30 YEARS of GIVING

49,310
Incredible donors have contributed to the cause

$23,226,792
Total dollars have fueled research grants & clinical trials

233 Grants have been awarded to
153 Researchers at
74 Institutions worldwide

For every $20 donation, every bake sale purchase, every 5K registration, every holiday gift, for every time you partenered with us to make change happen, we humbly say:

1,389
FA families worldwide have received education and support services

53%
Of all people living with FA who are registered with FARF are adults

THANK YOU.

128,695
Total number of gifts you and others have made to support this mission

It all started with ONE FAMILY

Lynn and David Frohnmayer founded the Fanconi Anemia Research Fund in 1989.

Three decades later, all three Frohnmayer daughters have passed away.

David died in 2015 from prostate cancer.

Lynn remains devoted to finding better treatments and a cure.

"In the 1980s, we learned that all three of our daughters had Fanconi anemia. We were told it was a fatal disease and that kids usually died in the first decade of life. Therapies then were practically nonexistent. I just do not have the words to tell you the extent of the anguish that we felt.

One of the harsh realities of life is that we're not always in control of all the things that matter to us the very most of all. We all do the best we can with what comes our way, and sometimes we're fortunate to see that progress, and even great good, can come out of our own misfortune. I think that's happened in my life, for sure."

- Lynn Frohnmayer

HOW OUR FAMILY FOUND HOPE & GRATITUDE

Three years ago, our biggest challenges were making sure school lunches were prepared, uniforms were washed, and teeth were brushed. Our world was completely knocked off kilter when our then 5-year-old son Lennon was diagnosed with Fanconi anemia in June 2016.

I immediately contacted FARF and joined the FAmily Support Group soon after. It feels impossible to adequately describe what these resources have provided for our family. To know and feel supported by others also walking this path helps to lighten our load and expand our perspective of knowing we are in this together.

Last summer we went to Camp Sunshine to attend the FA Family Meeting for the first time. When I asked Lennon how it felt to be around other kids with FA, he smiled and said "it feels nice."

Having the ability to talk to others who truly know what you are going through can make the difference between despair and hope.

We are now celebrating 2+ years since Lennon's transplant. He is enjoying being a cub scout and just won a trophy for best paint job at a derby. We are immensely grateful. This gratitude looks and feels a little different than it did even a year ago and it has been hard-fought; however, it has shaped us, changed us, and forced us to grow in ways that we never knew we needed.

- Dana, Lennon's mom

Lennon (center), with his family at Camp Sunshine in June 2018

5 THINGS TO LOOK FORWARD TO IN 2019

- CLINICAL REGISTRY
- FA BIO-REPOSITORY
- NEW CLINICAL TRIALS
- DRUG REPURPOSING
- NEW CLINICAL CARE GUIDELINES

THERE'S STILL A LONG WAY TO GO.

Thank you for partnering with us on this mission to give kids and adults with Fanconi anemia longer, better lives.

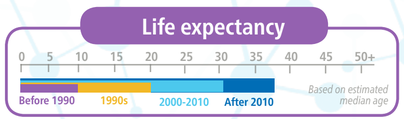
THANKS TO YOU.

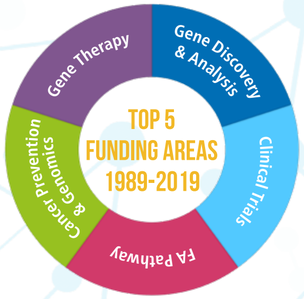
WE'VE COME A LONG WAY

2018 Fanconi Anemia Research Fund Impact Report

Pictured above: the most adults living with Fanconi anemia ever photographed together (46 attended the 2018 Meeting for Adults with FA)

WHAT IMPACT HAVE WE MADE AFTER 30 YEARS OF RESEARCH?



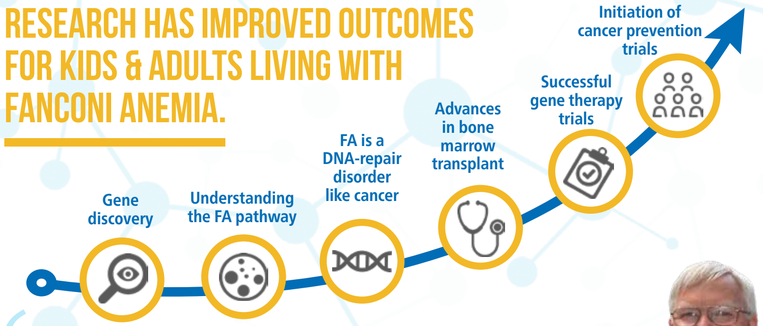


PEOPLE ARE LIVING LONGER.

Your gifts are leveraged by researchers

70% Of FARF-funded researchers who received a grant from the National Institutes of Health received a grant from FARF first. This means your gifts are multiplied many times over.

