Together with dedicated community members like you, we have funded Fanconi anemia research and supported affected families worldwide for 30 years...and counting. *Thank you.*

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

1980s

A DEVASTATING DIAGNOSIS

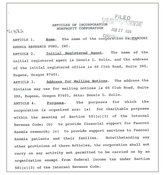
Oregon parents Lynn and David Frohnmayer learn their two daughters, Kirsten and Katie, have Fanconi anemia (FA), a rare genetic disorder that leads to bone marrow failure, leukemia, and cancer. They would later find out that their third daughter, Amy, also has the disease. The Frohnmayers learn that patients with FA rarely live to adulthood and that there is no cure for this illness. They also discover that the disease is scarcely known in the medical community.

The Frohnmayer family in 1985. From left to right, David, Lynn, Mark, Jonathan (baby), Kirsten, Katie.

The Frohnmayer children in 1987. From left to right, Amy, Kirsten, Jonathan, Mark, Katie.

THE ACCIDENTAL ORGANIZATION

In 1989, three institutions approach the Frohnmayers to raise money for their investigations. Lynn and Dave again write to their friends and ask them to make checks out to "Fanconi Anemia Research Fund". However, the institutions can't cash them as written! The Frohnmayers quickly decide to form a 501(c)(3) charitable corporation, name it the Fanconi Anemia Research Fund (FARF), form a board of directors, and establish articles of incorporation. They cash the checks, send each of the researchers $30,000, and the FA Research Fund is launched!



ARTICLES OF INCORPORATION
NONPROFIT CORPORATION

Article 1. Name. The name of the corporation is Fanconi Anemia Research Fund, Inc.

Article 2. Initial Registered Agent. The name of the initial registered agent is Dennis L. Bolin, and the address of the initial registered office is 60 Club Road, Suite 380, Eugene, Oregon 97401.

Article 3. Address for Mailing Notices. The address for this location may see for mailing notices is 60 Club Road, Suite 380, Eugene, Oregon 97401, attn: Dennis L. Bolin.

Article 4. Purposes. The purposes for which the corporation is organized are: (a) for charitable purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code; (b) to provide financial support for Fanconi Anemia research; (c) to provide support services to Fanconi Anemia patients and their families. Notwithstanding any other provisions of these Articles, the corporation shall not carry on any activity not permitted to be carried on by an organization exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code.

THE FIRST SCIENTIFIC SYMPOSIUM

The Frohnmayers invite scientists who have published about FA or are recommended by those scientists to a scientific meeting. Eighteen researchers are asked to "bring their brains" to Portland, Ore., where, together with the Frohnmayers and FARF board, they draft what would become FARF's guiding principles. These same principles continue to define the Fund's work today: encourage scientific collaboration and a multidisciplinary approach, hold annual scientific symposia, identify and support the best science possible, and fund researchers who would go on to leverage FARF's start-up grants into much larger grants from their institutions or government entities. The group endorses a five-year gene identification project with the goal of identifying one or more genes responsible for this disorder.

CONNECTING WITH OTHER FA FAMILIES

Feeling anxious, frightened and lonely, the Frohnmayers follow the advice of a researcher at The Rockefeller University and reach out to other FA families to create a support group. Nineteen families respond with interest. Lynn and Dave begin writing the FA Family Newsletter to share information they glean from scientists with other families.

EARLY OUTREACH TO EXPERTS

A scientist asks the Frohnmayers to raise $50,000 for research. They promptly write to family, friends, and acquaintanes to solicit donations to The Rockefeller University. The unofficial 'research fund' is born.

THE FIRST FA FAMILY MEETING

As a scientific community begins to take shape, the Frohnmayers also focus on family engagement as a central strategy. Although they were at first skeptical that families would be interested or able to gather together, in 1991 more than 100 FA parents and children attend the very first "FA Family Symposium" in Washington, D.C. This gathering marks the beginning of what would become a cornerstone of the FA community: an annual meeting of individuals with FA, their families, and physicians and researchers, with the purpose of educating and supporting families, forming connections and improving and extending the lives of those affected by FA.

1990s

THE FIRST FA GENE IS DISCOVERED

One of the first efforts of FARF is to identify the FA gene(s). Gene discovery enables scientists to study and begin to understand the function of the protein(s) encoded by FA gene(s), which might suggest how best to treat the disorder. In 1992, Manuel Buchwald and his team at the Hospital for Sick Children in Toronto, Canada, discover the first FA gene, *FANCC*. This is a major breakthrough for FA science and paves the way for many more research discoveries in the decades to follow.

Dr. Buchwald accepts a discovery award from Dave Frohnmayer.

EDUCATIONAL SUPPORT FOR FAMILIES & PHYSICIANS

With the help of the emerging FA community, Lynn and Dave Frohnmayer publish *Fanconi Anemia: A Handbook for Families and Their Physicians*, the first edition of what would later become the *Fanconi Anemia Guidelines for Diagnosis and Management*.

1990s: MOVING FORWARD

FARF surges forward in the 90s, funding new research grants each year and expanding family support services. Annual science and family meetings result in the growth of the FA community, consisting of researchers, clinicians, people with FA and their families, volunteers and staff. Educational resources and publications like the patient handbook and family & scientific newsletters keep the community informed and engaged.

Dave Frohnmayer and Ralf Dietrich with Hans Joenje (right) after he accepts the Award of Merit at the Family Meeting in 1996.

