

# Jameson's Journey

## Information & Resource Guide



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## What is craniosynostosis?

Craniosynostosis is the premature fusion of the cranial sutures. Normally, a baby is born with six bones in their skull separated by fibrous joints called sutures. These fibrous joints intersect at the soft spots in the front and back of the baby's head. The separation of these bones provides space for their brain to grow and develop, and typically fuse together around 2 years. Craniosynostosis can occur on one or more of the various skull sutures. Physically, craniosynostosis will present with an abnormally shaped head, and ridges may form along the fused sutures lines. Internally, if left untreated, craniosynostosis may cause increased intracranial pressure, blindness, seizures, brain damage, and even death. The four common types of craniosynostosis are sagittal, coronal, metopic, and lambdoid synostosis.

### Q: How common is craniosynostosis?

A: Craniosynostosis occurs in about 1 in every 2,000 births.

### Q: What causes craniosynostosis?

A: Craniosynostosis sporadically occurs, there is no known cause.

## What is syndromic craniosynostosis?

Syndromic craniosynostosis is caused by a genetic mutation that presents with additional physical anomalies. These anomalies typically affect the growth and development of the hands, feet, and facial features. Children with syndromic craniosynostosis are more complex medically and require a multi-disciplinary approach to care. There are many different types of syndromic craniosynostosis. The genes most typically affected are FGFR-1, FGFR-2, FGFR-3, and TWIST-1.

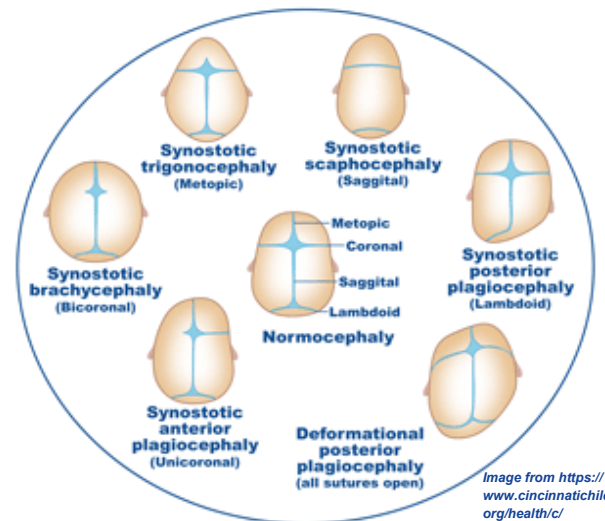


Image from <https://www.cincinnatichildrens.org/health/c/craniosynostosis>

Our mission at Jameson's Journey is to serve as a source of strength and support for families affected by craniofacial differences.

Through our efforts we hope to raise awareness, education, tolerance, and acceptance of children born with craniofacial differences.

If you would like to be a part of our journey please feel free to contact us.

For more information visit [www.jamesonsjourney.com](http://www.jamesonsjourney.com)



#craniostrong

## Treatment for craniosynostosis

Treatment for craniosynostosis involves surgically separating the fused bones. There are two types of surgical procedures that can be performed, endoscopic surgery or cranial vault reconstruction (CVR). Endoscopic surgery is less invasive and typically done on babies 6 months or younger, depending on the facility, followed by 3-12 months of helmet therapy. CVR is a more invasive approach where the surgeon creates a zig-zag opening from ear to ear and allows the surgeon to remove and reshape the bone, without the need for helmet therapy. Although there are two main surgical approaches, each child with craniosynostosis is unique and their treatment plan is highly individualized to their personal needs.

***If your baby's head isn't growing normally, or you think the shape is abnormal, make an appointment with your pediatrician. Your pediatrician will evaluate your baby for normal development.***

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