

Stepping up and into the **FUTURE**



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A newly diagnosed family
at the Family Retreat



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Editors' Note and Disclaimer

Statements and opinions expressed in this newsletter are those of the authors and not necessarily those of the editors or the Fanconi Anemia Research Fund. Information provided in this newsletter about medications, treatments or products should not be construed as medical instruction or scientific endorsement. Always consult your physician before taking any action based on this information.

Cover photo:

FA researchers and clinicians from Spain at the Scientific Symposium. Members from this group are running a newly funded clinical trial (see more on page 10).



FANCI leadership at the Annual Leadership Meeting.

A NEW CHAPTER AHEAD

LETTER FROM THE EXECUTIVE DIRECTOR

In this special donor newsletter, we are excited to present the Fanconi Anemia Research Fund's (FANCI) strategic plan for 2023-2027. This plan continues the remarkable progress we have made in understanding the genetics of FA and sets the stage for exponential growth in FA cancer research.

Since our founding in 1989, FANCI has raised over \$32 million for research, provided support to thousands impacted by FA, pioneered life-saving therapies, and made the ground-breaking discovery that the 23 FA genes we have identified, when working properly, constitute the body's defense against cancer. Building upon these achievements, we are now ready to embark on a reimagined approach to FA cancer research.

Our 2023-2027 strategic plan elevates FA cancer research within a consortium model, multiplying our efforts through collaborations with research centers all over the world. To achieve this, we will enhance our capabilities in research administration, support services, fundraising, and governance.

The aspirations outlined in this plan are ambitious, yet firmly rooted in our legacy of success, compassion, and an unwavering sense of urgency.

With your support, we will accelerate progress for individuals affected by FA and FA cancer.

In this newsletter you will also read about how your gifts have led to a major clinical trial in Spain and how the work you support has changed the lives of three of our adults with FA, Andie, Egil and Ana.

For a closer look at how your contributions are used to advance research, support families, and accelerate our mission, be sure to read *Your Gifts at Work* on page 23.

Thank you for your ongoing commitment and generosity as we embrace this new phase.

Sincerely,

Mark Quinlan

Executive Director





FA researchers and clinicians Juan Bueren, Paula Rio, Carmem Bonfim, Parinda Mehta, Eunike Velleuer, Susanne Wells, and Reinhard Kalb.

RESEARCH

The 2023-2027 strategic plan highlights FARF's commitment to accelerate FA cancer research by focusing on improving early detection, prevention, and treatment. Our goal is to expedite research progress by growing and formalizing the FA cancer research consortium, which fosters interdisciplinary collaborations, engagement with individuals in the FA community, and open data and resource sharing.

We will serve as the primary funder of new research projects within the consortium, establish sustainability and oversight policies, support international data sharing, and empower patient advocates to contribute to clinical research.

The strategic plan aims to achieve positive outcomes by increasing funding for FA cancer research through philanthropic support and strategic partnerships. By investing in research and people, we will foster the innovation necessary to enhance clinical care for FA cancer.



Pictured: internationally renowned FA clinicians Carmem Bonfim (left), Farid Boulad, and Margy MacMillan.

COMMUNITY

FARF remains committed to providing support services and fostering connection while enhancing the patient and family's role in research. Recognizing the complexity of patient and family needs, we acknowledge the limitations of our resources. To address this, we are engaging with external partners to broaden psychosocial research and support. This initiative aims to promote and improve well-being, while also empowering individuals to participate in FA research.

The strategic plan recognizes the trust placed in us by those impacted by FA and aims to empower them by involving them in decision-making and research design.

Adults living with FA seek agency in their cancer journey, and their voices are heard and valued. To this end, the establishment of a formal advocacy program is a part of this strategic plan.

To better meet the diverse needs of the FA community, we are actively working with global patient organizations to empower FA communities and amplify their impact. We will promote self-sustaining programs within international FA organizations to ensure this support and advocacy long-term.



Pictured: Ana Tabar, adult with FA, leader of the FA Support Group in the Dominican Republic, and voice in the Spanish-speaking FA community.





SUSTAINABILITY & GROWTH

Fundraising is vital to the success of our mission, and the 2023-2027 strategic plan focuses on the stewardship and expansion of fundraising efforts, strategic coordination of branding and messaging, and outreach to current and new stakeholders.

Refreshing our brand to reflect the increased focus on FA cancer holds significant promise for expanding our growth opportunities and establishing a presence beyond the FA and rare disease communities. Furthermore, the strategic integration of the FARF brand, messaging, and communications with the FA Cancer Consortium will enable us to maximize our impact.

Historically, FARF has heavily relied on the founder network and a dedicated yet relatively small group of FA families for fundraising support. However, to achieve our aspirational goals and ensure long-term sustainability, it is essential to transition from founder-driven funding to organization-driven funding.



Pictured: participants at the annual Coley's Cause Memorial golf tournament fundraiser.





Members of FARE leadership.

PEOPLE

The Frohnmayer (founder) legacy encompasses more than just financial support—it embodies drive, intellect, care, compassion, and success. The leadership and staff are propelled by a sense of urgency, matched only by their collective talent and dedication to their shared purpose.

