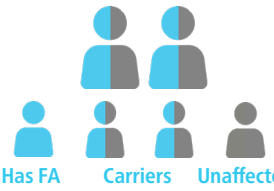
All about FANCONI ANEMIA

What is FA?

Fanconi anemia (FA) is a genetic DNA repair disorder that may lead to bone marrow failure, leukemia, and/or solid tumors (cancer). It is caused by one of at least 23 genes. FA can affect all systems of the body. It is a complex and chronic disease that is psychologically demanding.

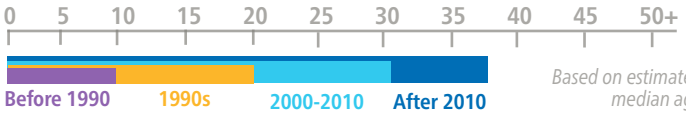
1 in 131,000

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

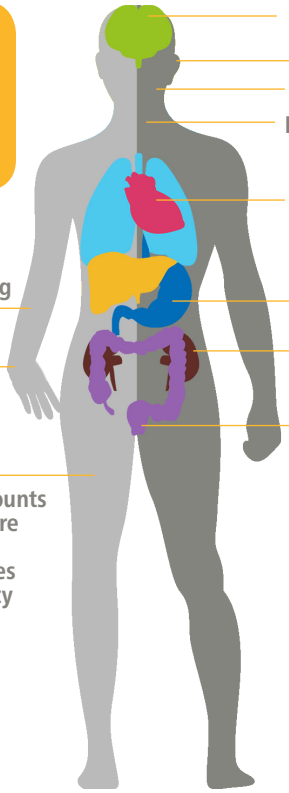


If both parents carry a mutation in the same FA gene, they have a 25% chance of having a child with FA.

Life expectancy



How does FA affect the body?



Psychosocial effects
Developmental delays
Hearing loss
Oral cancer
Head & neck cancer
Heart malformations
Digestive difficulties
Kidney & urinary tract malformations
Reproductive issues
Vulvar cancer
Anal cancer
Shorter or missing radius
Hand & thumb abnormalities
Whole body:
Abnormal blood counts
Bone marrow failure
Leukemia
Dermatologic issues
Hormone deficiency
Short stature

People with FA may experience any combination of these symptoms, ranging from one, to many.

Here's why you should care

It's simple: children and adults with Fanconi anemia need research to live. Without research, they won't get the advances in treatment that they need to survive. Here's another big reason you should care: FA research benefits the rest of the population, too. Bone marrow transplants have become much safer & more effective because of studies with FA patients. At least five FA genes are also breast cancer susceptibility genes, meaning therapies developed for FA patients would benefit breast cancer patients, too. And, Fanconi anemia research is in the process of unlocking the mysteries of DNA repair problems, which are at the root not only of FA, but of cancer.

Here's how FARF helps

Research has added years to the lives of people with FA. Decades ago, children rarely survived to adulthood. Now, there are adults with FA that live into their 30s, 40s and beyond.

Thanks to research, the rate of successful bone marrow transplants has gone from 20% in the 1990s to over 90% today.

FARF provides support to individuals with FA and their families by way of educational resources, support groups, and family meetings.

FANCONI ANEMIA RESEARCH FUND
Advancing Research. Supporting Families.

Here's what needs to happen next

- ☐ Fund clinical trials aimed at treating and preventing cancers in people with FA
- ☐ Develop treatment plans for all stages of FA cancers, recognizing limitations for those with FA (for example, no radiation)
- ☐ Establish a clinical registry to track history of disease and treatment outcomes

We need you.