

Chiari Organizations

Here are **12 leading organizations** that offer education, support, advocacy, and research resources for children and families affected by **Chiari malformation** (and related syringomyelia):

1. American Syringomyelia & Chiari Alliance Project (ASAP)

The largest U.S. nonprofit dedicated to Chiari and syringomyelia—offering patient guides, annual conferences, local support groups, scholarships, and active research funding.

 asap.org [Wikipedia+15asap.org+15Children's Hospital of Philadelphia+15](#)

2. Bobby Jones Chiari & Syringomyelia Foundation (Bobby Jones CSF)

Funds research, educational outreach, and advocacy efforts in Chiari and syringomyelia. Offers patient handbooks, webinars, community support, and a physician finder tool.

 bobbyjonescsf.org [National Organization for Rare Disordersbobbyjonescsf.org](#)

3. Conquer Chiari (C&S Patient Education Foundation)

Provides patient-friendly libraries of materials, pediatric handouts, school accommodations guides, support story sharing, and community events.

 conquerchiari.org [conquerchiari.org](#)


4. World Arnold Chiari Malformation Association (WACMA)

Global organization offering information, guidance, and community support for those impacted by Arnold–Chiari malformations.

 listed via rare diseases directory (**WACMA**) [bobbyjonescsf.org+9National Organization for Rare Disorders+9Wikipedia+9](#)


5. The Chiari Project

Community-driven nonprofit focused on pain management education, the Chiari Kids initiative, Brain Art programs, and regional peer support.

 chiariproject.org [National Organization for Rare Disorders+6chiariproject.org+6National Organization for Rare Disorders+6](#)


6. Chiari Clinic – Children’s Hospital of Philadelphia (CHOP)

While not solely an advocacy group, CHOP’s Chiari Clinic page links to ASAP and is a leading pediatric Chiari center with curated caregiver resources.

 chop.edu/centers-programs/chop-chiari-clinic [Children's Hospital of Philadelphia+1conquerchiari.org+1](#)

7. Chiari Malformation Center – Johns Hopkins Medicine

Provides multidisciplinary pediatric and adult care, telemedicine appointments, and educational materials, integrating research and surgical expertise.

 hopkinsmedicine.org/neurology-neurosurgery/specialty-areas/chiari-malformation-center [bobbyjonescsf.org+8Stanford Children's Health+8asap.org+8](#)

8. Chiari Malformation Resources – Stanford Children’s Health

Offers curated resources and links to CSF and ASAP, plus supportive programs for families traveling for care.

 stanfordchildrens.org/.../chiari-malformation/resources.html

[asap.org+5Stanford Children's Health+5thebraincharity.org.uk+5](#)

9. Child Neurology Foundation – Chiari Malformations Section


Provides overview articles, clinical trial info, and links to both Bobby Jones CSF and ASAP for families and providers.

 childneurologyfoundation.org/disorder/chiari-malformations/

[asap.org+3bobbyjonescsf.org+3bobbyjonescsf.org+3conquerchiari.org+14thebraincharity.org.uk+14asap.org+14](#)

10. Seattle Children’s Hospital – Chiari Malformation Info


Delivers comprehensive pediatric-centered Chiari guidance, including types, diagnostics, surgical options, and postoperative care.

 seattlechildrens.org/conditions/chiari-malformation/

[thebraincharity.org.uk+2Stanford Children's Health+2Wikipedia+2](#)

11. The Chiari Institute (Great Neck, NY)

Medical center and research institute specializing in treatment of Chiari malformation and syringomyelia, with clinical and academic outputs.

 thechiariinstitute.org (via institute profile page)

[Wikipedia+14Wikipedia+14bobbyjonescsf.org+14](#)

12. The Brain Charity – UK (Chiari Malformation Support)

UK-based nonprofit offering counselling, peer befriending, support groups, and information resources for people living with Chiari malformations.

 thebraincharity.org.uk > chiari-malformation [thebraincharity.org.uk](#)

Summary Table

#	Organization	Focus Area
1	ASAP	U.S.-wide patient support, research, education
2	Bobby Jones CSF	Research grants, guides, community, physician tools
3	Conquer Chiari	Patient education, pediatric-specific support
4	WACMA	Global awareness and support network

5	The Chiari Project	Pain education, youth outreach, creativity programs
6	CHOP Chiari Clinic	Leading pediatric care & resource referrals
7	Johns Hopkins Chiari Center	Advanced clinical care, telemedicine, expert surgery
8	Stanford Children's Chiari Resources	Family services, links to major U.S. Chiari charities
9	Child Neurology Foundation	Clinical overview, research links, provider-focused
10	Seattle Children's Chiari Info	Pediatric-focused treatment details and trusted overview
11	The Chiari Institute	Clinical treatment and research in New York
12	The Brain Charity (UK)	Emotional support, peer counseling, UK patient hub

How to Use These Resources

- **For medical care:** Johns Hopkins, CHOP, Seattle Children's, Stanford, and The Chiari Institute offer clinical services and referrals.
- **For support/community:** ASAP, Bobby Jones CSF, Conquer Chiari, and WACMA provide peer groups, informational libraries, conferences, and patient forums.
- **For research & advocacy:** Bobby Jones CSF and ASAP invest directly in research and patient education.
- **If located in the UK:** The Brain Charity offers local UK-based support and counseling services.