The 2023-2027 Strategic Plan builds upon a solid governance model established in the past while navigating the new challenges of pivoting to a more explicit focus on FA cancer and the consortium model.

Retaining highly qualified staff and preventing burnout are shared organizational priorities acknowledged by all leadership bodies. The Board of Directors recognizes the importance of establishing a development subcommittee to engage, support, and monitor the ambitious goals for

expanding and diversifying funding sources. Additionally, upholding diversity, equity, and inclusion (DEI) is an integral aspect of FARE's guardianship.

Finally, it is crucial to underscore the foundation of trust that the FA community has placed in FARE. People with FA and their families played a central role in the development of this strategic plan, and their involvement will continue to be vital during its implementation.



Staff.



THANK YOU

We wish to express our appreciation for your unyielding support and relentless dedication to the cause. We reaffirm our shared commitment to driving progress and transforming the lives of those impacted by Fanconi anemia.

RESEARCH

Expand cancer research and therapies through external partnerships

- Develop Consortium
- Identify therapies
- Test therapies

COMMUNITY

Accelerate research through community advocacy and engagement

- Develop advocacy program
- Fund psychosocial research
- Support community

SUSTAINABILITY & GROWTH

Diversify and expand funding

- Stabilize revenue
- Expand revenue
- Refresh branding

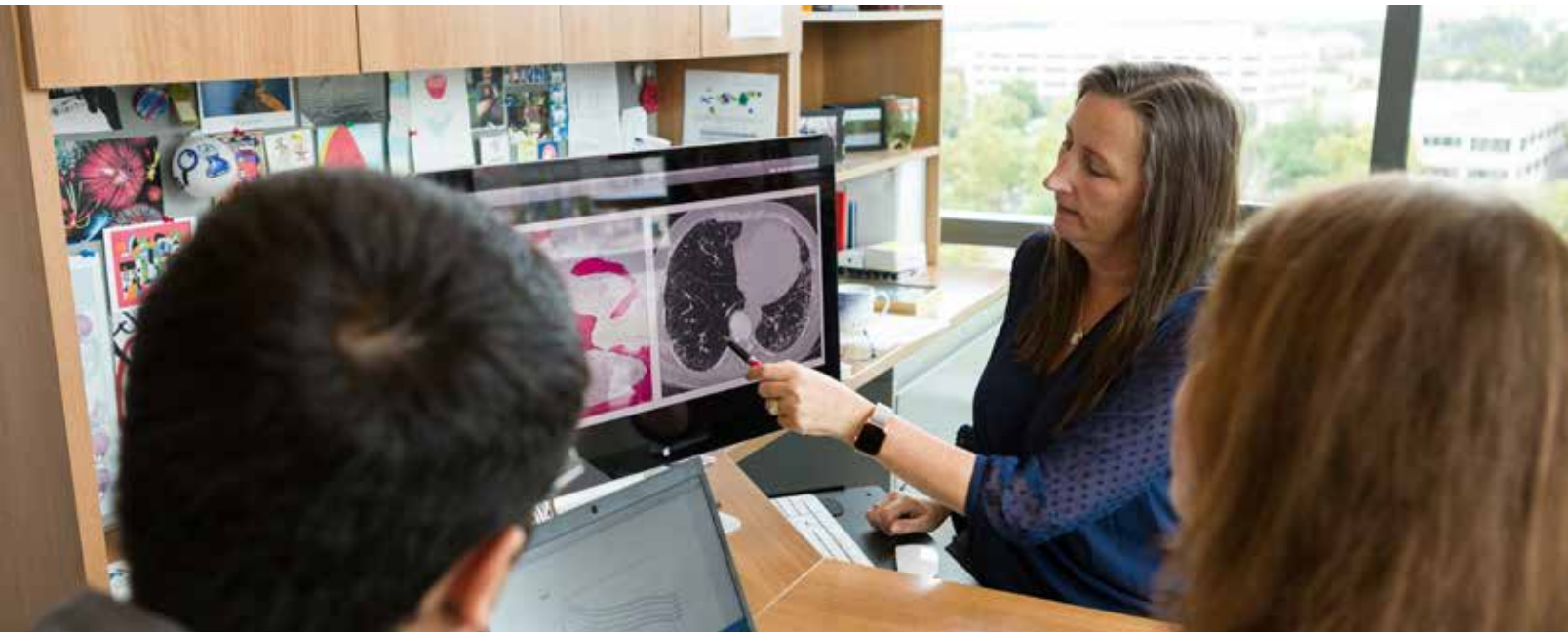
PEOPLE

Create optimal environment for people and leadership to contribute

- Measure progress
- Attract and retain talent
- Incorporate DEI principles

Our vision is a future where we can prevent and treat the primary cause of death and disability in people with FA, enabling them to live full and productive lives. This plan accelerates our vision.

ADDRESSING CANCER BEFORE IT DEVELOPS:



DONORS SUPPORT EARLY CANCER SCREENING STUDY FOR INDIVIDUALS WITH FANCONI ANEMIA

Thanks to generous donations from you, a significant study is now underway, spearheaded by National Cancer Institute (NCI) investigators Dr. Neelam Giri and Dr. Sharon Savage. This collaboration between the NCI and FARF aims to develop a comprehensive program for early diagnosis of squamous cell cancers (SCC) in people with Fanconi anemia (FA).

