Leo, 2, and his family, from Spain
No matter who you are or where you live, you felt the effects of the global health crisis brought on by COVID-19. The uncertainty, the fear, the loss, and the challenges of continuing everyday life got to each of us at some point or another. The last 18 months were hard. We faced hardship none of us imagined we would ever have to face. As we open our homes and ourselves up to the world again, I hope we all acknowledge the tremendous resilience we have shown.

There is one message I want to share with you: you have given FARF the power of resiliency throughout this pandemic. Simply put, we are thriving in 2021 because of the generosity of our donors, the dedication of our researchers and staff, and the perseverance of our FA families.

As a research community, we did not let shutdowns deter our progress. Over the last year, we developed, expanded, and strengthened several initiatives, with a major focus on cancer. This includes our new partnership with Stand Up to Cancer to address head and neck cancer, expanded support of the oral cancer brush biopsy program, and the funding of a gynecological cancer research effort. In addition, we continued to grow our FA cancer clinical registry and our virtual tumor board, which gives FA patients diagnosed with cancer access to a panel of experts to inform the best possible care.

Agility was key to us on the FARF team as we shifted all in-person events to virtual ones. This community thrives on connection, and although we felt immense disappointment to not be together at the Family Meeting or Scientific Symposium, suddenly our computer screens were full of faces of our friends from around the world. For the first time, many of our FA families and researchers in Europe, Africa, the Middle East, Australia, Canada, and Latin America could join these spaces of learning and connection. We will continue to embrace the power of technology to ensure our international friends have access to these opportunities.

These advances were possible because of you, our donors. I can’t overstate it enough. In 2020, 3,660 donors gave $3,335,174 to support research and family services. You continued to mail your annual checks and wishes of support. Some of you had your employer match your gifts and some donors gave stock. Though several fundraising events were canceled, you pivoted right along with us and gave online. Many of you stepped up and shared your plans to include FARF in your wills, trusts and estates. This generosity is nothing short of remarkable.

The pandemic marked a significant transition for us all. At FARF, we embrace the reminder of just how important connection is. For most of us, the challenges and setbacks we experienced in work and life were relentless, but in this community, we are not alone. There are FA families, researchers, support groups, and donors all over the globe. And you each showed us your commitment to this mission.

Thank you for all you have done, and I look forward to advancing our mission with each of you over the next year.

Mark Quinlan
Executive Director
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Thirty-two years ago, two parents desperate for answers started the Fanconi Anemia Research Fund.

Decades later, thousands of others have joined the Fanconi anemia community.

Families, researchers, doctors, and donors across the globe are all committed to one mission: to find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

Every new program, project, initiative, and service, is possible because donors like you say yes to this mission.

Thank you.
It all starts because you give... 
At an FA family event 
To support FA month 
For Giving Tuesday 
To honor someone’s memory 
To leave a legacy of hope 
Because someone asked 
Because you care 

Every new program, project, initiative, and service, is possible because donors like you say yes to this mission. 

Thank you. 

Joel Walker 
Cancer Ideas 
Lab Program
As a donor, you know that people with Fanconi anemia (FA) are at a very high risk of developing head and neck cancers because of the underlying DNA repair problem in FA. Research is the key to understanding, diagnosing, and treating these cancers. That’s why the Fanconi Anemia Research Fund (FARF) has joined Stand Up To Cancer® (SU2C) and three partner organizations to fund $3.25 million in grants to find new treatments for head and neck cancers.

This project reflects FARF’s commitment to directing, accelerating, and investing in cancer research. Over the past three decades, FA research largely focused on gene discovery (there are now at least 23 FA genes), mechanisms of the DNA repair pathway regulated by FA proteins, and bone marrow failure. Now that more people with FA can be successfully treated with stem cell transplants, the focus of FARF has shifted almost exclusively to supporting research on FA cancers.

To facilitate productive collaborations and cross-pollination of ideas between the FA community of researchers and experts in cancer biology, this year FARF developed a collaboration with Stand Up To Cancer (SU2C), a leading international cancer research nonprofit. Stand Up To Cancer harnesses the power of the entertainment industry to fund collaborative translational cancer research projects. The organization funds large integrated research teams comprised of leading scientists with varying expertise who focus their efforts on developing treatments for cancer.

