A YEAR OF GOING FURTHER
Thanks to you!

EXPANDING ACCESS

Virtual meetings allowed for hundreds of FA families, researchers, and clinicians to connect and learn.

Translation and interpretation services made educational materials accessible to the Spanish-speaking community.

INVESTING IN CANCER RESEARCH

Head and neck cancers

The successful brush biopsy project to prevent and detect head and neck cancers was extended. This team will expand their service of oral exams for patients and provide training for physicians to perform exams on their own patients.

Anogenital cancers

Donor gifts enabled FARF to fund the first research project focusing on anogenital cancer. Researchers will collect and study data about these cancers to help identify the best treatments.

Other cancer-related projects focus on drug discovery and building models to study cancer.

INCREASING SUPPORT TO INDIVIDUALS & FAMILIES

2020 brought new challenges to the FA community. Maintaining connection, health, and overall wellbeing became major topics of focus at FARF events and in educational materials.

BUILDING COMMUNITIES FOR A CAUSE

As the world changed, supporters found new and creative ways to move the cause forward. Fundraisers and donors supercharged their impact with the most fundraisers in a single year in FARF's history.
Receiving a cancer diagnosis is life-changing. Stress, uncertainty, and fear come with this diagnosis. People with FA face an added challenge: finding a doctor who knows how to treat FA cancer. That’s why FARF created the Virtual Tumor Board. This team of cancer and FA specialists provides advice to patients and their treating physicians to make sure patients get the best-informed care.

**Gene editing**
- **NEW** Correction of FA mutations using digital genome engineering  
  *University of Minnesota*

**DNA repair**
- **NEW** A small molecule approach to overcome replication dysfunction in FA  
  *University of Massachusetts Medical Center & Children’s Hospital of Philadelphia*

**Aldehydes**
- **NEW** Acetaldehyde exposure, oral microbiome, and DNA damage in the oral cavity of FA  
  *University of Minnesota*

**Cancer**
- **NEW** Reducing the burden of squamous cell carcinoma in FA  
  *Heinrich-Heine University*

- **NEW** Chemoprevention of cancer in FA  
  *Oregon Health & Science University*

- **NEW** Pathogenesis, clinical and treatment outcomes, and molecular characteristics of anogenital cancer in FA  
  *University of Washington & The Rockefeller University*

- **NEW** Synthetic lethal approaches to treatment of FA gene mutant head and neck cancer  
  *Yale School of Medicine & Georgetown University*

- **EXTENDED** The FA cancer translational resource  
  *University of Washington*

- **EXTENDED** Development of a safe antibody-based conditioning regimen for hematopoietic stem cell transplantation in FA  
  *Stanford University*

**Bone marrow failure**
- **NEW** Severe spermatogenic failure as a sentinel for early diagnosis of late-onset FA  
  *Fundacio Puigvert*

**Diagnosis**
- **NEW** Chemoprevention of cancer in FA  
  *University of Minnesota*

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**ONE YEAR OF THE PATIENT REGISTRY**
To better treat Fanconi anemia, we need to better understand it. The FA Patient Registry gathers medical data from participants, which can then be used by researchers and clinicians to develop an understanding of the disease and ways to treat it. More than 100 people with FA have joined the registry in the first year.

**ADVANCING RESEARCH**

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**SUPPORT TO PATIENTS WITH A CANCER DIAGNOSIS**

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**FUNDED PROJECTS**

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**10 projects awarded**

$1,998,225 in research $
newly diagnosed families received support

66

300+

individuals & families connected at our 2020 virtual events

WORLDWIDE SUPPORT, EDUCATION, AND CONNECTION

For the first time, FARF was able to significantly expand its services to those all over the world by bringing individuals and caregivers together through virtual events. Educational webinars brought the experts right into the homes of those affected by FA, and virtual support sessions made space for individuals and caregivers to collectively exhale.

NEW FA CLINICAL CARE GUIDELINES

The first FA Clinical Care Guidelines Manual was published in 1999. Two decades later, the 5th edition was released, complete with more extensive information about cancer in FA and living with FA as an adult.

This resource is irreplaceable for people with FA, their families, and their doctors.

Download or request your free copy at www.fanconi.org.

Dedicated advocates in Spain, Mexico, and Egypt each received $10,000 support grants to develop programs for the FA communities in their countries. The Spanish team is focusing on strengthening their organization, while the group in Mexico is planning the first meeting of people with FA, and the team in Egypt is improving the diagnostic process.

Supporting families

SUPPORT PROJECTS IN THREE COUNTRIES

Ana Alejandra Tabar is an adult living with FA from the Dominican Republic. After receiving an International Support Grant from FARF, Ana developed FA educational materials in Spanish and started a support organization for Spanish-speakers from all over the world.

Find her on Facebook & Instagram at @uncorazonporfanconi

A SPOTLIGHT ON CAREGIVERS

Caregivers, we see you! Caregivers are also impacted by FA and face their own set of unique challenges and experiences. The caregiver story is interwoven throughout the FA journey, which is why we have developed exciting initiatives to offer acknowledgment and more direct support for caregivers in the FA community.

SUPPORTING FAMILIES
2020 was a groundbreaking year for FARF donors considering bequests. Clint Johnson, who gives in honor of Team Bravery, a family fundraising team in Florida, shared why FARF matters to him: “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. This year I 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.”

Tiernan (left) and his brother Brennan held a bake sale to raise funds for other kids with FA.

A RECORD YEAR FOR FUNDRAISERS

One of the remarkable strengths of this community is the ability to persevere in the face of great challenges. Although many fundraisers were canceled in 2020, even more pivoted to virtual events and supporters created new ways to contribute. In 2020, the FA community put on a record 105 fundraisers!

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GOING THE SOCIAL DISTANCE FOR FA

As the world began to shelter in place last spring, members of the FA community from all over the country ‘went the social distance for FA’. In a collective day of movement, people walked, ran, biked, and hiked to raise funds for FA research and families. Over $7,000 was raised in one day!

INcredible LEGACIES

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4,976 generous gifts
$2,860,112 in donations
3,660 amazing donors
Your generous gifts are used to support our mission and programs, increase fundraising, and improve the effectiveness of the organization. Thank you.

**Income:** $3,335,174  
**Expenses:** $2,848,738

**YOUR GIFTS AT WORK**

- **Research:** $1,935,650  
- **Family Services:** $257,370  
- **Fundraising:** $233,832  
- **Admin:** $421,886

*These numbers are unaudited*