

a guide to understanding

fibrous dysplasia

a publication of **children's craniofacial association**

a guide to understanding frontonasal dysplasia

This guide was created to help answer common questions about fibrous dysplasia. We understand that receiving a diagnosis can feel overwhelming. Our goal is to explain this condition in a simple, clear way so you can better understand your child's care and feel more confident moving forward. Every child is unique. Treatment decisions should always be made together with your child's medical team.

how can children's craniofacial association (cca) benefit my family?

CCA supports families affected by craniofacial conditions. When one family member has a craniofacial condition, it can affect the whole family. CCA offers programs, resources, and connections to help support both children and caregivers. To learn more, visit **www.ccakids.com** or call us at **800.535.3643**.

The information provided here was written by a member of the Medical Advisory Board of the Children's Craniofacial Association in 2005 and revised in 2019 and in 2026 by Tayla Kalman, DDS Candidate.

This booklet is intended for informational purposes only. It is not a recommendation for treatment. Decisions for treatment should be based on mutual agreement with your craniofacial team. Possible complications should be discussed with the physician prior to and throughout treatment.

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what is fibrous dysplasia?

fibrous dysplasia is a condition that affects how bones grow and develop. In this condition, standard bone is replaced with softer, weaker tissue. This can cause the bone to become larger, frail, or uneven in shape.

Fibrous dysplasia is NOT cancer. It is also not inherited, which means:

- Your child did not get it from you
- Your child will not pass it on to their children

how do i recognize this condition in my child?

fibrous dysplasia is often first noticed when there is swelling or a change in the shape of a bone. Doctors usually diagnose it using imaging tests such as a CT scan. In some cases, a small sample of the bone (called a biopsy) may be needed to confirm the diagnosis.

how does the disease progress over time?

fibrous dysplasia usually develops during childhood. As a child grows, the affected bone may also grow and change in shape. In many cases, the condition slows down or stops progressing after puberty, when bone growth is complete. Depending on where it occurs, fibrous dysplasia can affect the shape of the face or skull.

how many types of fibrous dysplasia are there?

t here are three types of fibrous dysplasia:

MONOSTOTIC

Affects only one bone. This type accounts for about 70% of cases and often involves long bones such as the femur (thigh), ribs, or skull. This is the most common type

POLYOSTOTIC

Affects more than one bone. This type occurs in about 30% of cases and may involve the head and neck.

MCCUNE-ALBRIGHT SYNDROME

A rare form that occurs in about 3% of cases. It involves fibrous dysplasia in multiple bones and may also include skin changes (light brown patches) and hormone-related changes, such as early puberty.

how often does fibrous dysplasia affect the face and head?

fibrous dysplasia can affect the bones of the face and skull in 27% of **monostotic** and 50% of **polyostotic** patients.

In some cases, the affected bone may slowly grow and press on nearby areas such as the eyes, nose, or mouth. This can lead to changes in facial shape and, in more severe cases, vision or breathing issues. Your child's care team will monitor these areas closely to help prevent complications

what are the effects of fibrous dysplasia of the skull base?

When fibrous dysplasia affects the bones at the base of the skull, the bone may become thicker and expand over time. Because many important nerves pass through this area, the growing bone can sometimes put pressure on nerves that control hearing, vision, and facial movement. In some cases, this may lead to symptoms such as hearing changes, vision concerns, or facial weakness. Most children do not experience severe problems, but doctors will monitor closely and may recommend treatment if there are signs that these important functions are being affected.

can fibrous dysplasia turn into cancer?

fibrous dysplasia is almost always a benign (non-cancerous) condition. It usually causes problems by pressing on nearby structures as the bone grows. Very rarely, it can change into a cancerous growth, but this is extremely uncommon.

what is the treatment for fibrous dysplasia?

treatment depends on your child's symptoms and how the condition is affecting them. In many cases, doctors may recommend careful monitoring over time. If treatment is needed, options may include shaping or removing part of the affected bone, or surgery to improve appearance or relieve pressure on nearby nerves. When possible, doctors often wait until a child is older and bone growth has slowed. However, if important functions such as vision or hearing are affected, treatment may be recommended earlier.

CCA encourages families to research teams on the list of approved teams maintained by American Cleft-Palate Craniofacial Association (ACPA), found at: <https://acpacares.org/find-a-care-team> .

if surgery is recommended, how many will be necessary?

Some children may need only one surgery. Others may need more than one procedure over time, especially as they grow. In general, outcomes are very positive, and most children do well with treatment.

mental health

Children and adults may face mental health struggles when living with a facial difference. CCA advocates that parents try a multifaceted approach to creating mental resiliency, including counseling/therapy, social support groups/networking, and encouraging self-care for the entire family.



children's craniofacial association

to support and inspire individuals and families affected by facial difference

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