The collaboration between FARF and SU2C also includes three additional nonprofit organizations: the American Head and Neck Society, the Head and Neck Cancer Alliance, and the Farrah Fawcett Foundation. This collaboration aims to develop a head and neck cancer research team with funding from each organization.

The goal of this collaborative approach is to inspire powerful and purposeful cancer research that will lead to new and less toxic approaches to treating head and neck cancers, especially those associated with FA and human papillomavirus (HPV).

The incidence of head and neck squamous cell carcinoma in people with Fanconi anemia is 500- to 700-fold higher than in the general population and treatment options are limited. HPV is a very common virus that can cause cancer, including cancer of the throat; approximately 45,300 people with HPV will get a cancer diagnosis every year in the U.S.

Head and neck cancers associated with FA or HPV have something in common: genetic defects that cause FA, as well as genetic changes resulting from HPV infection, both adversely affect DNA repair systems, which can lead to cancer.

“This collaboration will collectively benefit people with Fanconi anemia and their families in a meaningful and impactful way,” said Mark Quinlan, Executive Director of the Fanconi Anemia Research Fund. “We’re excited to join the other funders and Stand Up To Cancer on this project, which will facilitate the collaboration between experts from multiple fields to help tackle some of the biggest challenges associated with head and neck cancers.”

The project began with a virtual Ideas Lab in April 2021. During the Ideas Lab, selected participants, including FA scientists and head and neck cancer experts, shared their perspectives on unanswered questions in the field, an overview of what their specific contributions would be to a SU2C research team, and their best ideas on how to target FA and HPV-related head and neck cancers.

Following the Ideas Lab, the participants formed interdisciplinary teams and crafted research proposals that were submitted at the end of June. These proposals will be reviewed by a committee of experts who will select the final research team to fund. The three-year translational research projects will start in fall of 2021.
Strides in Research

Researchers & FARF make further progress on the cancer problem

What are FA researchers focused on?

Fanconi anemia (FA) is a DNA repair disease that leads to the development of squamous cell carcinoma (SCC). SCC of the head and neck and anogenital regions are the most common for people with FA as they reach adulthood. Current therapies used in the general population are toxic for people with FA; therefore, there is an urgent need for novel interventions that will safely prevent or treat SCC in this population.

There are four key areas that researchers are addressing to benefit people with FA:

1. Understanding the natural history of FA cancer through genome sequencing of tumors and building patient registries focused on cancer;
2. Cancer prevention using oral screening, brush biopsy of oral lesions, and liquid biopsies of plasma and saliva;
3. Chemoprevention using compounds such as the antioxidant quercetin administered systemically; and
4. Targeted therapeutics and radiotherapy.

Overall, current research shows that we are beginning to understand the driving mechanisms of FA cancer and are identifying potentially effective and safe therapies.

The next steps for FA cancer research are to create preclinical models that mimic the disease so that targeted therapies can be tested. Additionally, further characterization of individual FA tumors is necessary to identify targetable drivers of the disease. Lastly, cancer-focused clinical trials for people with FA are needed to test potential prevention and therapeutic modalities.

How do FARF-donors support these efforts?

Donor funds are the only way we can advance research. Donations enable FARF to support researchers focused on FA cancer and allow FARF to create patient-centered programs for those diagnosed with cancer. Here are three ways your gifts support cancer research:

Analyzing anogenital cancers in people with FA

Researchers: Kathryn Pennington, MD, University of Washington and Agata Smogorzewska, MD, PhD, The Rockefeller University

Anogenital cancer in women with FA is a significant problem because of the very high frequency of these tumors and the limited knowledge about these cancers in the FA population. As part of this study, Drs. Pennington and Smogorzewska will document, analyze, and store anogenital FA cancer samples and clinical information in a patient registry. An essential first step in treating cancers in this vulnerable population is developing a registry of anogenital cancer in FA. This registry will detail extensive information about a patient’s diagnosis, their treatment, and long-term clinical outcomes.

Sequencing FA cancer samples

Researcher: Agata Smogorzewska, MD, PhD, The Rockefeller University

Understanding the underlying genetic changes of FA cancer is critical for charting the natural history of the disease and determining ideal prevention and therapeutic strategies. Data from FA patient tumors analyzed in this study by Dr. Smogorzewska and her team show significant genomic changes that illustrate how these tumors form, progress, and which strategies could be implemented to treat them. This ongoing project has provided the first genomic indicators of these cancers. Researchers will continue to analyze additional samples.

