

Related Conditions: Website Resources



To additionally assist, we have provided organizations below who provide more extensive related condition information and support.

American Syringomyelia & Chiari Alliance Project, Inc. (ASAP)

The American Syringomyelia & Chiari Alliance Project, Inc. (ASAP) is a non-profit, 501(c)(3) donor- supported organization founded in 1988 by Barbara and Don White. ASAP began as a grass roots organization in the White's spare bedroom due to the frustration they encountered when Barbara was diagnosed with Chiari malformation and syringomyelia. Since then, ASAP has grown tremendously but our fundamental goals of research, education and support remain the same. This organization is a Gold-level GuideStar Exchange participant, demonstrating its commitment to transparency.

<https://asap.org/>

American Migraine Foundation

The American Migraine Foundation provides free support for millions of Americans living with migraine. Their mission is to mobilize a community for patient support and advocacy, as well as drive and support impactful research that translates into advances for patients with migraine and other disabling diseases that cause severe head pain.

<https://americanmigrainefoundation.org/>

The Ehlers-Danlos Society

The Ehlers-Danlos Society is a global organization dedicated to advancing and accelerating research and education in Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). We support the development of effective and equitable EDS and HSD therapies and work collaboratively to improve the lives of individuals affected by EDS and HSD.

<https://www.ehlers-danlos.com/>

Hydrocephalus Association

Founded in 1983 by the parents of children with hydrocephalus, the Hydrocephalus Association (HA) is the nation's largest and most widely respected organization dedicated to hydrocephalus. We fund high-impact research, provide support and educational resources for patients and caregivers, and advocate on behalf of the hydrocephalus community on key policies and legislation. Since 2009, HA has invested over \$13 million in cutting-edge research, making us the largest non-profit, non-governmental funder of hydrocephalus research in the United States.
<https://www.hydroassoc.org/>

Child Neurology Foundation

The Child Neurology Foundation connects partners from all areas of the child neurology community so those navigating the journey of disease diagnosis, management, and care have the ongoing support from those dedicated to treatments and cures. Their expanding network of patients and caregivers, volunteers and advocates, researchers and clinicians is committed to helping one another along the path that leads to the best quality of care — and the highest quality of life—for every child.
<https://www.childneurologyfoundation.org/#>

Spina Bifida Association

The Spina Bifida Association's mission is to build a better and brighter future for all those impacted by Spina Bifida. Fueled by dedicated health care providers, parents, adults, caregivers, and others, they are committed to helping people live longer, healthier lives through:

- Research
- Education & Support
- Clinical Care
- Network Building
- Advocacy

<https://www.spinabifidaassociation.org/>