Craniosynostosis

What Is Craniosynostosis?

Craniosynostosis occurs when one or more of the joints in a baby’s skull closes too early. The condition is sometimes noticeable at birth, but it also can be diagnosed as infants grow and develop. Children who have craniosynostosis might have an abnormal skull shape, an abnormal forehead shape, or asymmetrical eyes and/or ears.

Craniosynostosis is one of the most common physical deformities in infants, occurring in about one of every 2,000 births.

What Causes Craniosynostosis?

In some families, craniosynostosis appears to be inherited. However, research can’t yet confirm a genetic link. Chances that parents of a child who has craniosynostosis will have another child with the condition are slim—about 4 percent or less. There is also a small chance that a child born with craniosynostosis will have children with the condition.

When craniosynostosis is coupled with conditions such as Crouzon or Apert syndrome, however, the situation changes. There is a 50 percent chance that either of these conditions, along with the related craniosynostosis, will pass from parent to child.

Craniosynostosis is often just one of many craniofacial and developmental concerns related to another condition. Consultation with medical geneticists and genetic counselors can help determine if your child has a related condition.

Craniosynostosis Symptoms and Effects

The most obvious symptoms of craniosynostosis include abnormal skull shape, abnormal forehead shape, or asymmetrical eyes or ears.

Because many babies born vaginally have abnormally shaped heads early in their lives, the condition often gets
missed. If a baby’s head shape remains abnormally shaped, craniosynostosis is a possibility.

If not corrected, craniosynostosis can create pressure inside the skull (intracranial pressure). That pressure can lead to development problems, or to permanent brain damage. If not treated, most forms of craniosynostosis can have very serious results, including death.

**Types of Craniosynostosis**

**Scaphocephaly**

Scaphocephaly is the most common type of craniosynostosis. It’s caused by the fusing together of a joint called the sagittal suture, which runs from front to back down the middle of the skull. Characteristics of this type include a long, narrow head shape from front to back (narrow from ear to ear) and an overall boat-shaped appearance.

**Trigonocephaly**

Trigonocephaly is caused by fusing together of a joint called the metopic suture, which runs from the top of the head to the middle of the forehead, toward the nose. Characteristics of this type include a triangular-shaped forehead and eyes that are abnormally close together.

**Plagiocephaly**

Anterior plagiocephaly is the premature fusing together of one of the coronal joints (sutures), which extend from ear to ear over the top of the head. The forehead and brow appear pushed backwards, and the eyes are shaped differently.

Because this type of craniosynostosis causes flatness on the affected side of the head, it is often confused with flat head syndrome (deformational plagiocephaly)—a condition that doesn’t require surgical correction.

**Brachycephaly**

Brachycephaly results when both sides of the coronal joints (sutures) fuse together prematurely. Characteristics include a wide-shaped head with a short skull. The fusion prevents the entire forehead from growing forward, creating a tall and flattened appearance.

**Craniosynostosis Treatment and Diagnosis**

In some cases, craniosynostosis can be diagnosed before your baby is born. Our craniofacial and plastic surgeons offer prenatal consultations. During a prenatal consultation, we teach you about current treatment options, provide counseling, and help plan a course of craniosynostosis treatment.

In other cases, craniosynostosis is noticeable at birth. It can also be diagnosed as your infant grows and develops. Except in very mild cases, babies born with craniosynostosis need surgery to repair craniosynostosis at 4 to 8
months. The craniosynostosis surgery is called cranial vault remodeling. Usually, one surgery is enough to separate the joints (sutures), reshape the bones and place them in the proper position. However, about 10 percent of children need a second surgery.

If your child has surgery, a craniofacial surgeon and neurosurgeon work together to correct abnormal head shape and give the brain enough room in the skull to grow. In rare cases, your child might need a cranial remodeling orthosis, such as a Gillette CranioCap® orthosis, to complete the correction.

Your child might also need therapy services to:

- Improve neck strength and movement.
- Help with feeding, swallowing or speech.
- Uncover any other developmental delays.

**Integrated Care**

If your child has craniosynostosis, our multidisciplinary team of experts will create a treatment plan that fits your unique needs. We provide services throughout the diagnosis and treatment process that might include:

- Audiology.
- Chaplaincy.
- Child life.
- Dentistry and orthodontics.
- Ear, nose and throat (ENT or otolaryngology).
- Medical genetics and genetic counseling.
- Occupational therapy.
- Physical therapy.
- Psychology.
- Radiology and imaging.
- Social work.
- Speech and language therapy.

Gillette is one of the region’s leading facilities for treating craniosynostosis. Your family can feel confident in our knowledge and expertise. Our surgeons perform more procedures to correct craniosynostosis than any other surgeons in the region. You’ll work closely with the nation’s top pediatric specialists in craniofacial and plastic surgery and neurosurgery in a family-centered environment.

Your child’s well-being and self-esteem guide every decision we make at Gillette. Our team of specialists will make
sure you have the information and support you need, every step of the way. Through advanced surgical techniques and treatment options—such as craniosynostosis repair surgery, we help your child feel their best.

Make An Appointment 651-290-8707 Refer a Patient 651-325-2200

This information is for educational purposes only. It is not intended to replace the advice of your health care providers. If you have any questions, talk with your doctor or others on your health care team.

If you are a Gillette patient with urgent questions or concerns, please contact Telehealth Nursing at 651-229-3890.