FA patients face an increased risk of developing cancer at a young age, with SCCs commonly appearing in the mouth, esophagus, and genital and anal areas. To address this critical issue, the study focuses on systematically screening visible changes non-invasively and conducting regular screenings of the esophagus and anal and genital areas.

Investigators have already begun recruiting participants and are working with FARF to enroll as many individuals with FA as possible. This kind of screening is crucial because currently the only treatment option for cancer in FA is surgery. If we can detect these cancers at a very early stage (pre-cancers or stage 1 cancers), we will improve the health and survival of individuals with FA.

This study is possible thanks to years of support provided by donors that enabled researchers to test for the best screening protocols. FARF-funded researchers in Germany spearheaded this effort for nearly two decades now, and this study at the NCI expands on their great work.



Neelam Giri, MD



Sharon Savage, MD

YOUR GIFTS DRIVE RESEARCH FORWARD

Last year we funded the largest number of new projects ever in a 12-month period. So far in 2023, we've funded another research study and a promising clinical trial.



Agnieszka Czechowicz, MD, PhD



Ramon Garcia-Escudero, PhD



Jordi Surrallés, PhD

GENE THERAPY AND GENE EDITING

DEVELOPMENT OF IN UTERO THERAPIES FOR FANCONI ANEMIA

Investigators: Agnieszka Czechowicz, MD, PhD
Institution: Stanford University
Amount awarded: \$250,000

Correcting Fanconi anemia (FA) mutations in all cells of the body may prevent issues such as bone marrow failure and cancer in people with FA. Since mutations in FA genes start during the gestational process, the ideal time to correct genes may be in utero. The goal of this study is to use laboratory-based experiments to determine whether gene editing in utero (during gestation) can correct FA gene variants in various tissues of the body.

The first study will test if delivery of normal blood forming cells helps correct the blood problem of the FA fetus after birth. The second will test whether precisely correcting the single DNA mistake that causes FA in the FA fetus can correct blood and other problems found in FA after birth. Because these approaches allow early treatment without use of toxic drugs, they will provide the first safe and effective prenatal treatment of FA.

FARF is committed to supporting research to further our mission of finding new treatments and a cure for Fanconi anemia.

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
Institution: Sant Pau Hospital Research Institute, Spain; Research Institute of the Hospital 12 de Octubre, Spain
Amount awarded: \$324,733

We know that individuals with FA have a high risk of developing head and neck squamous cell carcinoma (HNSCC) at young ages. We also know that these patients cannot tolerate conventional chemotherapy and radiation treatments due to issues related to toxicity, leaving surgery as the standard treatment.

This study is the first clinical trial focused on a therapy for FA-related HNSCC. It will investigate the efficacy and safety of the drug, Afatinib, when administered to people with FA who are diagnosed with advanced cancers in the head and neck.

The clinical trial design includes 25 individuals with FA from Spain and Germany. This trial represents a significant milestone in FA cancer research. It brings us one step closer to identifying effective treatments for these life-threatening cancers.

Your contributions to the FA Research Fund have made a tremendous impact, enabling us to support research like this. In fact, previous donations paved the way for this trial, as FARF funded preclinical research to this group back in 2019. This is the power of investing in research. Thank you!



**267
GRANTS**



**276
INVESTIGATORS**



**91 INSTITUTIONS
WORLDWIDE**

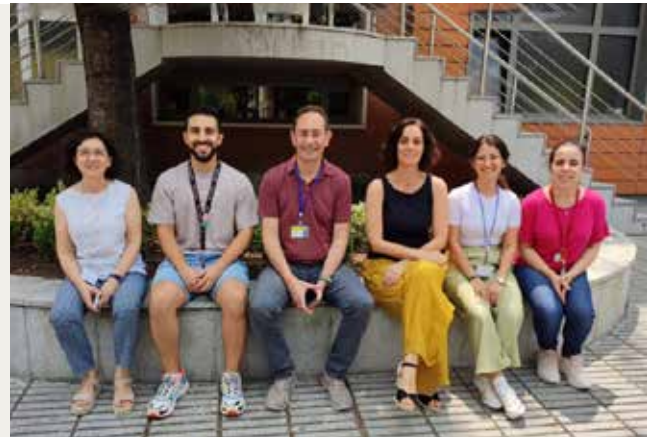
**TOTAL AMOUNT OF
RESEARCH DOLLARS
AWARDED IS
\$33,590,683**

BEHIND THE RESEARCH

Meet Ramon Garcia-Escudero, PhD, an investigator leading the clinical trial

Institution: Molecular and Translational Oncology Division at CIEMAT, Centro de Investigacion Biomedica en Red de Cancer, and Research Institute Hospital 12 de Octubre, Madrid, Spain.

Area of expertise: Disease models, biomarkers and therapies for head and neck cancer



Ramon Garcia-Escudero and Team

WHAT I'M WORKING ON

In order to prevent, treat, and cure cancer, we have to understand how it starts, progresses, and metastasizes. To do this, we need accurate disease models, comprehensive analytical technologies, access to patient samples, and systematic experimental and clinical approaches.

