251,269</b>
<b>Total Equity at End of Fiscal Year</b>	<b>\$ 6,873,599</b>	<b>\$ 6,911,273</b>	<b>\$ 8,480,544</b>

*Note: 2023 numbers are currently under our routine annual audit. Fully audited numbers can be found on our website [www.fanconi.org](http://www.fanconi.org) once available later this spring.*





WITH THANKS

## Donor Honor Roll

Each year, you allow us to make invaluable strides in research and support families around the world. Below is a list of donors who have given \$250 or more to the Fanconi Cancer Foundation in 2023. Although space prevents us from printing all names of our generous donors, please know that we appreciate every single dollar given to advance our mission. All gifts, of all sizes, matter.

**Thank you!**

In addition, we'd like to acknowledge the fundraisers and volunteers whose generosity also makes our mission possible every day. We appreciate you!

*A note to our supporters: we greatly appreciate your donations and we want to recognize donors with 100% accuracy. If we have inadvertently made an error, please let us know by emailing [info@fanconi.org](mailto:info@fanconi.org). Thank you.*

### Lifetime Donors

Philip and Penny Knight

### Distinguished Donors

#### \$1,000,000

Philip and Penny Knight

#### \$172,000

Fanconi Canada

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