Understanding acetaldehyde exposure in people with FA

Researcher: Silvia Balbo, PhD, University of Minnesota

The aim of this project is to understand the pathogenesis of head and neck squamous cell carcinomas (HNSCCs) in individuals with FA to find practical and proactive preventative strategies that improve their quality of life. Specifically, this research investigates the role of acetaldehyde (a reactive compound found in our environment, tobacco...
smoke, foods, beverages, and is formed upon alcohol consumption. Aldehydes increase incidence of oral cancer in FA patients. Researchers will measure the overall exposure to acetaldehyde resulting from food and a low dose of alcohol and measure the corresponding DNA damage in the oral cavity of FA patients. This will help us understand what leads to tumor growth in the oral cavity, and how we might prevent it.

**Virtual Tumor Board**

In addition to research, donor gifts are addressing the cancer problem through the creation of patient-centered initiatives like the Virtual Tumor Board (VTB) to help FA patients diagnosed with cancer. The VTB became a cornerstone of patient care for people with FA over the past year, especially for those with complicated cases. The VTB consists of surgical oncologists, medical oncologists, radiation oncologists, and other FA specialists who convene virtually to discuss a specific patient’s treatment plan. These specialists provide advice to patients and their treating physicians, who often have little exposure to the FA population. On average, the team receives a new case each week. The presence of the VTB ensures that patients get the best-informed care.

**New European multi-institutional gene editing research program focuses on fixing Fanconi anemia mutations**

The European Joint Program for Rare Diseases recently funded a consortium of European researchers to conduct a multi-year, multi-institutional initiative called **FANEDIT**. Dr. Paula Río, a FARF Scientific Advisory Board member, is the lead principle investigator on the project, which is a collaborative effort between scientists from Spain, Switzerland, Germany and France. The project also includes participation of the Fanconi Anemia Foundation, a FARF partner and patient advocacy organization in Spain.

The objective of the **FANEDIT** initiative is to establish new therapeutic options for patients with FA by exploring gene editing strategies to correct the genetic defects of FA cells. Hematopoietic stem cell (HSC) transplantation is currently the only curative treatment for bone marrow failure in FA. However, the use of toxic conditioning agents in transplantation contributes to severe side effects, which include increased incidence of squamous cell carcinoma. Correcting the genetic defects in FA cells using gene editing offers an opportunity to lower the incidence of bone marrow failure and the need for aggressive transplant procedures.

Recent studies from several scientists on the **FANEDIT** team have shown the efficacy of lentiviral-based gene therapy in FA clinical trials. Gene therapy does not correct the exact genetic defect in FA cells, but instead adds a “normal” FA gene into cells expressing mutated FA genes. The possibility of precisely correcting the innate genetic defects in FA HSC would be the ideal therapeutic strategy for bone marrow failure. The **FANEDIT** team aims to develop safe, clinically relevant, and more precise gene editing strategies that can be used to correct mutations in FA genes.

Research on gene therapy and gene editing has been a long-time focus area at FARF and we are very encouraged by this new initiative and the potential of gene editing as a therapy for FA.
Researchers work to increase fertility in people with FA

In addition to progressive bone marrow failure and the high risk of developing squamous cell carcinoma of the head and neck and anogenital regions, patients with FA also experience reduced fertility. Females with FA may experience a variety of gynecologic issues, including structural abnormalities, delayed puberty, decreased fertility, early menopause, and a high risk of SCC of the lower genital tract. Males with FA may have numerous structural abnormalities of the reproductive system and extremely low sperm count that affects fertility. Compared to other more commonly studied aspects of FA, not much is known about infertility in people with FA. As more individuals with FA reach adulthood, there is a growing need to address the issue of fertility in this population.

The good news for FA patients is that researchers like Dr. Eva Hoffman from the University of Copenhagen are working to make fertility restoration possible. In females, the goal would be ovarian tissue cryopreservation prior to toxic treatments used during bone marrow transplant procedures and in male patients this would be culturing sperm stem cells isolated during infancy and transplanting back into the stem cell niche during adulthood. Dr. Hoffman’s team has currently shown that sperm stem cells from male infants can be propagated in vitro and can populate the stem cell niche in nude mice. The goal of future experiments will be to test whether the procedure can be done in humans.

