IMPACT REPORT

Photo: Adults with FA at their Annual Retreat in 2022
For 34 years, our research fund has dramatically improved outcomes for those with Fanconi anemia.

Your gifts have led to the discovery of 23 genes, uncovered the connection between FA and cancer, and skyrocketed survival rates for bone marrow transplant.

In 2022, we took major steps forward in addressing our biggest problem yet: cancer.
Your support over the decades has led to major impact in the field...

**1990s**

**ACTION**
Invested in gene discovery and understanding disease history.

**IMPACT**
23 genes identified, with a greater understanding of FA clinical manifestations.

**2000s**

**ACTION**
Identified breakthroughs in bone marrow transplantation and connections between FA and cancer.

**IMPACT**
Transplants today have more than a 95% success rate, leading to increased life expectancy. FA is now defined as a cancer-susceptibility disease, putting it on the radar of oncologists around the world.

**2010s**

**ACTION**
Advanced FA gene therapy and expanded cancer research initiatives.

**IMPACT**
Gene therapy trials show early signs of success. Cancer studies create models that test drugs with potential to treat, or even prevent, FA cancer.

**2022**

**ACTION**
Pioneered the Fanconi Anemia Cancer Consortium, a multi-institutional cancer program.

**IMPACT**
The consortium will lead to faster discoveries of ways to prevent and treat cancer.

**NOW**

**Strengthen comprehensive, systematic approach to prevent and treat FA Cancer**
Expand the successful global Fanconi Anemia Cancer Consortium. This consortium provides the infrastructure and resources needed to drive cancer research, while offering best practice care to prevent and treat FA cancer.

**Invest in novel methods to prevent all manifestations of FA**
Drive advancements in gene therapy, including gene editing, that targets all body systems so that people with FA can live long and healthy lives.

and now we're taking research to the next level by funding a multi-institution cancer consortium.
In 2022, donor gifts supported 9 new and ongoing research projects, with a major focus on cancer.

$2,874,852 awarded in 2022

**CANCER CONSORTIUM**

- NIH Center Comprehensive Program for Natural History of Development of Squamous Cell Carcinoma in FA
  - University of Washington and Oregon Health and Science University
  - Yale University, Georgetown University
  - University of California, San Francisco

- Cytology-based DNA Analysis to Investigate the Malignant Potential of Oral Lesions in Patients with FA
  - BC Cancer Research Institute

- Building Collaborative Partnerships to Understand FA Tumor Pathogenesis, Prevention, and Treatment
  - The Rockefeller University

**MENTAL HEALTH**

- Psychosocial Experiences of Adults with FA
  - Oregon State University and University of Minnesota

**FA NEUROLOGICAL SYNDROME**

- FA-Associated Neurological Syndrome: Search for a Cause
  - University of California, San Francisco

While research is underway, people with FA need help now. That's why we also support psychosocial, clinical, and educational initiatives:

**PSYCHOSOCIAL**

- Caregiver Support
- Individual Support
- Grief Program
- Peer Support
- In-Person Retreat

**CLINICAL SUPPORT**

- Virtual Tumor Board
- Tissue Donation
- Cancer Registry

**EDUCATION**

- Cancer Screening Program
- Clinical Care Guidelines
- Webinars & Guides
- Resource Library
We are the #1 organization for individuals with FA and their families worldwide.

You make this possible. Thank you!

Bella, 18, Colorado

Bella spent the first 84 days of her life in the intensive care unit and has had dozens of surgeries since. In the future, she will likely need a bone marrow transplant to survive. In the meantime, she has annual bone marrow biopsies, dozens of specialist appointments, and early cancer screenings (a FARF-funded program).

For now though, Bella continues to overcome the odds and prove that FA does not limit who she will become. She loves horseback riding and stand up paddleboarding. She dreams of attending the University of Hawaii to study photography.

Will, 30, Maryland

Diagnosed with FA, at age five, Will attended FA Family Meetings as a child and began joining the FA Adult Meetings in 2017. A strong advocate for research, Will was a participant in the phase 1 gene therapy trial for FA patients in 2015. He went on to have his bone marrow transplant in 2020 at the height of the pandemic. He's now doing well and serves on the FA Adult Council at FARF when he's not working at his job in data operations.

Outside of all things medical, Will enjoys gaming, dogs and traveling the world. Next on his bucket list is Greece!

Kitt, 5, Minnesota

Born at just under five pounds, Kitt has always been a giant warrior in a small package. She's had several surgeries and received her bone marrow transplant last year. Thanks to advancements in transplant, she is recovering well and has recently returned to preschool!

Kitt loves to tell jokes and is a lip-synching star. She loves Darth Vader, all things space, and wants to be an astronaut when she grows up. Her parents are counting on research to help Kitt achieve her dreams.

Adults with FA serve on two of the FARF leadership boards; the FA Adult Council and Board of Directors. This photo was captured at the Annual Leadership Meeting in February 2023.
**Financial snapshot**

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, events, psychosocial support, and clinical programs.

**Income: $1,899,120**

**Expense Breakdown:**

- **Research** $2,638,685
- **Support Services** $227,375
- **Admin** $607,085
- **Fundraising** $325,134

**Total Expenses: $3,798,280**

Despite challenges in fundraising and a loss in our investment portfolio last year, FARF continued to honor all of its commitments to researchers, while awarding new grants by drawing on reserves. We look forward to a great year ahead and anticipate recovering these losses. As FA families need answers urgently, we must continue to move research forward.

**Thank you for continuing to make our research, education, and support programs possible.**

*NOTE: These numbers are unaudited. Updated numbers will be available on our website this spring and in the donor newsletter this summer.*

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**FA Adult Council**

Members of FARF boards and staff at the Annual Leadership Meeting in February 2023