



# Craniosynostosis

Craniosynostosis (krā-nē-ō-si-nā-'stō-səs) is a birth anomaly of the skull. When the skull is forming as a child develops in the womb, it is made up of many pieces that all join together like a puzzle. The areas where they join are called sutures, and the materials where they join is flexible. This allows the skull to grow rapidly around the fast-growing brain. If a baby has craniosynostosis, it means that one or more of these sutures closes too soon and becomes solid bone. This changes the shape of the skull and its ability to grow evenly. Normally, the sutures do not all close until late in the teen years. In craniosynostosis, there can be abnormal features of the face, ears, and hairline, and developmental disabilities. Craniosynostosis sometimes occurs together with other birth anomalies of bones, especially those of the arms and legs. For more information about craniosynostosis, see [tinyurl.com/ya4eowbo](https://tinyurl.com/ya4eowbo).

## Resources for families

### Northwest support resources

- FACT Oregon  
[factoregon.org](https://factoregon.org)
- Oregon Family to Family Health Information Center  
[tinyurl.com/ycwhffwc](https://tinyurl.com/ycwhffwc)
- Washington Parent to Parent  
[tinyurl.com/yaucv2mk](https://tinyurl.com/yaucv2mk)

### National/international/online resources

- Cranio carebears  
[craniocarebears.org](https://craniocarebears.org)
- Cranio kids support  
[tinyurl.com/yb9nwfqj](https://tinyurl.com/yb9nwfqj)
- CAPPs kids  
[www.cappskids.org](https://www.cappskids.org)
- Children's Craniofacial Association (CCA)  
[ccakids.org](https://ccakids.org)

### Information for you and your care team.

- CCA: Craniosynostosis booklet  
[/tinyurl.com/yax9a5t8](https://tinyurl.com/yax9a5t8)
- Center for Disease Control - Craniosynostosis fact sheet  
[tinyurl.com/y7nrlobm](https://tinyurl.com/y7nrlobm)

### Family stories

- Cranio Care Bears - success stories  
[tinyurl.com/yayemmt5](https://tinyurl.com/yayemmt5)
- CAPPs Kids - family stories  
[tinyurl.com/y826mrqc](https://tinyurl.com/y826mrqc)
- Akron Children's Hospital - Evie's story  
[tinyurl.com/ybm455cc](https://tinyurl.com/ybm455cc)

### Clinical trial information

- Children and Clinical Studies  
[tinyurl.com/y75s4twm](https://tinyurl.com/y75s4twm)
- Find an approved clinical trial  
[tinyurl.com/zp3jesq](https://tinyurl.com/zp3jesq)

### Insurance information and help

- Getting insurance for children (OR)  
[tinyurl.com/ydfaeoy](https://tinyurl.com/ydfaeoy)
- Getting insurance for children (WA)  
[tinyurl.com/yca9lkey](https://tinyurl.com/yca9lkey)
- Understand your health insurance  
[tinyurl.com/y46h8nvx](https://tinyurl.com/y46h8nvx)
- Learn about coverage  
[tinyurl.com/y4639rz6](https://tinyurl.com/y4639rz6)
- Road map to health  
[tinyurl.com/yysc6kv7](https://tinyurl.com/yysc6kv7)
- General/Oregon Health Plan Questions: 855-323-6744

### Other resources

- Camp Korey  
[www.campkorey.org](https://www.campkorey.org)
- CCA - family retreats  
[tinyurl.com/y9n2exad](https://tinyurl.com/y9n2exad)
- CCA - resource page  
[tinyurl.com/ya38ptk8](https://tinyurl.com/ya38ptk8)

### Books for parents and children

- Bibliography available by calling the Oregon Family to Family Health Information Center at 855-323-6744
- Swindells' online library search  
[tinyurl.com/y9t2jwcx](https://tinyurl.com/y9t2jwcx)