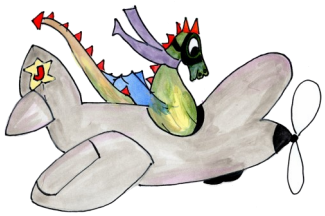
Jameson's Journey

Information & Resource Guide



In this issue:

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 suture lines. 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.

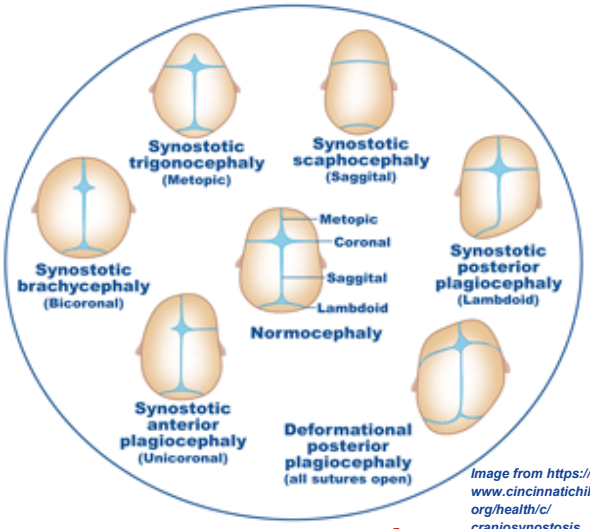


Image from https://www.cincinnatichildrens.org/health/c/craniosynostosis

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.

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 performed on babies 6 months or younger, 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, allowing for the removal and reshaping of the bone, without the need for helmet therapy. Both approaches have their advantages. 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.

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

#craniostrong