

**Chiari Malformations** are a set of neurological conditions which afflict approximately 1 in 1,000 people (300,000 people in the US), causing debilitating headaches, neck pain, weakness and numbness in the limbs, balance problems, visual disturbances, and a host of other symptoms.

Chiari Malformations are located at the base of the skull. Part of the brain, the cerebellum, descends out of the skull into the spinal area. This results in compression of parts of the brain and spinal cord, and disrupts the normal flow of cerebrospinal fluid (a clear fluid which bathes the brain and spinal cord).



I **HAVE** Chiari



I **DON'T** have Chiari

If left untreated, Chiari can lead to the development of a fluid-filled cyst in the spine (syringomyelia) and cause permanent nerve damage and paralysis.

Chiari is a complex disease which is poorly understood, initial diagnosis is an overwhelming experience. Parents are thrown into a whirlwind of medical jargon, tests and treatment options, asked to make decisions on their child's behalf, without a clear idea of their child's future wellness.

### *If you would like to*

- Learn more about symptoms, diagnosis, treatments, and living with Chiari and Syringomyelia;
- Get up-to-date on the latest research and expert opinions in the monthly on-line newsletter, "Chiari & Syringomyelia News";
- Review over 200 articles on Chiari and related topics in the newsletter archives;
- Read the stories of real people battling against Chiari, written in their own words;
- Join the Battle and be a Conquer Chiari volunteer;

VISIT: [www.conquerpediatricchiari.org](http://www.conquerpediatricchiari.org)

Email: [director@conquerchiari.org](mailto:director@conquerchiari.org)

Call: 724-940-0116

*Education, awareness, and research are our weapons. Compassion and conviction are our guides. Strength, courage, and determination will sustain us.*

**WE WILL WIN!**



This publication is for informational purposes only and is not intended as medical advice. Always consult a qualified professional for medical care.

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THROUGH RESEARCH  
**H**  
CONQUER PEDIATRIC CHIARI<sup>sm</sup>



## Who we are:

The C&S Patient Education Foundation, also known as Conquer Chiari, is a 501(c)(3) non-profit organization dedicated to improving the experiences and outcomes of Chiari patients by:

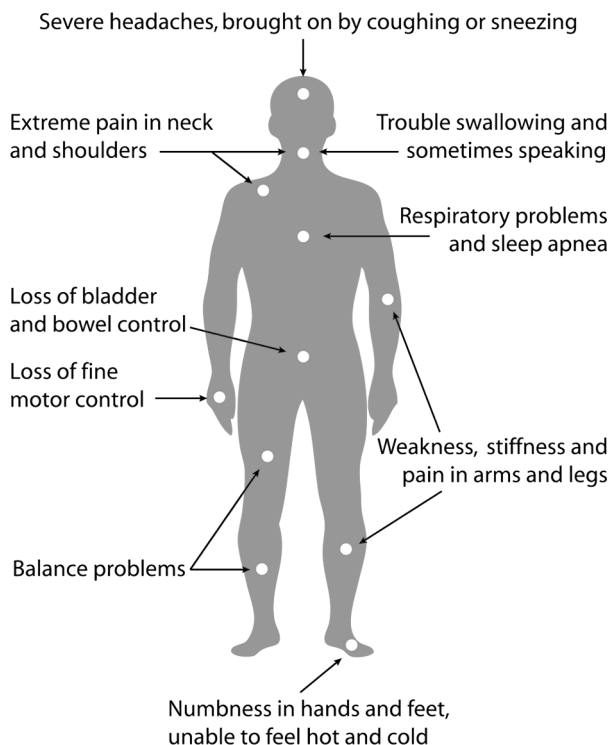
- Providing accurate, up-to-date, and easy to understand information to patients so they can take control of their health care and make intelligent, informed decisions.
- Raising awareness among family, friends, and the general public so they can understand what patients are going through and are better able to provide support.
- Raising awareness among, and providing accurate, up-to-date information to the medical community, so that accurate diagnoses are made earlier and errors in treatment are reduced.
- Providing support services to mitigate the overwhelming experience that coping with Chiari can be, and to reduce the rate and level of depression and anxiety among patients.
- Organizing and sponsoring research to advance the understanding of the condition.

We believe that for far too long Chiari has devastated families and robbed people of their health, hope, and dreams.

It is our goal, quite simply, to Conquer Chiari.

## Common Symptoms:

- Among young children, symptoms related to the mouth and throat, such as reflux, gagging, problems feeding, raspy voice, and chronic cough and poor weight gain are the most common.
- Among older children, scoliosis (*an abnormal curvature of the spine*) is a common symptom.
- There is a poorly understood link between scoliosis and Chiari. Research indicates that children with severe scoliosis and/or neurological symptoms should be evaluated for Chiari.
- Patients may experience any or all of the symptoms below due to Chiari and/or syringomyelia.



## Chiari Facts:

- Although it is estimated that Chiari affects about 300,000 people in the US, it is not known how many children are affected.
- Chiari is commonly diagnosed using a combination of MRI, neurological exams, physician's judgment, and other tests.
- 2002 study found that oropharyngeal problems (*having to do with the throat*) were the most common presenting symptom among very young children (3 and under).
- Up to 30% of children born with Spina Bifida also have Chiari.
- There is no real cure for Chiari, rather many children have to undergo a painful surgery in an attempt to alleviate symptoms, some children end up having multiple surgeries.
- Pediatricians are becoming more aware of Chiari, resulting in quicker diagnoses for children.
- While the data is not conclusive, there are indications that children in general have better outcomes than adults.
- The cognitive, emotional, behavioral, and developmental effects of Chiari have not been studied extensively, and are not well understood.
- The physical, mental, emotional, and economic strain caused by Chiari often pushes families to the breaking point.
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**\*Chiari Affects Everyone Differently\***