Stanford opens new clinical trial to address bone marrow failure using antibody conditioning

Hematopoietic cell transplant outcomes for patients with FA are excellent with newer standard treatments, but the procedure is still imperfect due to the use of toxic chemotherapy or radiation during the procedure. Long-term complications such as graft-versus-host disease and an increased risk of cancer following transplant are both concerning issues. Improved transplant procedures that do not use toxic reagents to clear diseased bone marrow prior to transplantation with healthy donor cells are desperately needed.

This was the problem Dr. Agnieszka Czechowicz from Stanford University sought to address with her FARF-funded research focused on non-toxic conditioning using an antibody called JSP191. This antibody targets C-KIT, which is a cell surface protein expressed primarily on hematopoietic stem cells. Dr. Czechowicz’s preclinical studies using mouse models showed that the antibody eliminates host diseased FA hematopoietic stem cells and is safe. In partnership with Janus Therapeutics, Stanford recently launched a clinical trial using JSP191 in transplants for patients with FA, which is now recruiting patients.

Better and safer therapies start with preliminary research funded by donors like you. That research becomes preclinical data and then moves into a clinical trial. Thank you for getting the pipeline to new treatments moving!
Donors enable change around the world

United Kingdom and Netherlands (2019)
This project aims to unite the existing FA support groups across the 23 member states of the European Union into an umbrella group that increases collaboration between countries and partnerships with EU healthcare networks and pharmaceutical companies. FA Europe connects patients, clinicians, and scientists, and acts as a facilitator for fundraising, sharing best practices and collaborating on research efforts.

Mexico (2020)
The opportunity for patients and families to meet in person is the first step to building a vibrant and organized FA community in Mexico. The aim of this project is to hold the very first meeting for FA patients in Mexico. Educational sessions tailored to target patients with FA and their families will be held to provide reliable and up-to-date FA information and research participation opportunities. The meeting will take place once it is safe for participants to gather.

Dominican Republic (2019)
Un Corazon por Fanconi, a foundation started by an adult with FA, Ana Tabar, received a grant to develop a diagnostic protocol for FA patients in the Dominican Republic (DR), provide support services for FA families, and build organizational capacity. With help from experienced FA researchers in Mexico, the team in the DR is working to form a network of doctors who can learn about the diagnosis and management of FA.
While the FA Research Fund is based in the United States, FA research, families, and support organizations span the entire globe. To strengthen the efforts of our partners in the international FA community, FARF established the International FA Support Grant program in 2018. Each year, FARF awards up to five $10,000 grants for one-year projects that address the needs of the global FA community. These needs include access to medicine, doctors, and facilities; organizational and infrastructure needs and access to family support services.

So far, seven international support grants have been awarded and programs are underway in nine countries as a result.

**Egypt (2020)**
FA patients in Egypt do not have a referral center, which results in the lack of clear diagnoses and little or no access to genetic counseling. A long-time FA researcher received a support grant to aid the clinical diagnostic process, offer carrier detection, prenatal and premarital genetic counseling, as well as help characterize FA mutations. Not only does this project help patients directly, but the data will improve the quality of genetic counseling and provide information about disease prognosis and management.

**Zimbabwe (2021)**
The Nate Foundation was founded by parents of two kids with FA in Zimbabwe. They recently received an FA support grant to address the lack of information about FA in their country and improve access to support and information for patients. First, they will create a support group for individuals with FA and their families. Next, they will prepare educational information and give seminars to medical institutions. Finally, they will partner with healthcare practitioners and local government to host an educational campaign to spread awareness about FA among the public and within the medical community.

**Spain (2020)**
The Fanconi Anemia Foundation (FAF) received a grant to support their efforts to increase fundraising and mobilize affected families as fundraisers. This grant enabled FAF to partner with a digital marketing company that developed a fundraising and communications strategy and plan. FAF continues to build their supporter base and increase their income to support research and FA families in Spain.

**Australia and New Zealand (2019)**
A relatively small population of people with FA spread out around Australia and New Zealand results in a lack of experienced FA specialists. FA parents – with support from researchers in Australia – used their grant to establish a support group for families and individuals with FA in Australasia and works to build knowledge of FA within the existing medical infrastructure.
On October 18, 2018, the sweet wait came to an end. During pregnancy, emotions are always on the surface. You imagine what it will be like to have the baby in your arms and even what kind of education you want for him. You imagine a perfect, innocent life, full of unconditional love.

That’s how it was during the first hour of Leo’s life. I can’t explain how much happiness I felt.

