FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

Frequently Asked Questions

What is Fanconi anemia?

Fanconi anemia (FA), named for the Swiss pediatrician, Guido Fanconi, is an inherited disease that may lead to bone marrow failure, leukemia, and/or solid tumors. Though considered primarily a blood disease, FA may affect all systems of the body. It is a complex and chronic disorder that is psychologically demanding. FA is also a cancer-prone disease. In 2010, the median lifespan for individuals with FA was 33 years. However, median lifespan can vary depending on a number of factors, including complementation group. Some FA individuals live into their 30s, 40s and 50s and 80% reach age 18 or older.

What causes Fanconi anemia?

FA is a very rare genetic disorder. FA is primarily a recessive disorder: if both parents carry a defect (mutation) in the same FA gene, each of their children has a 25% chance of inheriting the defective gene from both parents. When this happens, the child will have FA.

How many different FA genes are there?

FA is caused by 21 different genes, including the two breast cancer genes *BRCA1* and *BRCA2*. The three most common FA genes are *FANCA*, *FANCC*, and *FANCG*.

Who can have FA?

FA occurs almost equally in males and females and is found in all ethnic groups. The incidence rate, or the likelihood of a child being born with FA, is about 1 in 131,000 in the U.S., with approximately 31 babies born with FA each year in the U.S.

What are the symptoms of FA?

Individuals affected by FA can experience:

- Birth defects affecting thumbs, forearms, and other parts of the skeleton
- Kidney, urinary tract, and heart malformations
- Digestive difficulties
- Abnormal blood cell counts
- Hearing loss
- Bone marrow failure and/or leukemia, requiring a stem cell transplant
- Certain types of cancers (especially head and neck and gynecologic cancers) at a significantly younger age than the general population, even after a stem cell transplant.
- Intellectual developmental delay

What is the Fanconi Anemia Research Fund?

Lynn and Dave Frohnmayer started the Fanconi Anemia Research Fund, Inc. (FARF), in 1989, to find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide. Support includes: medical resource information, education, publications, online support groups, annual family meetings, and meetings for adults with FA.

- The Fund has awarded more than $20 million to fund over 220 research grants.
- FARF-supported research has made significant improvements in the bone-marrow transplant survival rates of FA patients.
- Research funded by FARF has helped to uncover important information about cancers that affect both FA and non-FA patients.
- More than 95% of the Fanconi Anemia Research Fund's annual budget comes from family fundraisers.

Fanconi Anemia Research Fund
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