Very importantly, we need collaboration between different laboratories and experts in the oncology field.

In my laboratory, we can generate and analyze different types of mouse models, including mice that share similar mutations to patients. In these mice, we can reproduce some of the non-genetic risk factors that lead to disease, and we can reproduce growth of human tumors. These animal systems are key to testing antitumor compounds in a preclinical setting.

We also work to integrate knowledge from genomics research using preclinical models and human samples to search for new early diagnostic tools and therapeutic opportunities. I hope that our research activities will be translated into new and better clinical interventions for FA patients.

WHAT MOTIVATES ME TO WORK ON FA

I believe our role as scientists is to translate our expertise to society. For me, this means focusing research into new methods that would improve people's quality of life. That's why helping FA patients by diagnosing, preventing, or curing their cancers is a major aim of my work. I am convinced that scientists, clinicians, patients, families, foundations, and all stakeholders will achieve this goal by working together.

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

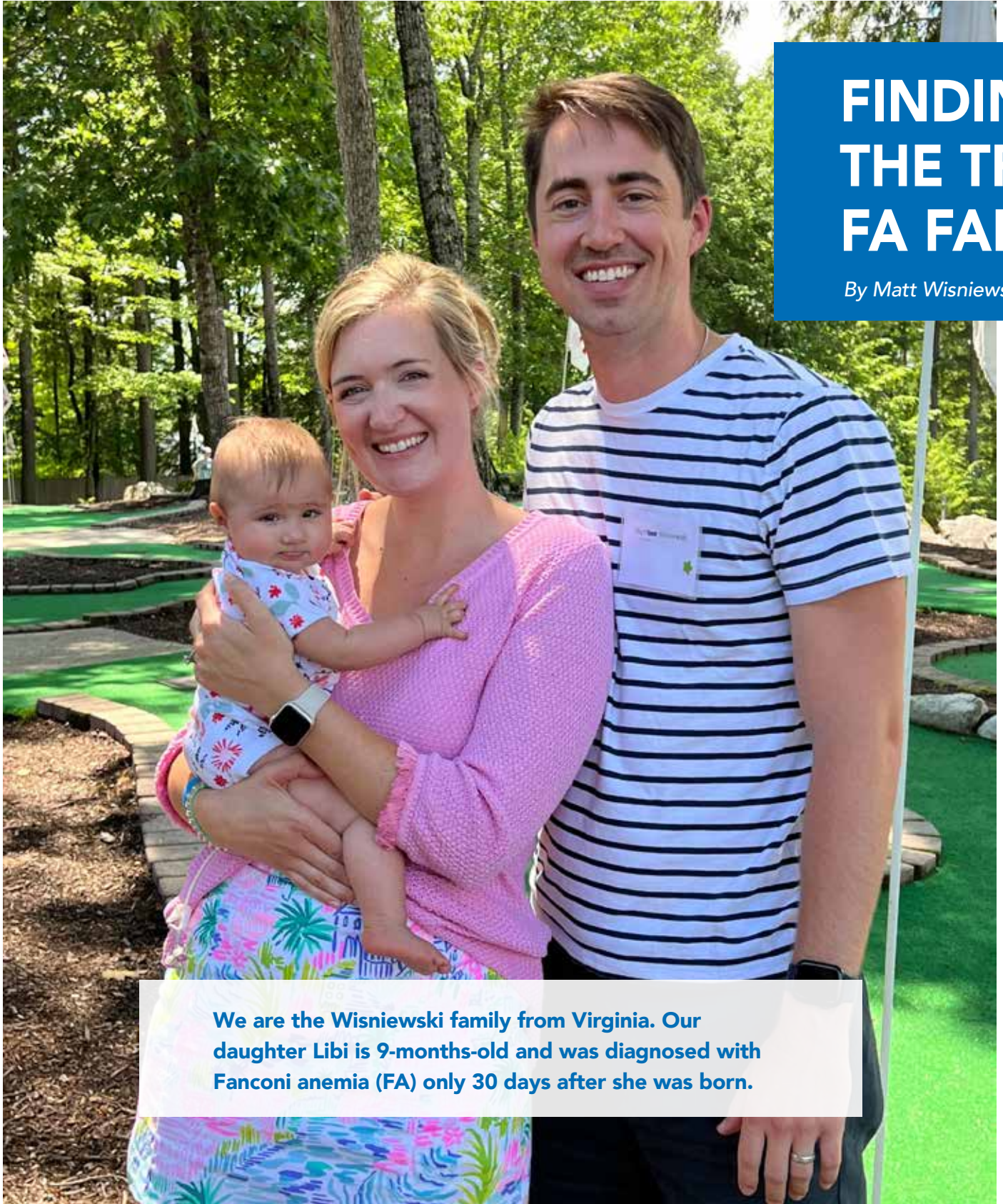
Either with my wife Cati and my son Miguel, walking and biking in the mountains in Madrid, or chatting and eating with my friends.