After that sweet and tender hour with my baby, I was told that plastic surgeons would come to the room to examine Leo’s little hand. The thumb of his right hand was literally dangling because the metacarpal bone was missing.

From that moment on, everything started to get complicated. The geneticists came to examine him, and then he was admitted because he was not eating, and his weight was very low. The desperation of a mother not being able to see or hold her baby is horrible. He was in the incubator and I could barely hold him for a few hours a day. After 10 days, he was discharged, and we were able to stay with him for five days at home before being admitted again for a urinary tract infection.

Our nightmare dragged on

This time, doctors detected that he had grade IV vesicoureteral reflux and the right kidney was smaller than the left. Three days after he was admitted, he began to convulse. A baby barely 20 days old convulsing is an image that I will never forget. Our nightmare dragged on longer than expected and new and increasingly disparate diagnoses emerged.

Leo had bilateral sinus thrombosis (blood clot forms in the brain’s venous sinuses). The neurologists told us that he would probably not be able to walk or speak and he would probably have other significant effects from the clots. We went into shock and all I could ask was, “What can I do?” We went to an early care center, and I asked for an evaluation at a specialized hospital in Spain. I bought some recommended books to do exercises and stimulation games at home. They detected a clotting problem, and Leo now needs Heparin or Sintrom for life.

Now he is two years old, and against all odds, he walks, talks, runs, jumps and is up to speed cognitively.

Once at home, we were able to enjoy Leo to the fullest for several months, while also visiting various specialists to monitor his development. We had appointments with several departments, from hematology to endocrinology; neurology to genetics.

The diagnosis

In January 2020, I received a call from the genetics doctor informing me that all the tests they carried out were negative. To me, that news seemed like the most encouraging in the world because it meant Leo did not have any disease. He then told me that he wanted to do one last test to rule out a disease called Fanconi anemia. It was the first time I had heard this of this disease and fear took over my body. I began to imagine the worst, but I decided to think that surely that would also be negative.

On August 20, 2020, while enjoying a family vacation in San Sebastián, the genetics doctor called me again and this time it was to confirm the fear that had been in my head since January of that same year: “Leo has Fanconi anemia”. I had to pass the phone to my husband because my world fell apart.

From that moment on, an enormous sadness invaded me. I see life from a different perspective. We have to fight...
every day to make Leo a happy child, while on the inside, I’m heartbroken. I cannot think about the future like I did during pregnancy; our future is the present itself.

**Learning to live with uncertainty**

In November 2020, doctors found a Wilms tumor in Leo and we are currently fighting to eliminate it. These are hard times, very hard times, and I also know that this is the beginning of something that we will have to live with. The path will be long – at least I hope so – and I don’t want to think about what will happen. Uncertainty is the factor that makes us the most nervous and anxious, but when it comes to your day-to-day life, you must learn how to live with it.

Since he was born, Leo has been a very curious, happy, energetic, loving baby and my goal is to ensure that he never loses any of those qualities because I love all of them and they make our life wonderful.

I must thank the Fanconi Anemia Foundation in Spain for all the support and hope they give us every day. Without them this path would be full of uncertainties and unknowns. **Being able to count on experts and families in the same situation means that we can control our own situation much better. They say that unity is strength and today this sentence takes on all its meaning.**

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**Our Warrior, Agustina**

*By Cecilia Cordoba*

Hello, my name is Cecilia and I am the mother of Agustina Kaucic, who we call Agus. We are from Argentina. Agus is five-years-old and she was diagnosed with Fanconi anemia at two and a half after many tests and hospitalizations.

When we learned of this diagnosis it was devastating. It has been a difficult and rocky path that we’ve fallen on many times, but we’ve always picked ourselves back up. In my country there is very little known about FA, and no specialists that I know of who really research it. A great deal of advocating and fighting for care is necessary, and in many cases, the focus is centered around quality of life rather than specialized treatment.

Let me tell you a little bit about Agus’ journey with the disease. She was born premature at 33 weeks. She has café-au-lait markings, small thumbs on both hands, pelvic and kidney issues, and more symptoms, all due to the disease. Of course, FA has also affected her bone marrow, which is now functioning at 10%.

In September 2019, she received a haploidentical transplant. I was her donor, but unfortunately the graft was rejected by her body after she developed graft-versus-host disease. Agus was then treated with Eltrombopag, but it caused nose, mouth, and vaginal hemorrhages. After that, we tried gamma-globulin, which did not work either. Today, Agus is alive thanks to weekly blood and platelet transfusions.

