

craniosynostosis

Discover 12 trusted craniosynostosis resources, including leading medical centers, advocacy groups, and educational platforms. These sites offer expert information on diagnosis, treatment, recovery, and long-term care—along with community support, referral options, and practical guidance for families.

1. Children’s Hospital of Philadelphia – Craniosynostosis

Offers a comprehensive overview of the condition, diagnosis, and treatment options backed by a multi-disciplinary craniofacial program

[Johns Hopkins Medicine+15Children's Hospital of Philadelphia+15FACES+15.](#)

chop.edu/conditions-diseases/craniosynostosis

2. Boston Children’s Hospital – Craniosynostosis

Provides detailed guidance on symptoms, causes, diagnosis, and surgical interventions via their Cleft and Craniofacial Center [Children's Hospital of Philadelphia+2Children's Hospital of Philadelphia+2Children's Hospital of Philadelphia+2Boston Children's Hospital+1cappskids.org+1.](#)

childrenshospital.org/conditions/craniosynostosis

3. Cincinnati Children’s Hospital – Cranial Reconstruction Center

Extensive health library on craniosynostosis, including types, diagnosis workflow, and treatments such as endoscopic and open surgery [mhfcu.uchicago.edu+15Cincinnati Children's Hospital+15Boston Children's Hospital+15.](#)

cincinnatichildrens.org/health/c/craniosynostosis

4. Stanford Children’s Health – Craniosynostosis Program

Leading-edge diagnostics and minimally invasive surgical treatment led by pediatric neurosurgeons and craniofacial surgeons [Cincinnati Children's HospitalStanford Children's Health+1Johns Hopkins Medicine+1.](#)

stanfordchildrens.org/services/craniosynostosis

5. Johns Hopkins Children’s Center – Craniofacial & Craniosynostosis Center

Multidisciplinary team offering advanced imaging, cranial vault remodeling, strip craniectomy, and family support services [Verywell Health+15Johns Hopkins Medicine+15Boston Children's Hospital+15.](#)

hopkinsmedicine.org/craniofacial-craniosynostosis

6. Weill Cornell Medicine – Craniosynostosis Program

Surgical expertise in cranial vault reconstruction and endoscopic techniques, led by specialized pediatric neurosurgeons

neurosurgery.weillcornell.org[Johns Hopkins Medicine+1](#)[Verywell Health+1](#).

neurosurgery.weillcornell.org/craniosynostosis



Family & Support Organizations

7. Children’s Craniofacial Association (CCA)

A long-standing nonprofit offering peer support, information for families, events, and advocacy for craniofacial differences

neurosurgery.weillcornell.org[Children's Hospital of Philadelphia+2](#)[Children's Hospital of Philadelphia+2](#)[FACES+2](#).

[\[CCA via CHOP resource list\]](#)

8. FACES: The National Craniofacial Association

Support group with newsletters, care packages, and online community services for individuals affected by craniosynostosis and craniofacial disorders

[Children's Hospital of Philadelphia+1](#)[Children's Hospital of Philadelphia+1](#)[FACES+1](#)[Children's Hospital of Philadelphia+1](#).

faces-cranio.org/craniosynostosis

9. CAPPs: Craniosynostosis & Positional Plagiocephaly Support, Inc.

Parent-to-parent support, mailing lists, hospital support packages, and educational materials

[Boston Children's Hospital+15](#)[FACES+15](#)[Children's Hospital of Philadelphia+15](#).

cappskids.org

10. Cranio Care Bears

Sends care packages to families whose child is facing craniosynostosis surgery, and shares success stories and emotional support resources

[ERN CRANIO website+10](#)[FACES+10](#)[Child Neurology Foundation+10](#).

craniocarebears.org

11. Child Neurology Foundation – Craniosynostosis

Offers family-oriented information, shared success stories (“Cranio Care Bears” linkage) and neurological context for the condition

[Child Neurology Foundation](#).

childneurologyfoundation.org/disorder/craniosynostosis



International & Guideline Resources

12. ERN-CRANIO (European Reference Network for Rare Craniofacial Anomalies)

Provides clinical guidelines, explanatory videos, patient-family versions of care protocols, and research into syndromic craniosynostosis

Children's Hospital of Philadelphia+2ERN CRANIO website+2Nationwide
Children's Hospital+2.