MY MESSAGE TO THE FA DONOR COMMUNITY

Cancer is a disease that has struck my own family. Resilience, work, hope: these are the key words that came to my mind when thinking about FA families. Your support of FARF and other FA funding organizations like the Spanish Fundación Anemia de Fanconi (<https://anemiadefanconi.org/>) is essential to helping us find new advances and treatments. Thank you.

FINDING THE TRA FA FAMILI

By Matt Wisniewski



We are the Wisniewski family from Virginia. Our daughter Libi is 9-months-old and was diagnosed with Fanconi anemia (FA) only 30 days after she was born.

HOPE, UNITY, AND STRENGTH: TRANSFORMATIVE EXPERIENCE OF THE FAMILY RETREAT AT CAMP SUNSHINE

As you can imagine, it's been a very intense last several months.

But earlier this summer, we got to go to the FA Family Retreat at Camp Sunshine. And this experience has given us more hope than we thought we'd find.

Have you ever stepped out of a cold, dimly lit building into a mild, humid-free summer day? That was Camp Sunshine. Warm. Bright. Hopeful. Fully seen. Fully known. Accepted.

About 25-30 other FA families greeted us in the lakeside wooded retreat of Casco, Maine. The time we spent together was unforgettable, and could comprise multiple pages. But to summarize, we had 3 major takeaways:

HOPE

We learned more about FA from nationally renowned doctors and researchers. They didn't sugar-coat their findings about this disease, but they did offer a consistent message of hope. More than a decade ago, the life expectancy for someone with FA was around 18 years old. About 5 years ago, that number increased to the late 20s. Today, many adults are living into their 40s and beyond. There are now more adults with FA than children! As advancements in science and medicine occur, this may push life expectancy even further. I had the pleasure of meeting one of the oldest known individuals in the FA community who is 45 years old. The emotional impact this had on me was indescribable.

COMMUNITY

We met people from different ages, incomes, racial backgrounds, countries, marital statuses, and gender

identities. What is so profound about this group of people is how tightly bonded we all are. We are united against this terrible disorder. We struggle together. We are for each other. We rejoice with those who rejoice, and weep with those who weep. We just get each other.

UNIQUENESS

Libi's turbulent birth story and early diagnosis are a rarity, even among a rare crowd like this one. There is something about her story that is so unique, so meaningful that it couldn't have happened by chance. Some families didn't receive an FA diagnosis until their children were in their teens. For us, this diagnosis came so early that it feels as if we're ahead of the curve. Early detection is everything in the medical world, and it couldn't get much earlier than this. For that, we are grateful.

Our week at Camp culminated in a wish boat release by each FA child. The weather was not cooperating, but we proceeded with the activity nonetheless. A candle was placed on each boat which was decorated by the child. As the boats were sent off, the candle represented a wish from each child and family amidst the uncertainty that not all of us will make it to next year. Each day represents a wish for life, for love, and for joy in the sorrow.

Life is precious. It's short. This is especially true for the FA community. Krissie and I feel we've been given new eyes that see each day as an immeasurable gift.

Thank you for reading, and thank you so, so much for supporting families like ours. We are at the beginning of this journey and your support gives us something to hold on to as we move forward.

LIVING LIFE TO THE FULLEST AS AN ADULT WITH FA

By Andie Kalemba

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

The beginning of my childhood was filled with countless medical appointments and long drives to find the best hospital to see me through bone marrow transplant and to provide the life-long care I needed. Though I received my bone marrow transplant at the age of five, I still go through annual doctor appointments and cancer screenings.

LIVING WITH FA AS AN ADULT

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

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

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

LIFE IN COLLEGE

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

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



Despite my concerns, I found my perfect sorority, Tri Delta, and I love my sorority sisters!

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

MY HOPE FOR THE FUTURE

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

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

EMBRACING RESILIENCE AND GRATITUDE WHILE LIVING WITH FA

By Egil Dennerline

I was just 16 when my world turned upside down. Being told that I had an incredibly rare, incurable, and life-threatening disease felt like a surreal nightmare. As a teenager, all I wanted was to skateboard, attend concerts, and hang out with friends. But instead, I found myself facing a diagnosis of Fanconi anemia (FA), a condition that doctors said might limit my life expectancy to just 23 years. It was a harsh reality check, and my family was also deeply affected. The weight of this new reality pressed upon us like a siege, and we each reacted in our own ways. For me, it was denial and secrecy.

As a teen and through my 20s, I kept my diagnosis hidden, scared to be seen as weak. Gradually, and over many years, I realized that what I perceived to be my

greatest weakness might also be my greatest strength. But only if I started opening up, accepting my journey, and breaking free from silence.

Now, 33 years, one stem cell transplant, and 11 cancers after my diagnosis, I'm a thick-skinned old-timer in the FA community. Recently, a doctor reminded me that I'm now one of the oldest FA patients worldwide and that statistically speaking, my time is running out. Well in my world, statistics have not always been the best measure of outcomes. I've defied expectations before, surviving beyond my mid-twenties and into my late forties, experiencing life in ways I never thought my diagnosis would allow. As such, I will continue to dream and set goals as long as I possibly can. So, what can I take away from this journey?



PEOPLE AREN'T NUMBERS

Every patient is unique, and I've stumped statisticians numerous times throughout my journey. While statistics can serve as guardrails, they don't necessarily define individual cases. I stand as living proof that exceptions to the rules do exist. We are not mere data points but individuals with our own paths to tread.

