My $________________donation is enclosed.

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Bobby Jones Chiari & Syringomyelia Foundation
29 Crest Loop
Staten Island, NY 10312

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Have you joined the international patient registry yet?
Join the growing number of patients and caregivers participating in the Bobby Jones CSF international patient registry for Chiari, syringomyelia and related disorders like Ehlers-Danlos Syndrome and dysautonomia. csfinfo.org/keytoacure

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DONATE ONLINE AT WWW.BOBBYJONESCSF.ORG

VISIT US AT WWW.BOBBYJONESCSF.ORG*

Here you will find…

• One-page fact sheets to download and print
• Free access to physician lecture videos
• unite@night walks and awareness opportunities
• Advocacy news
• Educational and fundraising events in your area
• How to register for the international patient registry

*For complete resources go to CSInfo.org until the new website is completed.

EXECUTIVE OFFICE
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LAST MEDICAL REVIEW 4/19
REV 4/19
CSF (Chiari & Syringomyelia Foundation, Inc.) is a non-profit organization that was founded in October 2007. In 2019, the Bobby Jones family and the Chiari & Syringomyelia Foundation partnered to form the Bobby Jones Chiari & Syringomyelia Foundation (Bobby Jones CSF), remaining a non-profit organization with the goal of raising awareness and finding a cure for Chiari malformation (CM), syringomyelia (SM) and related disorders.

The Bobby Jones Chiari & Syringomyelia Foundation, formerly known as CSF (Chiari & Syringomyelia Foundation), has funded over $6 million dollars’ worth of education and research projects and meetings in its first nine years and has impacted more than 2 million people around the world who are looking for answers.

WHO WE ARE

MISSION

To advance knowledge through research and to educate the medical, allied sciences, and lay community about Chiari malformation, syringomyelia and related disorders.

FOR MORE INFORMATION ON CHIARI MALFORMATION, SYRINGOMYELIA AND RELATED DISORDERS, VISIT OUR WEBSITE AT bobbyjonescsf.org.

YOUR SUPPORT WILL HELP BOBBY JONES CSF...

• Educate physicians, individuals and families
• Fund targeted research projects and create a research endowment to support ongoing projects
• Continue work on the International Patient Registry
• Provide educational lecture videos and information on the Bobby Jones CSF website
• Develop new and expand existing programs to spread awareness of these unrecognized conditions
• Advocate for federal research funding to improve the quality of life of those affected
• Establish regional chapters

ABOUT THE DISORDERS

Chiari I malformation (kee-AH-ree)
Chiari I malformation (CM) is a congenital or acquired (rare) malformation in which the back compartment of the skull is too small, resulting in crowding of neurological tissues. The lower part of the cerebellum, called the cerebellar tonsils, hangs down through the opening at the bottom of the skull, preventing cerebrospinal fluid (CSF) from flowing freely into the spinal canal.

Syringomyelia (seer-in-go-my-EEL-ya)
Syringomyelia (SM) occurs when a cavity, or syrinx, is formed inside the spinal cord from a build-up of fluid, which results from a blockage, either from a Chiari malformation, spinal trauma, tumor, or other cause. Syringomyelia can cause stretching and, eventually, permanent injury to nerve fibers.

SIGNS AND SYMPTOMS

Chiari
• Headache
• Imbalance
• Weakness in limbs
• Choking
• Dizziness
• Ringing in the ears
• Neck pain

These symptoms occur particularly in the arms and legs.

CM, SM and many related disorders can bring on other neurological symptoms that may overlap with those listed above.

Syringomyelia
• Numbness
• Tingling
• Pain
• Weakness

DIAGNOSIS AND TREATMENT

An MRI of the brain and spine will definitively show if a patient has CM, SM or other abnormality.

Currently, the only effective treatment is surgery. The decision to proceed with surgery should be carefully based on symptoms and neurological findings and should be made only after consulting your physician(s).