



Resources Related to Chiari Malformation

Chiari Connection International (CCI)

CCI's mission statement, excerpted from its website www.ChiariConnectionInternational.com, is:

“Chiari Connection International is dedicated to bringing emotional and tangible support and understanding to the patients afflicted with Arnold Chiari Malformation and its related conditions, such as Syringomyelia and Ehlers-Danlos syndrome, as well as to providing patients and their friends and families with current, accurate information explaining ACM and its associated diagnosis, treatment and lifestyle. We plan to accomplish these goals through an ongoing support list, which connects ACM patients with people in similar situations for the sharing of emotional support, understanding and knowledge. Our web page will also act as a connection point for reliable information, supplied by acknowledged Chiari experts and patients themselves, which is intended to help the ACM patients lead the best lives possible, as well to provide an easily referenced source of information for the medical community at large, to help broaden their knowledge and awareness of these problems.”¹

CCI provides a message board where individuals can exchange questions, thoughts, and comments for adults, parents, and children: These links are as follows:

To subscribe, go to: <http://health.groups.yahoo.com/group/ChiariConnectionInternational/>
For Parents: <http://health.groups.yahoo.com/group/CCIparents/?yguid=124775342>
For Kids: <http://health.groups.yahoo.com/group/CCIkids/>

The World Arnold Chiari Malformation Association (WACMA)

The mission, as quoted from the WACMA website www.WACMA.com, is as follows:

“Staffed by volunteers, the World Arnold Chiari Malformation Association is committed to providing support, current information, and understanding to those affected by the Arnold Chiari malformation and Syringomyelia.

It is also our goal to raise the awareness of, and educate the medical community as to the complex nature of this disease and how it affects the lives of those who have it. With the help of our members from around the world we hope to be able to provide further research into the areas of symptoms, diagnosis, treatment and outcomes related to ACM and Syringomyelia.



We recognize the importance of linking patients, specialists, and researchers from around the world to improve our understanding of this disease and are committed to helping establish WACMA chapters across the globe.”¹

WACMA provides support groups for adults, parents, and children through a message board where individuals can exchange questions, thoughts, and comments. These links are as follows:

GENERAL: <http://health.groups.yahoo.com/group/chiari/>

FOR PARENTS: <http://health.groups.yahoo.com/group/wacmaparents/?yguid=124775342>

FOR KIDS: <http://health.groups.yahoo.com/group/wacmakids/?yguid=124775342>

Other Websites:

The Chiari Institute: www.chiariinstitute.com/

Our very own website offers over nine hours videos which have been used since 2003 to educate patients and their families about Chiari Malformation and related subjects. Via our website, we have recently made them available to the general public.

American Syringomyelia Alliance Project, Inc. (ASAP): www.asap.org

Conquer Chiari: www.conquerchiari.org

Chiari & Syringomyelia Foundation (CSF): www.csfinfo.org/