

About Us

The International Chiari Association (ICA) was founded in 2011 by Pete Dal Bello, with the assistance of high school friends Robert Mislang and Jason Floyd. Dal Bello went from doctor to doctor for eight years before finally being diagnosed with Chiari in 2008. An MRI revealed the malformation and Dal Bello underwent surgery on May 11, 2009. Feeling frustrated at the lack of resources and support for the disorder, Dal Bello formed this organization. The ICA is a California-based 501(c)(3) Nonprofit, Public-Benefit Organization.

Our Mission

The mission of the International Chiari Association (ICA) is to educate and inform the public about Chiari malformation. It is the ICA's goal to bring awareness and research to this little-known, serious neurological disorder and to help those with Chiari and the people that care about them.



"Smiling when in pain just shows how strong you are as a person!"

- Alexis, 9-Year-Old Chiari Sufferer

What Causes Chiari? How is it Treated?

The cause of Chiari is unknown. In the more serious cases, posterior fossa decompression surgery is performed to relieve pressure on the cerebellum. In 80% of the cases, it eases or prevents further progression. A neurosurgeon will then remove a small part of the back of the skull and part of the first vertebrae of the spine to widen the bottom part of the skull. Dura mater, the tough membrane that covers the brain in the affected area, is opened up and a dural patch (tissue taken from either the patient, a cow or a cadaver) is sewn to expand the space and restore normal CSF flow.

SOURCES:

University of Wisconsin Hospital and Clinics, Princeton Brain & Spine Center, Seattle Children's Hospital, Research and Foundation, Mayfield Clinic, CNN Health, The Chiari Institute, Child Neurology Education and Research Foundation, and Mayo Clinic.

DISCLAIMER:

This publication is for information purposes and is not intended as medical advice.

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What is Chiari Malformation?

Chiari (kee-AR-ee) malformation is a serious neurological disorder where the lower part of the brain, the cerebellum (which controls balance and coordination) descends into the spinal canal. Since the skull is not big enough, the tips of the cerebellum, called the cerebellar tonsils, are pushed down through the foramen magnum (the bottom part of the skull) where the brain attaches to the spinal cord. The tonsils obstruct the normal flow of cerebral spinal fluid (CSF, which surrounds and protects the brain and spinal cord) and the resulting pressure on both the brain and spine causes many symptoms.

Many Chiarians (people with Chiari) also suffer from syringomyelia (sear-IN-go-my-EEL-ya), a disorder in which a fluid-filled cyst (or syrinx) forms within the spinal cord. The syrinx can expand over time and, if not treated, can cause paralysis.

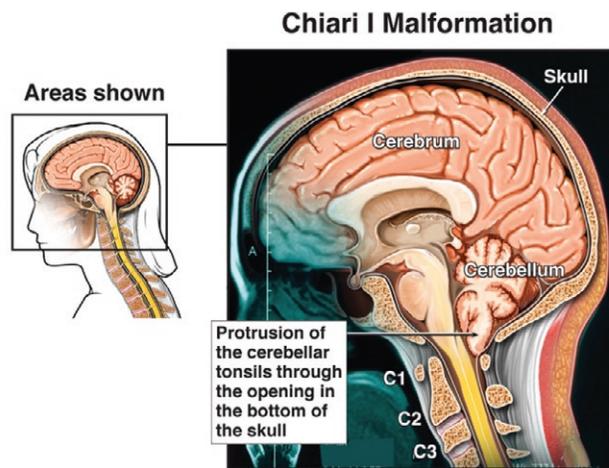


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What are the Symptoms of Chiari?

Some symptoms of Chiari include:

- Headaches (made worse by coughing, sneezing or straining)
- Neck pain
- Difficulty sleeping
- Muscle weakness
- Numbness
- Unsteady walking
- Poor hand coordination
- Slurred speech
- Blurred vision

The History of Chiari

Chiari malformation is named after Dr. Hans Chiari, an Austrian pathologist, who classified the malformations into Types I to III in 1891. There is also a Type IV.

There have been roughly 300,000 people diagnosed with Chiari in the United States. Females are affected three times more often than males. It is usually congenital (present at birth) and is seen all over the world. If left untreated, it can cause paralysis in some people. Death usually affects those with Chiari III or IV, which are rare.

What are the Four Types of Chiari?



Chiari I is the most common and the posterior fossa (back area of the skull) is too small or poorly shaped.



Chiari II is usually seen in infants born with myelomeningocele (my-e-lo-MENING-o-seal), a type of spina bifida in which the backbone and spinal canal do not close before birth. It also involves more of the brain than Chiari I. The symptoms are the same, but are usually worse and occur earlier.



Chiari III is an extremely severe condition and is rarely survivable. In Chiari III, a portion of the brain extends through an abnormal opening in the back of the skull.



Chiari IV is also rare and the patient has a slim chance of surviving. In Chiari IV, the brain itself has not developed normally.