It is not easy, but we do our best to live day by day. We have learned that we can laugh in the midst of pain. We work hard to seek answers for ourselves and others who are affected by FA in Argentina. Our goal is to be well known advocates in our country, so that others in similar situations may find hope.

Agus has a big brother, Facundo, who works hard to learn everything under the sun about this disease. Agus is a warrior who is full of life, and her will to live, her smile, her courage and gratitude make up the engine that drives us through our struggles. As parents, it is extremely painful to watch your child fight these battles. Positivity, acceptence, and love seem to be the recipe that holds everything together for our family.
Joanne (Eggby) Smith was born in England on September 22, 1965. Weighing only 4lb 7oz, Joanne exhibited many of the physical anomalies associated with Fanconi anemia, (FA) including missing digits, dislocated hips, ectopic kidneys, type 1 diabetes, and gastrointestinal abnormalities. “It took until she was nine years old before we were given a diagnosis. We were never told anything about Fanconi anemia, or where to get any help, and just had to cope with things as they cropped up,” her parents, Den and Fran, shared.

In spite of her many health obstacles, Joanne grew to be a lively child who loved Elvis Presley and animals. Her older sister, Helen, always admired how easily Joanne made friends. “She was such a good sister and much-loved Auntie to my three children. We always enjoyed our family get togethers both as children and as adults.”

In 1983, Joanne met Kevin, the love of her life. The two were married three years later and spent their marriage traveling through 23 countries, attending various athletic championships, and mastering new skills like playing darts. “She even won a darts competition in Germany,” Kevin fondly recalled. Joanne and Kevin lived in Munich, Germany for seven years, where she learned German and started porcelain painting.

It wasn’t until 2010 that the two noticed that Joanne was not able to do the things that she used to do. Cancer crept into the picture and eventually she had to use a walking stick and wheelchair.

On April 16, 2020, Joanne passed away. But in true Joanne-fashion, she made two final gifts to the FA community which have been dedicated to advancing the efforts of Fanconi Hope, in the UK, and providing international scholarships for adults living with Fanconi anemia who wish to attend FARF events in the United States.

You see, Joanne had never met another person with Fanconi anemia until she was nearly 50 years old. When reflecting on her first experience at a FARF Adult Meeting in 2012, Joanne said, “this was the first time I had met anyone else with FA, and it was a great inspiration to share our experiences. Even though we are all FA warriors, we all have different characteristics. With the help of FARF, I feel like I have an extended family and great support.

Joanne’s life and legacy lives on through her family and her spirit of generosity. She inspires us all to ask, ‘what will our legacy be?’
LASTING IMPACT
IN ACTION

In recent years, you’ve heard us talk a lot about legacy planning. It all started with a generous gift made by Joel Walker in 2016. Joel was diagnosed with Fanconi anemia in his thirties. When he passed away from complications of head and neck cancer, Joel left a generous bequest to the Fanconi Anemia Research Fund to target research and treatment options in the head and neck cancer space.

That’s the true power of legacy gifts:

“It extends your impact, not just in terms of traditional capital, but also in terms of your human capital—who you are in terms of your knowledge, values, relationships, and spiritual beliefs, as well as your contributions to society. Most importantly, legacy planning is about life, not death. Legacy planning empowers you to choose the life you want to ultimately leave behind and to write the story you want others to tell when you are gone.” — Forbes

2020 was a groundbreaking year for donors considering these types of gifts. Clint Johnson, a donor who supports Team Bravery in Sarasota, Fla., said:

“I became involved with FARF because my fraternity brother has a granddaughter with FA. Our fraternity’s motto is ‘Not for College Days Alone’. We have maintained our close brotherhood and friendship for nearly 50 years. I donate to many causes, but now FARF is my major charity because it will help find a cure for children with FA—I have changed my will to donate 20% of my net worth to FARF. I hope you will also consider making a donation or a legacy gift in honor of the family you know who is impacted by FA.”

Around the world, donors like Joel and Clint explored how their financial—and human—capital will leave a lasting impact in the Fanconi anemia community in the years to come.

If you are interested in joining FARF’s Legacy Society or exploring other ways to give, please connect with McKenna Knapp, FARF’s Philanthropy Director, at: mckenna@fanconi.org or 541.687.4658 ext. 503.