EMBRACE LIFE FULLY

Even in the face of pain, sickness, uncertainty, waiting, and anxiety, I've learned it's crucial to embrace life to its fullest. I strive to find something to hold onto, a handle amidst the chaos. Whether it's the love of family, cherished friendships, the joy of storytelling, creating music, or simply the beauty of light filtering through leaves, these joys, these moments, become as essential as the medications and treatments I receive. They remind me that life is worth fighting for. Each day with my wife, Nanna, is a precious gift, as is every smile from my daughter, Flora.

PERSPECTIVES CHANGE

Over the years, FA has profoundly altered my perspective on living with a life-threatening illness. Shedding my fear of opening up has allowed room for valuable lessons. These insights have come over time, through different life-stages and shifting viewpoints.

Whether we face life-threatening illnesses or not, we all experience milestones and changing perspectives. I know you, too, can think back to major events or moments that have changed your life forever. Being diagnosed with FA, going through transplant, and navigating cancer diagnoses are among mine, and although they only represent a few, they're the ones where your path and mine intersect. Each of these intersections occurred because supporters like you advanced research so that I could get an accurate diagnosis, so that I could survive my transplant and my cancers.

Your contributions and belief in the power of research have made a profound impact on my life and that of my family and the lives of so many others facing FA. For that, I give my deepest gratitude.



EGG DONATION AND SURROGACY MADE MY DREAM COME TRUE

By Ana Tabar Concha

To begin this story, I want to share that my dream of being a mother came true because three of the most powerful types of love I know came together: the love of a couple, the love of a sister, and the love of others. I believe God made this possible.

Since I was young, I always dreamed of being a mom. I felt that since many women share this dream, somehow my own desire wasn't a strong enough reason to believe it would come true. However, I never lost hope, even though I had reason to. Living with Fanconi anemia has deprived me of many things, including the inability to conceive naturally due to early menopause.

I have always considered myself incredibly fortunate because I am surrounded by an abundance of love: love from my family, my friends, my husband, and from all the people who have touched my life. So, whenever I share this story with my daughter Violeta, I remind her that she is the product of three profound loves:

The love of a couple: My husband and I deeply love each other, and we have traversed this long journey with immense patience and cooperation. When we reflect on the path we have traveled, we can hardly believe it. All

we can do is express our gratitude to God for the miracle that has unfolded.

The love of a sister: My sister selflessly became my egg donor. From the moment I approached her, she readily agreed without any hesitation. She underwent ovarian stimulation twice because our initial attempts were unsuccessful. I love my sister dearly, and her act of love granted us the gift of life.

The love of others: We encountered our angel, the woman who carried Violeta in her womb for 35 weeks (approximately 8 months), caring for her throughout the journey. She remained steadfastly committed to us, walking alongside us for four years, striving to make our dreams come true. We experienced two failed attempts, but on the third try, our great miracle arrived.

It has been a lengthy road of four years, encompassing a pandemic, numerous medical appointments, therapy sessions, and countless

meetings with lawyers. At the opportune moment, we even switched doctors. Our prayers were answered many times over. This surrogacy case is the first to be carried out and approved by CONANI (National Council for Children and Adolescents) and the court for children and adolescents in the Dominican Republic. We are immensely grateful for the support we received from the doctors, lawyers, friends, and our entire family, as they provided us with the strength to persevere.

That's how the love between a couple transformed into parental love, the love of a sister expanded our family, and the love of others on February 8, 2022, resulted in our miracle named Violeta Estévez Tabar.

Today, Violeta is a year and three months old. She has filled our lives with unparalleled joy and made us the luckiest people in the world. Having her with us makes us better individuals each day.

THANK YOU NOTES

INSPIRING DONORS LEAVE A LEGACY OF HOPE

We are delighted to highlight Peter and Lynn Lewis, exceptional members of the FARF Legacy Society. Their recent Legacy bequest to the Joel Walker Cancer Fund at FARF has made us incredibly grateful for their generosity and compassion. Peter and Lynn's story is one of love, dedication, and a deep connection to family and home.

Lynn devoted nearly four decades to shaping young minds as a high school teacher in England, while Peter served as a Director of Education in multiple counties throughout the country. Their lives were filled with adventure, living in various locations across England until they finally settled in Stoke-on-Trent, Peter's beloved hometown.

To Joanne (Walker) Hamilton and Joel Walker, Peter and Lynn were cherished Aunt and Uncle. Tragically, both Joanne and Joel succumbed to complications from FA and cancer in 2013 and 2016 respectively. Peter's passing shortly after Joel's, and Lynn's brave fight against cancer until 2022, left indelible marks on their loved ones' hearts.

In their wills, Peter and Lynn bequeathed a significant portion of their estate to relatives, with the majority benefiting five medical charities that held a special place in their hearts, including FARF.

Peter and Lynn's extraordinary contribution to the Joel Walker Cancer Fund at FARF is a shining testament to their profound care and dedication to making a difference. 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 FARF Legacy Society. Their legacy will continue to inspire and transform lives for generations to come.



