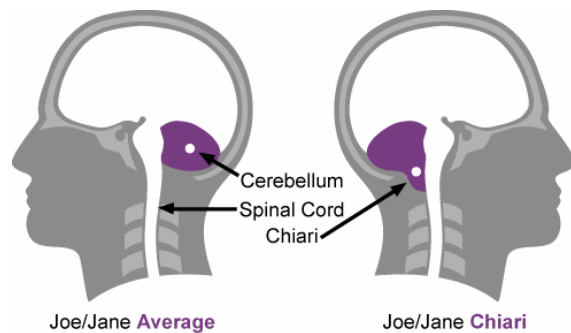


**Chiari Malformations** are a set of neurological conditions which afflict approximately 1 in 1,000 people (300,000 people in the US), causing debilitating headaches, neck pain, weakness and numbness in the limbs, balance problems, visual disturbances, and a host of other symptoms.

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).



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, and being diagnosed is an overwhelming experience. Patients are thrown into a whirlwind of medical jargon, tests, and surgery, all the while not knowing how things will turn out in the end.

### *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.conquerchiari.org](http://www.conquerchiari.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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# CONQUER CHIARI®



*From Knowledge, Strength.  
Through Research, Hope.*

[www.conquerchiari.org](http://www.conquerchiari.org)

## 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:

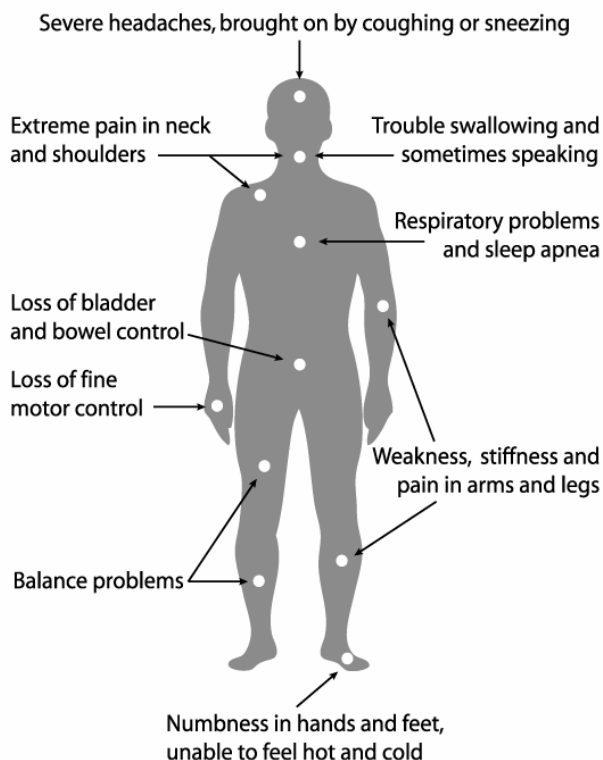
- Providing accurate, up-to-date, and easy to understand information to patients so they can take control of their health care and make intelligent, informed decisions.
- Raising awareness among family, friends, and the general public so they can understand what patients are going through and are better 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:

- Most common symptom among adults is severe headaches, usually in the back of the head, made worse by straining, coughing, sneezing, or bending over.
- 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.
- Among young children, symptoms related to the mouth and throat, such as reflux, gagging, problems feeding, raspy voice, and chronic cough are the most common.
- Patients may experience any or all of the symptoms below due to Chiari and/or syringomyelia.



## Chiari Facts:

- Affects people of all races and ages; in fact, at least 30% of children born with spina bifida also are born with a Chiari malformation.
- Causes a wide ranging, diverse set of symptoms. Research has shown that 95% of patients experience at least 5 symptoms.
- Diagnosed using combination of MRI, neurological exam, physician's judgment, and other tests; patients often go 5 or more years before being properly diagnosed.
- A study of over 300 patients found that 57% had at one time been told by a doctor they were suffering from a mental or emotional problem.
- A world-wide survey of neurosurgeons found there is little agreement on how best to treat Chiari, leaving patients in the position of having to put total faith in their doctor.
- Many physicians are not familiar with the latest findings, so treatment plans may be based on old, inaccurate data.
- Many patients undergo traumatic surgery in an attempt to stop symptoms from progressing.
- Upwards of 50% of patients continue to suffer from symptoms, such as chronic pain and nerve damage, even after surgery; many patients end up on disability, socially withdrawn, and depressed.
- The physical, mental, emotional, and economic strain caused by Chiari often pushes families to the breaking point

**\*Chiari Affects Everyone Differently\***