Points To Remember About Fibrous Dysplasia

- Fibrous dysplasia happens when healthy bone is replaced with other types of tissue.
- Bones may become oddly shaped or even break. You may also feel pain.
- Fibrous dysplasia is caused by a problem with a gene in the cells that form bone and other tissues.
- Medications, surgery, and a cast may be used to treat symptoms of the disease.
- Talk to your doctor about an exercise and diet program that will keep your bones healthy.

What is fibrous dysplasia?

Fibrous dysplasia happens when healthy bone is replaced with other types of tissue. Bones may become weak, oddly shaped, or even break. You may also feel pain.

The disease can affect any bone in the body. The most common bones affected are in the skull and face, leg bones, upper arm, pelvis, and ribs. Affected bones are often found on one side of the body, although the disease does not spread from one bone to another.

Who gets fibrous dysplasia?

Fibrous dysplasia is not common, although anyone can get it. It is usually starts in children and young adults. Once a person has the condition, they will have it for the rest of their life.

What are the symptoms of fibrous dysplasia?

The most common symptoms of fibrous dysplasia include:

- Pain.
- Bones that are oddly shaped.
- Broken bones, which are more common between the ages of six and 10.

Other symptoms depend on the bones that are affected and can include:

- Legs of different lengths, leading to a limp.
• Sinus problems.
• In very rare cases, vision loss or cancer.

What causes fibrous dysplasia?
Fibrous dysplasia is caused by a problem with a gene that forms bone and other affected tissues. This gene is not inherited from your parents, and you will not pass the disease to your children.

Is there a test for fibrous dysplasia?
To diagnose you with fibrous dysplasia, your doctor may use one or more of the following tests:
• X-rays of your bones.
• Magnetic resonance imaging (MRI) or computed tomography (CT).
• Small bone sample.

It’s not clear whether testing for the problem gene is useful.

How is fibrous dysplasia treated?
There is no cure for fibrous dysplasia. Doctors will treat the symptoms with treatments such as:
• Cast for broken bones.
• Surgery to:
  ○ Repair broken bones.
  ○ Prevent fracture.
  ○ Correct the shape of a bone.
  ○ Relieve bone pain.
• Medications, such as bisphosphonates, that can reduce pain associated with the disease.

Living with fibrous dysplasia
Besides seeing your doctor, there are a few things you can do to keep your bones healthy:
• Exercise: talk to your doctor before beginning an exercise program.
• Diet: you should eat foods that are high in calcium, phosphorus, and vitamin D.

For more info
U.S. Food and Drug Administration
Toll free: 888-INFO-FDA (888-463-6332)
Website: https://www.fda.gov

Drugs@FDA at https://www.accessdata.fda.gov/scripts/cder/daf. Drugs@FDA is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics
Website: https://www.cdc.gov/nchs

National Institute of Dental and Craniofacial Research
Website: https://www.nidcr.nih.gov

Genetic and Rare Diseases Information Center
Website: https://rarediseases.info.nih.gov/diseases/6444/fibrous-dysplasia

American Academy of Orthopaedic Surgeons
Website: https://www.aaos.org

Fibrous Dysplasia Foundation
Website: https://www.fibrousdysplasia.org

The MAGIC Foundation
Website: https://www.magicfoundation.org

Rare Bone Disease Alliance
Website: http://rbdalliance.org/

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- Asian Language Health Information
- Spanish Language Health Information