

# GROWING FORWARD



FANCONI ANEMIA  
RESEARCH FUND

2020 IMPACT REPORT

# A YEAR OF GOING FURTHER

*Thanks to you!*

Dr. Karen Queliza joined several doctors to share the latest info with FA families



## 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.

Dr. Katy Pennington leads the anogenital cancer research project



Lucy and her mom happy to connect with other FA families



## 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.

FA parent Kevin McQueen and friends cycled 100 miles to raise funds for research







Researchers in Spain  
working on gene  
therapy in FA

## ADVANCING RESEARCH

### FUNDED PROJECTS

#### 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*

#### Bone marrow failure

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

#### Diagnosis

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

#### 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*



### 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.



### SUPPORT TO PATIENTS WITH A CANCER DIAGNOSIS

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.

**10** projects  
awarded

**\$1,998,225** in research \$

# 66

**newly diagnosed families received support**

# 300+

**individuals & families connected at our 2020 virtual events**



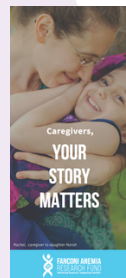
## WORLDWIDE SUPPORT, EDUCATION, AND CONNECTION

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.



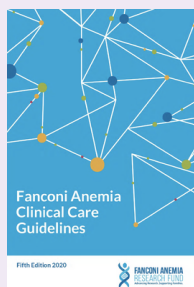
## A SPOTLIGHT ON CAREGIVERS

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.



## 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](http://www.fanconi.org).*



## SUPPORT PROJECTS IN THREE COUNTRIES

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

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





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!



## 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!

Ryan (right), and her brother Christian rode scooters as part of the "Going the Social Distance" challenge



## INCREDIBLE LEGACIES

2020 was a groundbreaking year for FARE donors considering bequests. Clint Johnson, who gives in honor of Team Bravery, a family fundraising team in Florida, shared why FARE matters to him: "I became involved with FARE 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 FARE 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 FARE. 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."



Clint chooses to give back to FARE as part of his legacy

**4,976**  
generous gifts

**\$2,860,112**  
in donations

**3,660**  
amazing donors



Alex and Jacqueline,  
teens with FA, and  
their parents

## LEADERSHIP

### Board of Directors

André Hessels, President  
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Aileen Carlos, JD  
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Lynn Frohnmayer, MSW  
Win Gouldin, PharmD  
Tracy Strimling  
Joyce L. Owen, Director Emeritus

**YOU MAKE  
AN IMPACT**

*Thank you!*



### YOUR GIFTS AT WORK

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**

**\$1,935,650**  
**Research**

**\$257,370**

**Family Services**

**\$233,832**

**Fundraising**

**\$421,886**

**Admin**

### Scientific Advisory Board

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### FA Adult Council

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Matthew Pearl, co-chair  
Angela Bedoya  
Egil Dennerline  
Amelia Hawkshaw  
Mary-Beth Johnson  
Duncan Nunes  
Alejandra Tabar Concha  
Jack Timperley

*\*These numbers are unaudited*



**FANCONI ANEMIA  
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Advancing Research. Supporting Families.

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