



Fibrous Dysplasia

Overview, Symptoms, & Causes

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Research & Resources

Overview of Fibrous Dysplasia

Fibrous dysplasia happens when abnormal fibrous (scar-like) tissue replaces healthy bone. The fibrous tissue weakens the bone over time, which can lead to fractures (breaks) and misshapen bones.

Some people with fibrous dysplasia have no symptoms, or only a few symptoms, usually in one bone (monostotic). Other people may have multiple affected bones (polyostotic) and experience more symptoms. The disease may occur alone or as part of a condition known as McCune-Albright syndrome, which affects the bone as well as the skin and endocrine (hormone-producing) tissues.

Unfortunately, there is no cure for fibrous dysplasia; however, treatments may help to relieve pain, and supportive measures such as physical therapy may help strengthen muscle and improve range of motion.

What Happens in Fibrous Dysplasia?

Fibrous dysplasia happens when a gene mutates (changes) while the baby is developing in the womb. The changes in the gene cause bone-forming cells to fail to mature. Instead, they produce abnormal fibrous tissue in certain bones. Because the gene change happens while the baby is developing, only specific bones will have the disease. This means fibrous dysplasia does not spread from one bone to another.

The disease can affect any bone in the body; however, for some people, it occurs in the bones on one side of the body. The most common bones affected by fibrous dysplasia include:

- Skull and facial bones.
- Femur (upper leg) and tibia and fibula (lower leg).
- Humerus (upper arm bone).
- Pelvis.
- Ribs.

Who Gets Fibrous Dysplasia?

Fibrous dysplasia is not common, but anyone can develop the disease. It is usually diagnosed in children and young adults; however, it was probably present but not diagnosed at birth. Race, sex, environmental exposures, and geographic location do not influence who develops the disease.

Symptoms of Fibrous Dysplasia

People with a milder form of the disease may not have any symptoms and do not learn they have fibrous dysplasia until they have an x-ray for another reason. Other people may have a more severe form of the disease and develop symptoms in early childhood. The most common symptoms of fibrous dysplasia include:

- Bone pain, which may happen because of fractures or fibrous tissue changes in the bones.
- Misshapen bones or bowing of bones. This is most common in the femur (thigh bone) and is called a coxa vara (shepherd's crook).
- Fractures due to weak bone structure.

Other symptoms may develop depending on which bones are affected. Changes in the:

 Leg bones may cause the bones to shorten, bow, or change in length, leading to a limp or changes in mobility.

- Facial bones and sinuses can cause long-term sinus congestion.
- Spine can lead to <u>scoliosis</u>.
- Skull and facial bones around the eyes and ears may rarely lead to vision and hearing loss.

In very rare cases, some people may develop a malignant form of bone cancer.

Cause of Fibrous Dysplasia

Fibrous dysplasia happens when a gene mutates (changes) after conception, early in the pregnancy. There is nothing that the mother can do to prevent this from happening. Unfortunately, researchers do not know what causes the gene to mutate; however, they have identified the gene and continue to study why fibrous dysplasia develops. Because the disease develops from a mutated gene, children do not inherit the gene from their parents and will not pass the disease to their children.