Ann Walker, Peter Lewis, Joel Walker, Joanne (Walker) Hamilton, Nigel Walker, Lynn Lewis



Brian Horrigan

DONOR ELEVATES IMPACT FROM MONTHLY GIVING TO GIVING THROUGH HIS IRA

Brian Horrigan, a devoted father to his daughter with FA and a loving grandfather, has been a long-term supporter of FARF through the FAM Support Club, making monthly donations for many years. Today, we celebrate Brian's decision to amplify his contributions to FA research by transitioning from monthly donations to a generous annual gift through his IRA.

Why is this cause for celebration? At FARF, we deeply appreciate and value our donors, and we are always here to provide guidance on the most effective and personalized giving options. By switching to an annual gift through his IRA, Brian gains a significant tax break applicable to his age group.

Thank you, Brian, for choosing to enhance your giving in a way that benefits both you and the FA community. Your generosity and care for those impacted by FA is greatly appreciated!

COLORADO COMMUNITY UNITES FOR A CAUSE

It is no secret that the key to advancing FA research lies in the collective effort of communities raising funds. We would like to acknowledge an exceptional community that serves as an inspiration in uniting for a cause: the donors, supporters, and volunteers at the Kendall and Taylor Atkinson Foundation (KATA).

Established in 2006 by the Atkinson family, who had two children with FA, we are truly amazed by the unwavering loyalty and enthusiasm shown by this Colorado-based foundation. Year after year, they have tirelessly raised funds to create a significant impact in FA research. In 2022 alone, the dedicated supporters of KATA raised more than \$145,000 for research and support services, all the while celebrating individuals with FA around the world. We cannot express our gratitude enough to KATA and everyone involved in their mission!



KATA



Grossman Family

CELEBRATING A LEGACY OF JOY AND LOVE

Something unique and special about individuals with FA is a certain joie de vivre that so many exhibit. Among these remarkable individuals, Jacob Grossman, a beloved member of the FA community, who passed away in 2021.

This year, the Grossman family organized Journey with Jacob, a luncheon filled with friends and family who raised an astounding \$24,000 in a single afternoon. This remarkable achievement serves as a testament to the lasting impact that individuals with FA have on us, as well as the devotion of supporters like those within the Grossman community. They honor the memory of their loved ones and continue to change the futures of others living with FA.

Our hearts are filled with warmth and gratitude for all bereaved families and the generous supporters who honor the legacies of those no longer with us. We consider ourselves truly fortunate to have you standing alongside us.

THE FAM SUPPORT CLUB'S MONTHLY DEDICATION MAKES A BIG IMPACT

Supporters like you choose to give in many ways, each one meaningful to our mission. The FAM Support Club is a special group of donors who supports the FA community by giving to FARF monthly.

Nancy Rausch, a member of the FAM Support Club, shared her motivation to give, saying, "A few years ago, I had never heard of Fanconi anemia. When our precious grand-niece, Kitt, was diagnosed, I quickly learned how devastating and underfunded this disease is. My husband and I give in hope of a cure in the very near future!"

This dedication forms the foundation of FARF's mission. As monthly donors, you play a vital role. Thank you, FAM Support Club, for the difference you make in the lives of the cherished FA community!



Nancy Rausch and family

DONOR HONOR ROLL 2023

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 Anemia Research Fund between July 1, 2022 and June 30, 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!

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. Thank you.

The photos throughout the donor honor roll give us a big reason to celebrate: these are kids, teens, and adults with FA graduating earlier this summer. We love to see and share these milestones!

Sustaining Life Donors

Philip and Penny Knight

Legacy Society

Ralph Chapman
Carol Ceresa
Mira Frohnmayer & Sandy Sweet
Clint Johnson
Joanne Smith
Joel Walker
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Pamela Wharton
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\$1,000,000

Philip and Penny Knight

\$140,000+

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G. Clint and B. G. Johnson Richard
N Johnson
JPG, INC.
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Dexter graduated college

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 Nancy Knutson
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 Townsend Wood
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 Betty Soreng and Eben Dobson



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Maralyn graduated college

YOUR DEDICATED FUNDRAISING TEAM: MEET LAUREN KENNEDY AND ROSIE HOLCOMB

As we move into a new and exciting chapter for FARF, we continuously look at how we can help you, our dedicated donors, make the most impact for people with FA.

One way we do this is by expanding our fundraising team here at FARF. We are excited to introduce Lauren Kennedy, Philanthropy Director, and Rosie Holcomb, Development Officer.



LAUREN KENNEDY

Lauren brings over 15 years of experience in the nonprofit sector. She is a graduate of Miami University and began working for The Leukemia & Lymphoma Society (LLS) following graduation. There, she focused on growing the annual fundraising program as well as the corporate giving program. After nearly a decade at LLS, she continued her career at Juvenile Diabetes Research Foundation, where she led the development program, with a special focus on community engagement.

Based in Atlanta, Lauren enjoys spending quality time with her husband and two young, adorable children.

ROSIE HOLCOMB

An Oregon native, Rosie attended the University of Oregon before beginning her career in nonprofits, first at United Way of Lane County then at FARF. Rosie joined our team in 2021 as Family Services Program Manager at FARF. In that role, she developed educational resources, and provided direct support along the FA journey.

