FANCONI ANEMIA
RESEARCH FUND

IMPACT REPORT

2022

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

FA researchers at the 2022 Scientific Symposium in Austin, Texas

$2,874,852 awarded in 2022

CANCER CONSORTIUM

NIH Center Comprehensive Program for Natural History of Development of Squamous Cell Carcinoma in FA
National Cancer Institute

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

Oral Gene Therapy as a Prevention for FA-Associated Cancers
University of Washington and Oregon Health and Science University

Synthetic Lethal Approaches to Treatment of FA Head and Neck Cancer
Yale University, Georgetown University

Development and Characterization FA Head and Neck Cancer PDX Models
University of California, San Francisco

Modeling Environmental Responses of FA Cancers
Stanford University, University of Minnesota, and Columbia 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

Bella, 18, Colorado

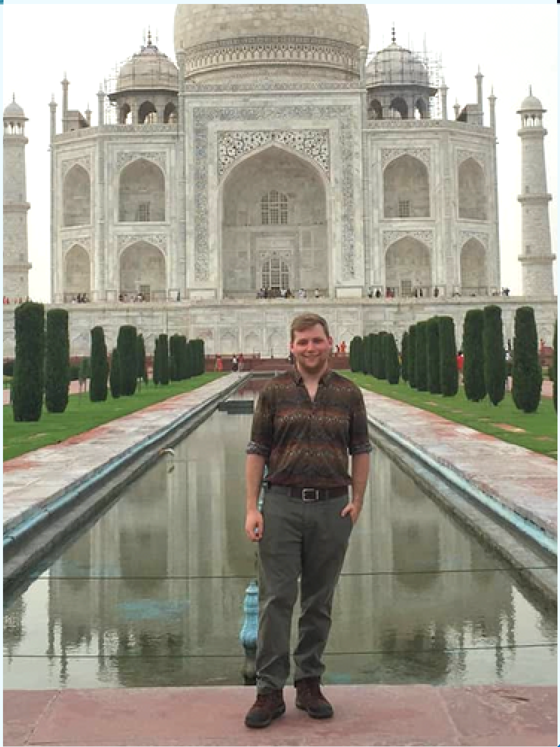
Bella spent the first 84 days of her life in the intensive care unit and has had dozens of surgeries since. In the future, she will likely need a bone marrow transplant to survive. In the meantime, she has annual bone marrow biopsies, dozens of specialist appointments, and early cancer screenings (a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

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!

Will, 30, Maryland



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 FAdult Council and Board of Directors. This photo was captured at the Annual Leadership Meeting in February 2023.

We are the #1 organization for individuals with FA and their families worldwide.

You make this possible. Thank you!

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	Support Services	Admin	Fundraising
$2,638,685	$227,375	$607,085	$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.

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

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