

## MISSION.

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



## VISION.

Within a generation, we will be the premiere world-wide resource for professional and lay people seeking accurate and current information about treatments and best practices for the management of Chiari, syringomyelia & related disorders, and the driving force promoting ongoing programs and research focused on earlier diagnosis and better outcomes.



## VALUES.

- Honesty and Integrity is uppermost in everything we do
- Commitment to quality is central to all activities
- We strive to exceed the expectations of patients and physicians
- Our volunteers are a respected source of knowledge and experience
- Social responsibility
- Fiscal responsibility
- Advocacy for the patient







2023 BY THE NUMBERS:

# EDUCATION



Your donations to Bobby Jones CSF are put to work *exponentially*. We support in-person and online lectures where patients and parents can ask questions directly of the experts who study and treat Chiari, syringomyelia and related disorders.

Countless individuals also watch lectures from our entire catalogue, at *any* time, for more asynchronous learning.

**663** lectures in-person & online

**10k** hours of educational videos watched every month

**570** individuals attending educational programs in 2023



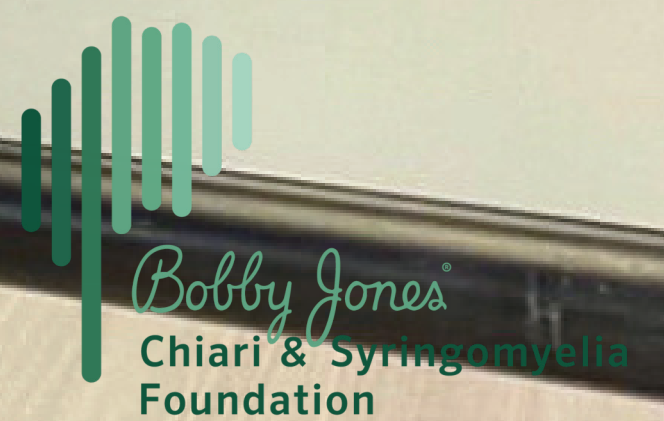
Thank you for supporting this important work!





2023 BY THE NUMBERS:

# SUPPORT & ADVOCACY



Your donations to Bobby Jones CSF are put to work *exponentially*. We directly serve countless patients and caregivers, providing peer-to-peer support and facilitating advocacy efforts!

**23** face-to-face support group meetings in 2023

**700** Inspire.com support group members impacted



**1,160** total individuals received peer-to-peer support in 2023

**3,848** downloads of The Chiari Champion podcast

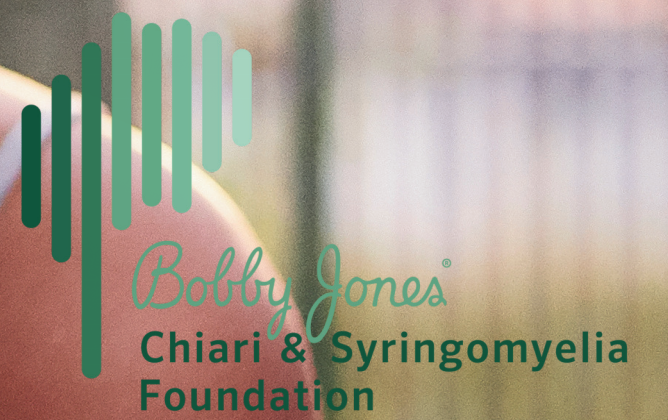
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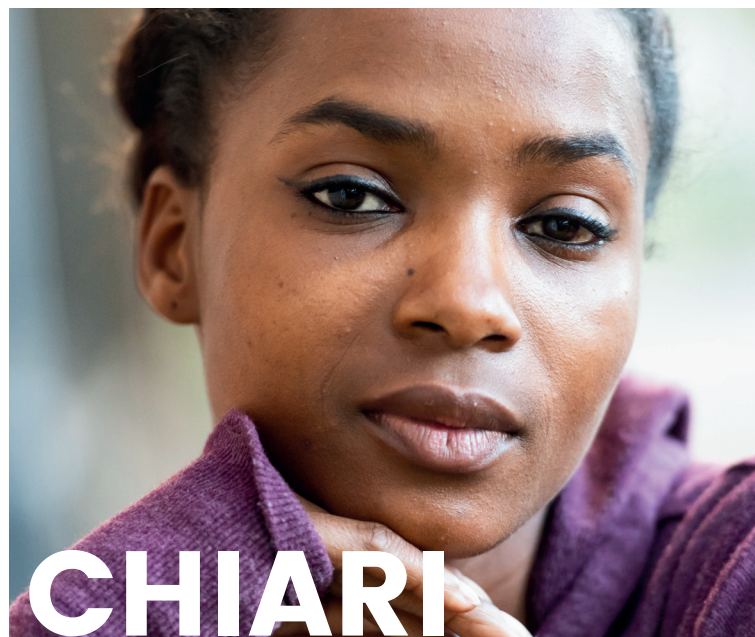