This spring, Rosie stepped into fundraising for the organization as Development Officer. In this role, she supports the mission by working closely with donors and strengthening our fundraising programs.

Outside of work, you can find Rosie reading a mystery novel, biking next to the river, or working on her new home with her husband.



We want you, our valued donors, to continue feeling confident that your contributions are making a tangible difference in the lives of those affected by FA. As a team, we will continue to keep you updated on the impact of your support and ensure that your philanthropic goals are met.

We are grateful to have Lauren and Rosie on board, and we encourage you to reach out to them with any questions, ideas, or suggestions you may have. Thank you for your unwavering support and dedication to the Fanconi Anemia Research Fund. We couldn't accomplish our mission without you.

YOUR GIFTS AT WORK

We envision a future in which we can prevent and/or eliminate the primary causes of death and disability in people with FA, enabling them to live full and productive lives. The best way to do this is by funding research. That's why most of our budget is committed to research. We also support individuals and their families by providing them with education, family and adult gatherings, psychosocial support, and clinical programs.



Kids with FA at the Family Retreat

In our annual Impact Report for 2022, released earlier this year, we shared our 2022 income and expense breakdown. Since this report is shared in the beginning of the year, before our annual audit, we use this donor newsletter to provide updated, audited numbers.

This newsletter also aims to provide you with clarity regarding our 2022 finances. In our Impact Report, we had previously disclosed that our income for the year was \$1,899,120, while our expenses reached \$3,798,280. It's important to note that the income figure factors in the unrealized value of our investment portfolio.

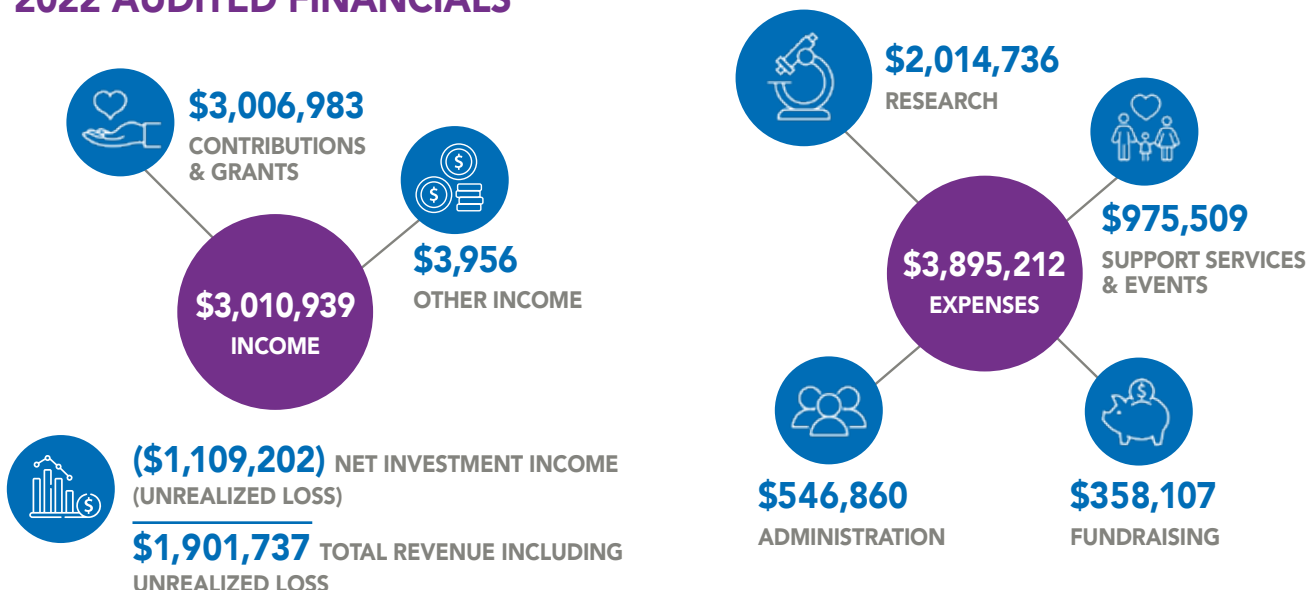
The financial market was challenging in 2022, resulting in most investors, including FARF, experiencing an unrealized loss in value. We expect the value to recover

over the next few years. So, while we received \$3 million from our generous donors, the decrease in our investment portfolio created a shortfall for the year. However, we are happy to report that we are already seeing recovery, with a \$400,000 increase in the investment portfolio during the first half of 2023. To see our full financial audit for 2022, visit www.fanconi.org/explore/financials.

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 gifts are used, we would love to connect with you. Please feel free to reach out to Mark Quinlan, Executive Director at mark@fanconi.org or 541-687-4658. Thank you for making our mission possible.



2022 AUDITED FINANCIALS





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

RETURN SERVICE REQUESTED

Our mission is to find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

HOW YOU CAN HELP

Donations Online:

Donate via our website (www.fanconi.org)

Donations by Phone:

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

Donations by Mail:

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

Donations of Appreciated Stock:

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

info@fanconi.org • www.fanconi.org