



## 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 18 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 this country.

### **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, Inc.?**

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 \$17 million to fund over 200 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 80% of the Fanconi Anemia Research Fund's annual budget comes from family fundraisers.

### **Fanconi Anemia Research Fund, Inc.**

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