Unicoronal Craniosynostosis
A guide for parents and caregivers
What is Craniosynostosis?

At birth, a child’s skull is made of separate bones with growth plates called ‘sutures’ between them. These sutures allow the skull to grow. Over time, the sutures close and the bones fuse. Craniosynostosis occurs when bones in a child’s skull fuse too early.

WHAT IS UNICORONAL CRANIOSYNOSTOSIS?

Unicoronal craniosynostosis refers to the early closure of the suture that runs at the top of the head, from ear to top of the forehead. Unicoronal synostosis causes forehead and brow flattening on the affected side. Compared to the unaffected side, the forehead tends to project more. The eye on the affected side may also have a different shape.

HOW IS CRANIOSYNOSTOSIS TREATED?

Craniosynostosis can be treated with **Open Repair** or **Endoscopic Repair**. Both surgeries create a normal head shape and involve a plastic surgeon and a neurosurgeon. The Open Repair, or cranial vault remodeling, involves removing and reshaping skull bones, then securing them with plates and screws that dissolve. The Endoscopic Repair uses a small camera to help the surgeon remove the suture. Patients must then wear a helmet until one year of age to guide normal skull growth. Both repairs have equivalent head shape outcomes, similar complication rates and require similar post-surgery precautions.

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Craniosynostosis Timeline For Care

**INITIAL EVALUATION**

- **Open Repair**
  - 1 to 2 Weeks Before Surgery
  - Helmet fitting
- **Endoscopic Repair**
  - 1-3 Days After Surgery
  - Receive Helmet
- **4 Months or Older Surgery**
  - 2-5 Months Old Surgery
  - 4 Months or Older Surgery
  - 3 Weeks After Surgery
  - Follow up with Plastic Surgeon
- **Every 2-4 Weeks After Surgery**
  - Every 1-3 Months After Surgery
  - Follow up with Orthotist
  - Follow up with Plastic Surgeon

**GRADUATION FROM TEAM!**

- **1 Year After Surgery**
  - Craniofacial (CF) Team visit: Plastic Surgeon, Speech and Psychology to check overall development and head growth and shape
- **3, 5 and 8 Years Old**
  - CF Team visit: Plastic Surgeon, Speech and Psychology to check head shape and growth
- **11 and 13-17 Years Old**
  - CF Team visit: Check to see if another surgery is needed.
Open Repair

The open surgery involves reconstructing the skull bones into a more typical shape.

Endoscopic Repair

The Endoscopic repair uses a small camera to remove fused sutures through two 1-inch incisions.

Overview

<table>
<thead>
<tr>
<th>HOSPITAL STAY</th>
<th>A few days with a short stay in the ICU</th>
</tr>
</thead>
<tbody>
<tr>
<td>SURGERY TIME</td>
<td>3 hours</td>
</tr>
</tbody>
</table>

Factors

<table>
<thead>
<tr>
<th>BLOOD LOSS</th>
<th>Most children will need a blood transfusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>DISCOMFORT</td>
<td>Typically more discomfort</td>
</tr>
<tr>
<td>SCARRING</td>
<td>Longer, zig-zagged from ear to ear across the top of head</td>
</tr>
</tbody>
</table>

Post Operation

<table>
<thead>
<tr>
<th>FOLLOW UP</th>
<th>One visit with the surgeon 3 weeks after surgery, then again 1 year after surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>HELMET</td>
<td>No helmet needed</td>
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</tbody>
</table>

Please circle the issues that are most important for you and your child.

<table>
<thead>
<tr>
<th>HOSPITAL STAY</th>
<th>SURGERY DURATION</th>
<th>BLOOD LOSS</th>
<th>DISCOMFORT</th>
<th>SCARRING</th>
<th>FOLLOW-UP</th>
<th>HELMETETING</th>
<th>FACIAL SYMMETRY</th>
<th>ADDITIONAL EYE SURGERY</th>
</tr>
</thead>
<tbody>
<tr>
<td>OPEN</td>
<td>longer</td>
<td>longer</td>
<td>more</td>
<td>more</td>
<td>more</td>
<td>less</td>
<td>no</td>
<td>less improvement</td>
</tr>
<tr>
<td>ENDO</td>
<td>shorter</td>
<td>shorter</td>
<td>less</td>
<td>less</td>
<td>less</td>
<td>more</td>
<td>yes</td>
<td>more improvement</td>
</tr>
</tbody>
</table>

After discussing this together, we want:

☐ endoscopic repair  ☐ open repair  ☐ more time to decide

Next step:

Schedule surgery or follow-up with your physician.
ENDOSCOPIC REPAIR & HELMETING FAQ

How many hours each day does my child need to wear the helmet? Can he/she take it off?
The helmet should be worn 23 hours a day. The helmet should be kept on except to clean or bathe the child.

How often will my child have to be seen to have the helmet adjusted?
In the beginning it may be as often as every 1-2 weeks. By the end of helmet treatment, it can be spaced out to about once a month.

How long will my child have to wear a helmet after surgery?
Your child will wear the helmet until they turn 1 year old.

How long after surgery will it be before my child gets his/her helmet?
If you live close to our hospital, your child will be fitted with his/her helmet the morning after surgery. If you do not live in the area, it may take one or two days after surgery to get your child’s helmet. This allows for travel time to get home and to meet with your local helmet specialist.

I don’t live near the hospital. Will I need to travel out of my city for helmet treatment?
No. We work with a national orthotics company to find the closest helmet specialist to your home.

How do infants adjust to the helmet?
Infants typically adjust to the helmet in a couple of days. It does not hurt them or cause headaches. It will also not delay their growth or development.

How many helmets will my child need?
Most children need between 2 and 4 helmets.

OPEN REPAIR FAQ

What changes in appearance can I expect after the open repair?
Your child will have bandages after surgery to protect the incision. There will be stitches over the top of your child’s head from ear to ear. Your child’s face may be swollen and the eyelids may also be swollen shut. Swelling is normal and expected after surgery. The swelling will go down with time.

Will there be any bandages to change after surgery?
Bandages will be removed 2 to 3 days after surgery while in the hospital. There is no need to apply bandages at home. The incision will have stitches that dissolve. You will need to apply Vaseline to the incision.

Can my child resume normal activities and sleep?
Your child will need close supervision and should avoid rough activities until the bones heal. At first, your child will need to sleep with the head of the bed elevated to help decrease swelling.

How long will it take for the bones to heal after surgery?
It will take about 12 weeks for the bones to fully heal.
St. Louis Children’s Hospital
One Children’s Place
St. Louis, Missouri 63110

314.454.KIDS (5437)
800.678.KIDS (5437)

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