Grover Bagby addresses the audience at the 10th Annual FARF Symposium in Denver in 1998.

A GAME-CHANGING DISCOVERY

FARF awards the University of Minnesota a grant to determine if one drug, fludarabine, can improve bone marrow transplant outcomes. Almost immediately, success rates go from 20% to 60%. Today, at any one of the three FA comprehensive care centers, more than 90% of young patients survive transplant.

Right: Dave Frohnmayer presents John Wagner an award at the 14th Scientific Symposium in Philadelphia in 2002.

Above: headlines from the Fall 1999 issue of the FA Family Newsletter.

Dave Frohnmayer and John Wagner, MD

Israel Achieves Early Success Using Fludarabine; No Radiation

Memorial Sloan-Kettering Reports on Two Successful Nonmatched Transplants, Using Fludarabine

Alternative Donor Transplants Using Fludarabine

Cincinnati Uses Fludarabine in New Alternate Donor Protocol

Minnesota Reports on Six Alternate Donor Transplants Using Fludarabine

John Wagner, MD, University of Minnesota, Minneapolis, received the first *Pioneer Award for Therapeutic Advancement* bestowed by the Fund. The Board of Directors acknowledged Wagner's outstanding contributions to the science relating to stem cell transplantation of FA patients. The success of Dr. Wagner's pioneering work, including the use of fludarabine, has increased dramatically the odds of FA patients surviving a transplant, especially from an unrelated donor. Frohnmayer also acknowledged Wagner's unselfish leadership in pushing FA science forward.

CANCER CONNECTION

Researchers discover that *BRCA2*, one of the breast cancer genes, is also an FA gene, *FANCD1*. This discovery supports the belief that the primary defect in FA is the inability to repair DNA damage, and is consistent with the finding that those with FA are at far greater risk for cancer. This cancer connection puts FA on the radar of oncologists around the world.

ScienceExpress Report

Fanconi Anemia Gene Identified as Candidate for Hematopoietic Stem Cell Disease

2000s

2000s: GROWTH CONTINUES

Children and teens at the Family Meeting in 2000.

Throughout the 2000s, FARF continues to extend its outreach, funding several research projects each year, welcoming more scientists and families to regular meetings, and publishing clinical care guidelines, newsletters and family directories. During this decade, FARF sponsors seven regional family meetings in addition to the annual FA Family Meeting at Camp Sunshine. In addition to the annual Scientific Symposium, FARF holds nine focused workshops on topics such as bone marrow transplantation, small molecules as possible therapeutics, and squamous cell carcinoma.

Arleen Auerbach and Farid Boulad at the 14th Symposium in 2002 in Philadelphia.

Blanche Alter presents at the first Meeting for Adults with FA in 2003 in Virginia. Seven adults with FA and one teen with FA are in attendance.

FA families and community members at the 2010 Family Meeting.

GENE DISCOVERY
FANCE, FANCF

GENE DISCOVERY
FANCG

GENE DISCOVERY
FANCA

GENE DISCOVERY
FANCD2

GENE DISCOVERY
FANCL

GENE DISCOVERY
FANCB, FANCJ (BRIP1)

GENE DISCOVERY
FANCM

GENE DISCOVERY
FANCI, FANCN (BALB2)

2010s

GENE DISCOVERY
FANCO (RAD51C)

GENE DISCOVERY
FANCP (SLX4)

INTERNATIONAL GENE THERAPY EFFORTS

FARF enters a partnership with Fanconi Hope of the United Kingdom to expedite gene therapy trials through the creation of the International FA Gene Therapy Working Group. This group meets annually to share expertise and initiate gene therapy clinical trials.

The FA Gene Therapy Working Group in Madrid in 2016.

GENE DISCOVERY
FANCS (BRCA1) is also a breast cancer susceptibility gene.

GENE DISCOVERY
FANCQ (ERCC4)

STEPPING IT UP

After years dedicated to gene identification, improving bone marrow transplantation, and uncovering connections to breast and other cancers, FA scientists are now poised to create less toxic therapies and improve and extend lives. The Council to Focus and Accelerate Research (CFAR) is created in 2016 to address prevention, detection, and treatment of cancers that occur in people with FA.

GENE DISCOVERY
FANCU (XRCC2), FANCV (REV2)

GENE DISCOVERY
FANCR (RAD51), FANCT (UBC2T)

A RECORD-BREAKING YEAR

Longtime FARF supporters Phil and Penny Knight pledge $10 million to advance research over the next 10 years. Their incredible gift focuses on bold initiatives to prevent and cure the cancers that affect the adult FA population.

Lynn Frohnmayer with Phil Knight.

GENE DISCOVERY
FANCW (RFWD3)

ADULT FA POPULATION GROWS

In 2017, for the first time ever, there are more adults than children with FA registered in FARF's database of nearly 1,000 individuals with FA.

Adults with FA at the 2017 meeting in Atlanta.

LOOKING FORWARD

FARF continues to advance FA research and provide support to families. Gene therapy trials are now open on two continents and two new clinical trials were approved in early 2018, one of metformin (Dana Farber Cancer Research Center) and the other of quercetin (Cincinnati Children's Hospital). The incredible progress achieved over these years can be attributed to the hard work, dedication, and commitment of our FA families, researchers, clinicians, donors, staff and volunteers.

Adults with FA at the 2018 Family Meeting.

Eli and Lucy at the Family Meeting in 2018.

The Kairas Lab at MD Anderson Cancer Center.