RESEARCH HAS IMPROVED OUTCOMES FOR KIDS & ADULTS LIVING WITH FANCONI ANEMIA.



"The expansive reach of FARF's impact is beyond anything we could have imagined. The multiplier effect that FARF has had on the Fanconi anemia field and scientific progress is astonishing."

- Richard Gelinas, PhD, Institute for Systems Biology, Seattle, FARF board member 1989-2017

FUNDED PROJECTS IN 2018

Eunike Velleuer, FARF-funded researcher

CANCER DETECTION & PREVENTION

The Fanconi Anemia Cancer Translational Resource
University of Washington

Reducing the Burden of Squamous Cell Carcinoma in Fanconi Anemia
German Fanconi Anemia Support Group and Research Fund

Identification of Novel Therapeutic Targets Against FA-Associated Squamous Cell Carcinoma
The Rockefeller University

GENE THERAPY & GENE EDITING

Use of Triplex-Forming PNAs as a Strategy for Correction of the FA Phenotype
Yale University

Direct in Vivo Gene Correction of Hematopoietic Stem Cell Populations in Fanconi Anemia
Fred Hutchinson Cancer Research Center

Defining Tractable Approaches for Gene Editing of FA Hematopoietic Stem Cells
University of California Berkeley

BONE MARROW TRANSPLANT

Development of a Safe, Completely Non-Genotoxic Anti-CD117 Antibody-Based Conditioning Regimen for Hematopoietic Stem Cell Transplantation in Fanconi Anemia
Stanford University

Project spotlight

Donors like you helped to fund this project in 2016
Drug screening and repurposing in Fanconi anemia therapeutics - Jordi Surrallés

COULD ANTICANCER DRUGS WORK IN FANCONI ANEMIA?

People with Fanconi anemia (FA) are hundreds of times more likely to get cancer than people without FA. Standard treatments for cancer, like radiation and chemotherapy, are highly toxic to people with FA, making alternative therapies desperately needed.

In a recent FARF-funded study, researchers in Spain performed a screen of 3,800 drugs on head and neck cancer cell lines from patients with FA. The goal of the study was to identify drugs that could kill tumor cells without harming normal cells or causing DNA damage.

In late 2018, the team showed promising results on two drugs that block activity of the epidermal growth factor receptor (EGFR). When EGRF is active, it leads to increased cell growth and the spread of the tumor. That's why it has long been a target for therapies. The two drugs identified by the Spanish team currently have FDA-approval for treating a kind of lung cancer, though they have never been tested before in the context of FA cancers.

This study is the first to show that FDA-approved drugs stopped head and neck cancer without damaging DNA. When mice with FA tumor cells were treated with these drugs, the research team observed that the drugs inhibited tumor growth efficiently. In addition, no side effects were seen, suggesting that these drugs could be safe in people with FA.

This is exciting because targeted therapies for FA cancers that do not cause DNA damage are desperately needed. We are now funding this team to develop this project into a clinical trial.

Right: Drs. Surrallés and Minguillón from Spain

FINANCIALS

Every dollar raised is used to support our mission and programs, to maximize fundraising, and to improve the effectiveness of the organization.

2018 INCOME: $3,067,853

**Unaudited numbers*

LEADERSHIP

www.fanconi.org | info@fanconi.org
541.687.4658

I LIVE WITH FANCONI ANEMIA. MY NAME IS JASMINE.

I was a normal, healthy kid until I went for my 13-year-old booster shot and a blood test 14 years ago. That was the first sign something was wrong. After a bone marrow biopsy, I was diagnosed with aplastic anemia (bone marrow failure). I thought that was the worst of it. Three years later, I was diagnosed with Fanconi anemia.

At that time, the doctors told us most patients with FA didn't make it to adulthood. I was 16 years old. I had all sorts of plans for my future – things I wanted to do, places I wanted go, a career I wanted to pursue – but from that moment on, my life as I knew it would never be the same.

Steve Jobs said "you can't connect the dots looking forward; you can only connect them looking backward." Looking back on that day, I had made a crucial decision to fight back and chase after all the things I was passionate about, despite how little time we assumed I had left.

That was 11 years ago. I am now 27 and my body is holding strong. I am officially "adulting" – and very well, might I add. I finished school, I have my own home, started my own clothing line, I travel, I am a published photographer, and I work for a wonderful company that you may have heard of: Apple. However, my bone marrow is still failing and a transplant is in my future.

Yet I am here today living my best life because of the research that came before me and continued after my diagnosis. None of it could have happened without awesome donors like you: heroes who give generously so that scientists and doctors have the resources they need to keep advancing science so people like me have a chance.

My mother always says "stay as healthy as you can for as long as you can, so science has the chance to catch up."

On behalf of all patients and families fighting this battle, thank you so much for giving science the opportunity to catch up. You truly are the Bruce Waynes of this world. For those of you who don't speak nerd, I just called you Batman, because you are the heroes in the shadows.