RESEARCH & CLINICAL PROJECTS:

# CSSS STUDY



EVERY



CHIARI

**GOAL:** To create a scale that doctors can use with patients. We hope that the scale will allow doctors to predict surgical outcomes in Chiari patients. If so, it can help determine if surgery or medical management is a better treatment plan for a given patient based on their clinical signs & symptoms.



PATIENT



IS

**18**

participating sites, inclusive of both academic & private practice; the first international site is joining in 2024!

**50+**

dedicated study personnel *already* working on this project



DIFFERENT.



**18**

have all data collection completed!

**100+**

participants enrolled... so far!

**...HOW DIFFERENT EXACTLY?**

Thank you for supporting this important work!





RESEARCH & CLINICAL PROJECTS:

# CRANIO-CERVICAL INSTABILITY

Bobby Jones  
Chiari & Syringomyelia  
Foundation



Craniocervical instability (CCI) is a medically contentious issue. There are no well-established criteria to diagnose the pathology. Instead, it is a diagnosis made by clinicians based largely on opinion, since the medical evidence does not have high-quality data. We have begun a Delphi-process to come to consensus on diagnosis and treatment. We are including clinicians on all sides of this controversy as to what "qualifies" as CCI. The goal is to identify objective radiographic and clinical signs that may better indicate surgery.

The next steps are to take the developed consensus definitions and prospectively study the treatment options to improve the quality-of-life for patients around the world who currently have no clinical guidance for their treatment.



**30** experts participating in next pediatric Delphi meeting in Oklahoma City

**100%** of those invited experts agreed to participate in this project

**\$1M** estimated cost for the first prospective study in this pipeline

Thank you for supporting this important work!





RESEARCH & CLINICAL PROJECTS:

# CLINICAL GUIDELINES

  
Bobby Jones  
Chiari & Syringomyelia  
Foundation



Despite being discovered centuries ago, Chiari malformation still has no written clinical guidelines available for the neurosurgical treatment of Chiari malformation. The goal of the original project was to develop evidence-based guidelines from the existing medical literature to provide a better standard-of-care in Chiari. Bobby Jones CSF was the first organization to ever be invited by the Congress of Neurological Surgeons Guidelines Committee to take part in these efforts. The results were published in the journal *Neurosurgery* in October 2023.

The results of this project showed that there are little to no high-quality studies to support strong guidelines in the care of Chiari. To rectify this, Bobby Jones CSF is funding large-scale projects that will provide quality evidence. And in the meantime, we are working with Dr. Bauer and the Guidelines Committee to develop practice parameters to better guide care in the interim.



**3** papers published in *Neurosurgery* to educate doctors and scientists

**1.5** hours of educational material for medical professionals produced

**14.5** hours of time already spent by neurosurgeons to take next steps!

Thank you for supporting this important work!