Meet some of the FAmily

Karly, 21

"I want to be a role model, so when I leave this world behind, I will be proud of the life I lived." Fourteen years post-transplant, Karly's journey with Fanconi anemia has given great purpose to her life. She was diagnosed in 2002 at age seven. Currently, she is pursuing a nursing degree and aspires to work in the Pediatric Oncology ward of a children's hospital. Having lost many friends to FA and battled most of her life, her goal is to inspire and give hope to children struggling with diseases like FA, leukemia and cancers.

Aria, Forever 4

Before she was born, Aria's parents were told she would likely not survive outside the womb. Yet, in January 2011, Aria came into the world, determined to defy the odds. She had multiple disabilities, experienced 21 surgeries and lived most of her life in the hospital, but despite this, Aria experienced the world vibrantly. She rode horses. She loved the school bus. She was enthralled by bright lights and fascinated with Disney princesses. She smiled often and enthusiastically. Aria died Sept. 20, 2015. She inspired many people during her life and continues to touch those who hear her story.

Joy, 6
Dylan, 9

This brother and sister pair haven't been slowed down much by their FA diagnosis. Dylan is a major Lego enthusiast who loves biking and hiking. Like most kids, his iPad is also a favorite. He underwent a bone marrow transplant in 2016 and is excited to be back at school. Joy is the little monkey of the family, fearlessly climbing on any and everything. She also adores arts & crafts. Both Dylan and Joy are enamored with their 2-year-old brother, Ryan. The trio keeps their house alive with energy!

Mariana, 4

Bashful at first, Mariana quickly warms up to new friends and happily shares her playful and lovable side. Painting, coloring, and 'writing' notes are among her favorite activities – she also loves to dance and sing when she thinks no one is watching. Nicknamed "Sassy" by her family, this brave fan of princesses and the color pink received a bone marrow transplant in December in Minneapolis. Mariana is recovering well with her family by her side, notably, her favorite person in the world, her big brother Isaac.

Daniel, 41

Eat. Love. Laugh. "To us, it really is that simple," says Daniel. That is the motto he and his wife, Aileeng, live by every day. He was diagnosed with Fanconi anemia in 1981 and had a transplant four years later. In 2014, he lost half his tongue to cancer, but has been doing very well since then. Daniel lives in his native Denmark, where he works at a daycare center and as a gaming journalist. He's even used his gaming skills to raise funds for FA research by participating in Mario Kart marathons!

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

How can I help?

- Donate
- Plan an event
- Spread the word

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@FAresearchfund

www.fanconi.org
1801 Willamette Street, Suite 200, Eugene, OR 97401
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2016 Impact Report

2016 Our impact

$1,925,698
$ granted

10
Grants awarded

$3,090,162
$ raised

48
Fundraisers

92
FA families attended FARF meetings

All thanks to donors like you

Grants give hope

Projects awarded in 2016

Towards improved clinical management of FA-related cancer via a novel functional genomics approach
Dept. of Clinical Genetics, VU University Medical Center | $234,320

Cancer in Heterozygote Carriers of Fanconi Anemia
National Cancer Institute | $300,000

Reducing the burden of squamous cell carcinoma in Fanconi anemia
German Fanconi Anemia Family Support Group and Research Fund | $183,318

Drug screening and repurposing in Fanconi anemia therapeutics (acronym: REPAIR-FANC)
University Autonoma, Barcelona | $160,000

Targeting lipid metabolism in FA for the prevention and treatment of squamous cell carcinoma
Cincinnati Children's Hospital Medical Center | $250,000

A Training Grant for Development of a Fanconi Anemia Cohort in Mexico
National Cancer Institute | $75,500

Investigating the impact of lentiviral transduction on Fanconi anemia hematopoietic stem cells for improved gene therapy
San Raffaele Telethon Institute for Gene Therapy (TIGET) | $175,000

How environment shapes the consequences of mutation within the Fanconi anemia pathway
Whitehead Institute for Biomedical Research | $160,000

Targeting LNK(SH2B3) to ameliorate hematopoietic stem/progenitor defects in Fanconi anemia
The Children's Hospital of Philadelphia | $204,593

Detection and characterization of ubiquitinated FANCD2 and FANCI
St. Vincent's Institute | $182,967

5 awesome things donors made possible in 2016

In 2016, the Fund awarded more than $1.9 million in grants to 10 investigators at nine institutions worldwide.
Pictured: Wei Tong, PhD, grant recipient and 2016 Symposium abstract winner.

New Grants Awarded

FARF co-sponsored the 7th International FA Gene Therapy Working Group meeting in Madrid, Spain, with record attendance of more than 40 scientists and clinicians from around the world.

Gene Therapy Meeting

Fifty-one FAmilies from four countries gathered at Camp Sunshine for a week of festivities, bonding activities, research opportunities, psychosocial support and informative sessions.

Family Camp

Nearly 200 FA researchers and clinicians gathered in Bellevue, Wash. for the 28th Annual FA Scientific Symposium to share insights and form new collaborations.

Scientific Symposium

The 6th meeting for adults with FA was held in Fla. for 50 adults. By the end of 2016, for the first time ever, there were more adults with FA than children (of the nearly 1,000 people with FA registered with FARF).

Meeting of Adults with FA

"Growing up I didn't think a lot about having FA, but recently, the fears started creeping in. My life is so unexpectedly beautiful, and I want it to be long. I'm so proud to be one of the FA adults, and I'm hopeful in the work FARF is doing to find a cure for FA. Cheers to progress and happy tears and hope. - Mary-Beth, 24

Financials

Every dollar goes:

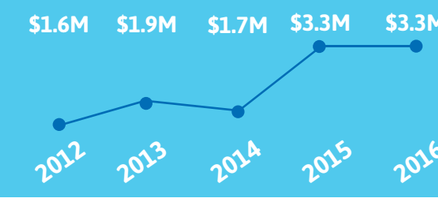
To our **mission** of finding better treatments and a cure for FA and providing education and support services to affected families

To maximize **fundraising**

To improve effectiveness of the **organization**

FIVE YEAR GROWTH

Annual income in millions



STATEMENT OF ACTIVITIES

Total revenue and gains	**$3,327,290**
Fundraising	$3,090,162
Other	$237,128
Total expenses	**$3,300,889**
Research	$2,533,888
Family Services	$260,776
Fundraising	$197,476
Administration	$308,749

Unaudited number

EXPENSES