Other creative ways to give:

Stock: If you own stock or a mutual fund that has appreciated in price since you purchased it, please consider using that asset for your charitable giving.

Employee Matching Gifts: Employee matching gift programs are corporate giving programs in which the company matches donations made by employees to eligible nonprofit organizations. Check out our website to learn more!

Recurring Giving: Make your gift go further by joining our community of monthly donors. Each month, the amount you choose will be donated to FARF and at the end of the year, we’ll send you a report of your annual giving as well as a tax receipt. Recurring giving is 100% automated, meaning more of your gift supports the mission you care about.
Every May, FA families from around the world come together to share their stories and raise funds for research and support services. This is an opportunity for those in the FA community to talk about how living with a rare disease affects their lives. It’s a time when FA families gather their friends and family – in person in past years and virtually this year – and humbly ask for your support. This year’s theme was “Family Around the World” and you all showed us exactly that. Six hundred fifty-six amazing donors from 14 countries raised over $100,000 for FA research and support services. Thank you for celebrating the FA family in your life and those living all over the world, FA month donors.

Todd and Kristin Levine have hosted the Coley’s Cause Memorial Golf Tournament for 17 years in memory of their daughter Nicole, “Coley.” Earlier this summer, Coley’s Cause supporters came out for a fun day of golf and raised over $38,000 for FARF! Thank you so much to all of Coley’s Cause donors, sponsors, and supporters for continuously sharing Coley’s story and giving to fund FA research and family support services. We are so grateful!

When Roel Harryvan retired from Deloitte last year, he asked that funds for his retirement party be redirected to support the FA Research Fund on Giving Tuesday. The Harryvan family are longtime friends of the Pearl family, who have two adult children living with FA. When asked what prompted his generosity, Roel responded, “Are we living for the moment or are we wanting to leave a real legacy and make a promise to others? Everybody has their own little things, but when we think about the hardships in FA, it really puts things into perspective. The way FA families show up in the world despite those hardships is inspiring.” Thank you so much for your thoughtful generosity, Roel!
After their daughter was diagnosed with FA in 2000, Kevin and Katie Rogers jumped into all things Fanconi Anemia Research Fund – serving on the board of directors, fundraising, and traveling to both the Family Meeting and the Scientific Symposiums to connect with others in the FA community. Last year, grandparents Talmage and Jean Rogers made their biggest commitment yet: a $50,000 gift to support head and neck cancer research. Gifts like theirs move research forward faster, offering better outcomes to individuals impacted by cancer in the FA community. Thank you for your incredible generosity, Talmage and Jean!

Receiving an FA diagnosis is life changing and everyone reacts to this change in their own ways and in their own time. For 22-year-old Callie Toal from Connecticut, taking action and making a difference were among her priorities only months after being diagnosed. Callie and her family created an FA month page and shared about Fanconi anemia with their friends and family. By the end of the month, they raised over $9,000 for FA research and family support services. Thank you so much to Callie and to all her friends and family who supported her first fundraiser!

Based out of Denver, Kendall and Taylor Atkinson Foundation (KATA) donors have consistently supported FA research through large, fun, and creative fundraisers. In 2020, this determined group did not let the pandemic stop them. They cleverly pivoted their annual “Hoot N Holler” gala event into the “Hoop N Holler.” They rented a helicopter and filled it with mini cowboy hats purchased by supporters. They flew over a field full of hoops and dropped the hats from the sky. The hats that fell into the hoops won a range of prizes. The exciting event raised more than $125,000! Thank you, KATA Foundation and donors, for continually raising the bar to fund FA research!

Donate While You Shop on Amazon
Visit smile.amazon.com, select Fanconi Anemia Research Fund as your charity, and start shopping. That’s it!
DONOR HONOR ROLL

We would not be able to make strides in research or provide family support services without you, our wonderful donors. Below is a list of donors who contributed $250 or more to the Fanconi Anemia Research Fund between July 1, 2020 and June 30, 2021. Although space prevents us from printing all the names of our generous supporters, please know that we appreciate every single dollar raised—gifts of $10, $20, and $50 all add up and give us the power to make a difference through FA research and support. 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.

