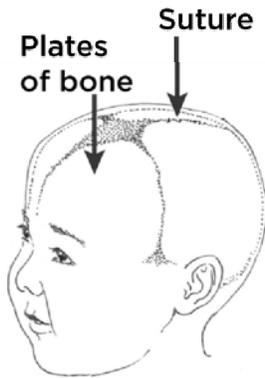


Craniosynostosis

What Is Craniosynostosis?



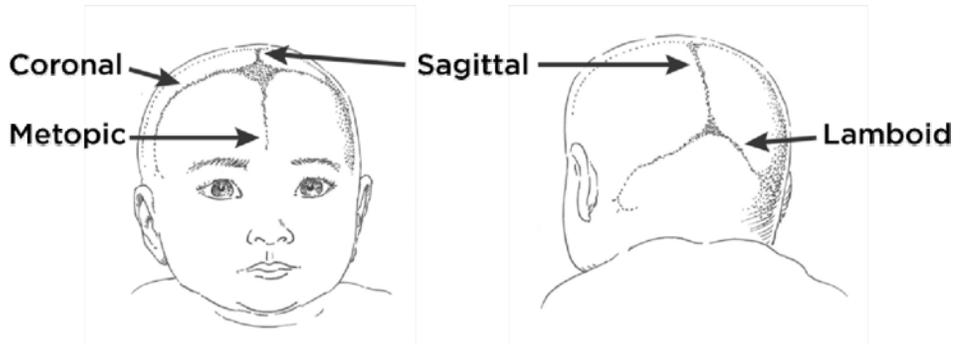
Your child's skull

The skull is made up of plates of bone. In children, there are soft fibrous seams, called sutures, between the plates of bone. When these sutures are open, the skull can grow normally as the brain grows.

What is craniosynostosis?

Craniosynostosis (kray-nee-oh-sin-os-TOE-sis) is the early closing of 1 or more of the sutures that separate the plates of the skull. When the sutures close too early, the skull cannot grow normally.

The shape of the skull of a baby with craniosynostosis varies depending on which suture has closed. For example, when the sagittal suture closes too early, the skull cannot grow from side to side and grows too much from front to back. This causes a skull with a shape that is long and narrow. The 4 sutures that are most often affected are shown in the picture below.



The 4 sutures most commonly affected in craniosynostosis

What causes craniosynostosis?

We do not know why some children have craniosynostosis. Most children with craniosynostosis have only 1 affected suture and do not have anything other conditions or health problems.

Craniosynostosis sometimes happens as part of genetic syndromes like Crouzon, Apert, Pfeiffer or Saethre-Chotzen. Children with genetic syndromes may have more than 1 suture that is affected. Sometimes these syndromes are passed down in the family. You may know other relatives who have it. The doctors will tell you if genetic testing is recommended for your child.

How is craniosynostosis treated?

The most common treatment is surgery. There are 2 kinds of surgery to correct craniosynostosis:

- **Open remodeling:** The surgeon makes cuts in the skull bones to reshape the head to a more normal shape. Resorbable plates and screws are used to hold the bones in place while they heal. Open surgery requires a larger cut (incision) in the scalp, more cuts in the bones, and sometimes a blood transfusion. However, the head shape is corrected at the end of surgery and your child does not require a helmet after surgery.
- **Endoscopic strip craniectomy:** Surgery through 2 smaller incisions using a tool like a small telescope (endoscope) to see the skull. This type requires fewer cuts in the bones. It can often be performed without the need for a blood transfusion and requires less time in the hospital after surgery, but the head shape is not completely corrected at the end of surgery. Your child will need a helmet to mold the head to a more normal shape after surgery. Your child will wear the helmet all the time for 3 to 12 months, except during bathing.

The type of surgery your child will have depends on their age and the sutures that are affected. Sometimes, doctors suggest waiting and watching a child with mild craniosynostosis to see how the skull grows.

Why is surgery done?

There are 2 reasons for the surgery:

1. To improve the shape of the skull. Without reshaping the skull, craniosynostosis will cause a more severe deformity as your child grows.
2. To prevent an increase in pressure inside of the skull. Pressure can build up when the skull cannot grow normally. For children with 2 or more closed sutures, this can be a serious problem and can cause brain damage over a long period of time.

What is the best age for the surgery?

The best time for surgery depends on which suture is affected. Your child's health and growth and development are also considered when deciding on the right time for surgery. Parents often wish that the surgery could be done as soon as the diagnosis is made. But surgery is safer and gives a better result when it is done at the proper age. Most children only need 1 surgery to repair the craniosynostosis.

What happens before surgery?

You will come to the clinic so that you can talk with the surgeons, anesthesiologists and nurses to ask questions. Your child may need to have some blood tests if your surgeon thinks your child might need a blood transfusion during surgery.

If your child is undergoing endoscopic surgery, they will need to be scanned for a helmet before surgery. Your child's health care team will tell you about how to prepare for the day of the surgery, like when your child can eat or drink before the surgery and what to bring with you to the hospital.

What happens on the day of surgery?

Usually, your child will be admitted early on the same day that the surgery is scheduled. A nurse will show you where you can wait. We will update you during the surgery to let you know how it is going. After surgery, the surgeons will talk to you about the surgery while your child has a CT scan and is transferred to the Pediatric Intensive Care Unit (PICU). Your child will be cared for on this unit for the first 1 to 2 nights.

What happens after surgery?

It can be overwhelming to see your child for the first time after surgery. Your child will be sleepy and may have facial swelling. Swelling and bruising is normal and often gets worse for a few days before it gets better. Mild swelling can last for a month or more, but it does go away over time. Many children are not able to open their eyes for a few days because of the swelling. The nurses will help you hold and comfort your child. Your voice, your child's toys, blankets and music may also help comfort your child.

Your child will have IV tubes for fluids and medicines. Your child will also have an arterial line, or a thin plastic tube put into a blood vessel in their leg or arm to check blood pressure and get blood samples. Your child may have a small drainage tube to help to drain extra blood and fluids from under the scalp for 2 or 3 days. Your child may receive oxygen and will be connected to machines that monitor the heart and breathing. This is normal after surgery.

Your child will get pain medicine to keep your child comfortable. Once your child is drinking fluids, the medicine will be given by mouth. When your child is ready, they will be transferred to a room on the surgical unit. When your child is able to take liquids by mouth, the amount of IV fluids will be decreased. The nurses will teach you how to take care of your child at home, like how to clean the incision and give medicine.

What happens after leaving the hospital?

Once home, your child will gradually return to normal eating, sleeping and playing habits. For the first 4 weeks after surgery, you will need to watch your child closely when they play to be sure that there is not a bad fall or serious hit to the head. The repair is very secure, and the minor bumps that children often get will not cause problems.

When do we come back for a follow-up appointment?

You will come back to the clinic 2 to 6 weeks after your child goes home for a follow-up. The nurse or doctor will check your child's incision, swelling, head shape and take out stitches (if needed). You may need to return to the clinic again 2 to 6 months after surgery.

To Learn More

- Craniofacial
206-987-2208
- Your child's healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

After this, we will want to see your child every year to watch the head shape as your child grows. Two years after the surgery, we will get another CT scan to make sure all of the bones in the skull have healed completely. If you or your child's doctor has questions or concerns, we will see your child sooner. If your child underwent endoscopic surgery, you will need to be seen more frequently to have the helmet adjusted.

Who do I call when I have a question?

For questions about your child before surgery, call the Craniofacial nurses at 206-987-1117 during working hours. For urgent concerns during evenings, weekends and holidays, call the hospital operator at 206-987-2000 and ask to speak with the Craniofacial provider on call.