Sustaining Life Donors
Phil and Penny Knight

Legacy Society
Carol Ceresa
Ralph Chapman
Mira Frohnmayer and Sandra Sweet
Edna Houston
Clint Johnson
Joanne Smith
Nigel and Ann Walker
Bruce West
Pamela Wharton

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Phil and Penny Knight

$125,000
Kendall & Taylor Atkinson Foundation with the Nash and Griggs Families

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Pat and Stephanie Kilkenny
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Sanders Family Foundation

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David Altman Foundation
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Patricia Peterson
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$5,000 - $9,999
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Atlas Insurance
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David and Mary Ann Fiaschetti
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Harold and Margaret Taylor Foundation
Kevin Hartz
Dr. Shawn and Joann Hennigan
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Tillie, Jennie & Harold Schwartz Found
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Berman Family Foundation
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Blackbaud Giving Fund
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YOUR FA RESEARCH DOLLARS AT WORK

From July 1, 2020 – June 30, 2021, your contributions allowed FARF to award $1,868,988 to the following projects:

**Investigators:** Barbara Burtness, MD; Gary Kupfer, MD  
**Institutions:** Yale University School of Medicine/Georgetown University School of Medicine  
**Title:** Synthetic Lethal Approaches to Treatment of FA Gene Mutant Head and Neck Cancer  
**Amount Funded:** $250,000

**Investigators:** Sharon B. Cantor, PhD; Peter Kurre, MD  
**Institutions:** University of Massachusetts Medical Center/Children’s Hospital of Philadelphia  
**Title:** A Small Molecule Approach to Overcome Replication Dysfunction in FA  
**Amount Funded:** $250,000

**Investigator:** Markus Grompe, MD  
**Institution:** Oregon Health and Science University  
**Title:** Chemoprevention of Cancer in Fanconi Anemia  
**Amount Funded:** $97,067

**Investigator:** Csilla Krausz, MD, PhD  
**Institution:** Fundació Puigvert  
**Title:** Severe Spermatogenic Failure as a Sentinel for Early Diagnosis of Late-Onset Fanconi Anemia  
**Amount Funded:** $103,900

**Investigators:** Branden Moriarity, PhD; John Wagner, MD; Beau Webber, PhD  
**Institution:** University of Minnesota  
**Title:** Correction of Fanconi Anemia Mutations Using Digital Genome Engineering  
**Amount Funded:** $250,000

**Investigators:** Kathryn Pennington, MD; Agata Smogorzewska, MD, PhD  
**Institutions:** University of Washington/The Rockefeller University  
**Title:** Pathogenesis, Clinical and Treatment Outcomes, and Molecular Characteristics of Anogenital Squamous Cell Carcinomas in Individuals with Fanconi Anemia  
**Amount Funded:** $150,589

**Investigators:** Eunike Velleuer, MD; Christine Krieg  
**Institutions:** German Fanconi Anemia Support Group & Research Fund/Heinrich-Heine University  
**Title:** Reducing the Burden of Squamous Cell Carcinoma in Fanconi Anemia  
**Amount Funded:** $732,432

**Investigator:** Silvia Balbo, PhD  
**Institution:** University of Minnesota  
**Title:** Acetaldehyde Exposure and DNA Damage in the Oral Cavity of FA Patients Before and After the Consumption of a Low Alcohol Dose  
**Amount Funded:** $35,000

FARF is committed to supporting research to further our mission of finding new treatments and a cure for Fanconi anemia. Over our 32-year history, we have funded 265 grants, to 198 investigators and 71 Institutions worldwide. The total amount of research dollars awarded is more than $26,141,217!
FARF receives 4-star rating from CHARITY NAVIGATOR for the fourth year in a row

FARF recently received a letter from the president of Charity Navigator, one of the premier organizations that evaluates and ranks non-profit organizations in the United States:

“I wish to congratulate Fanconi Anemia Research Fund on attaining the coveted 4-star rating for demonstrating strong financial health and commitment to accountability and transparency.

This is our highest possible rating and indicates that your organization adheres to sector best practices and executes its mission in a financially efficient way. Attaining a 4-star rating verifies that Fanconi Anemia Research Fund exceeds industry standards and outperforms most charities in your area of work.

Only 21% of the charities we evaluate have received at least 4 consecutive 4-star evaluations, indicating that Fanconi Anemia Research Fund outperforms most other charities in America. This exceptional designation from Charity Navigator sets Fanconi Anemia Research Fund apart from its peers and demonstrates to the public its trustworthiness.”

— Michael Thatcher, President and CEO of Charity Navigator
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

Donate While Shopping on Amazon:

Donations of Appreciated Stock:
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