2023

# ANNUAL REPORT

Bobby Jones Chiari & Syringomyelia Foundation

# Vision & Mission

**Our 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 malformation, syringomyelia and related disorders, and the driving force promoting ongoing programs and research focused on earlier diagnosis and better outcomes.

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

# Introducing Our Team

## Board of Directors

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## Board of Trustees

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## Staff

**Dorothy Poppe • Chief Executive Officer**
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Andrea Grosz • Marketing, Communications & Design
Cathy Poznik • National Walk Director
Mary Poppe • Education, Social Media & Events

# Medical Board

## Scientific, Education & Advisory Board

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## Senior Advisory Panel

**Allison Ashley-Koch, PhD • Duke University Medical Center**
Paolo Bolognese, MD • Chiari EDS Center, Mt. Sinai South Nassau
Barth A. Green, MD • The Miami Project to Cure Paralysis
Victor Haughton, MD • University of Wisconsin
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Misao Nishikawa, MD • Osaka City General Hospital
Mark M. Souweidane, MD • Weill Cornell Medical College
Marcus Stoodley, MD • Macquarie University Hospital

# Year in Review

## Research

Last year, we began enrollment in the Chiari Surgical Success Scale study as part of the Chiari Clinical Research Consortium. This multi-center project is the first study of its kind to collect data pre- and post-operatively to determine if there are a set of symptoms or characteristics that make a positive outcome after surgery more likely. Bobby Jones CSF has an active role in this study and overall project, actively engaging in the research efforts, and ensuring that the patient voice is heard throughout the study. The initial 5 sites will soon grow to at least 20 participating sites by the end of next year. Excitingly, these sites include both academic and private practice centers to collect more real-world evidence in Chiari and syrinx diagnosis and treatment.

We also continue to expand our research and educational programming. We have provided 3 awards for research excellence in Chiari and syringomyelia. These awards are the first of their kind and have helped grow interest among young investigators and researchers in this area. Our international patient registry will also have completed data collection on 2 distinct projects, with analyses and publications expected in 2024. We also have completed a study protocol for a randomized control trial comparing tethered cord syndrome surgery in patients with and without radiological evidence on MRI; our next steps are to engage willing sites to participate. We also started a long-term project to better define, diagnose and treat cranio-cervical instability. First steps include a Delphi process to define what CCI is, and the funding and execution of a retrospective study of fusion surgery outcomes— both of which got underway in 2022.

## Education

Our educational lecture series and support group meetings also continued both in-person and online, safely for patients and caregivers. These programs continue to add value to patients and caregivers who have nowhere else to turn.

# Your Support at Work

Every dollar you donate in support of the Bobby Jones Chiari & Syringomyelia Foundation is put to work *exponentially*.

## Chiari Surgical Success Scale

In 2023, we enrolled more than 100 adults and children in the Chiari Surgical Success Scale study, collecting data pre- and post-operatively in order to be able to predict an individual patient's possible surgical outcome before they ever enter an operating room. Bobby Jones CSF has an active role in this study, monitoring research data and ensuring that the patient voice is heard throughout the course of the project. Approximately 20 sites will be enrolling by the start of 2024. Excitingly, these sites include both academic and private practice centers to collect the largest ever dataset of real-world evidence regarding the diagnosis and treatment of Chiari and syringomyelia.

## Research & Educational Programming

We also continue to expand our research and educational programming. We provide an annual award for excellence in research in Chiari and syringomyelia. Selected by researcher and clinician-peers, not by the Foundation, this year's award will be the fourth annual and will continue to foster interest in the study of Chiari, syringomyelia, and related disorders amongst young and emerging investigators. Additionally, our international patient registry continues to grow. Analyses, abstracts and publications from the registry are expected in 2024 with new studies always being generated.

## Related Disorders Projects

We also have started several projects on related disorders to Chiari and syringomyelia, including tethered cord syndrome and craniocervical instability (CCI). A modified Delphi process began in the spring of 2023 to develop consensus on the definitions of CCI in pediatric and adult patients. Meanwhile, we plan to develop protocols for retrospective and prospective studies to understand surgical outcomes in patients with CCI who have undergone fusion surgery.

## Lecture and Support Meetings

Our educational lecture series and support group meetings also remain extremely strong. Virtual and in-person education and support group meetings have continued for patients and caregivers. These programs provide awareness, education and critical interpersonal connection for patients and caregivers who have nowhere else to turn.

# By the Numbers

Our work affects **almost 8 million patients** in the United States and in countries around the world.

In 2023, we held **29 virtual & in-person support group meetings**, **4 physician/ researcher meetings**, and **15 virtual & in-person "Ask the Expert" lectures** to disseminate information and support and educate patients, physicians, and scientists.

We've funded **$7.2 million in educational programs and research**.

Our **virtual educational lectures** have received over **5.6 million** views, with a growth rate of **12 thousand** views per month.

In 2023, we held **20 unite4answers events**, **7 solo walks**, and **5 national and international fundraising events.** These events help us bring patients and families together and to support our mutual interest in changing the way we treat individuals diagnosed with Chiari malformation, syringomyelia, and related disorders.

# Financial Position

**CHIARI & SYRINGOMYELIA FOUNDATION**
**STATEMENT OF FINANCIAL POSITION**
**As of December 31, 2023 with comparative totals as of December 31, 2022**

| | 2023 | 2022 |
|---|---|---|
| **ASSETS** | | |
| **Current assets** | | |
| Cash and cash equivalents | $ 307,740 | $ 242,951 |
| Prepaid expenses | 23,956 | 28,725 |
| **Total Current assets** | 331,696 | 271,676 |
| **Investments portfolio** | 767,238 | 610,125 |
| **Property plant & equipment, net** | | |
| Computer equipment (Less Accum. Dep. $11,596) | - | 2,785 |
| **Total property plant & equipment, net** | - | 2,785 |
| **Other assets** | 1,212 | 1,212 |
| **TOTAL ASSETS** | 1,100,146 | 885,798 |
| **LIABILITIES AND NET ASSETS** | | |
| **Current liabilities** | | |
| Accounts payable | 682 | 70,630 |
| Prepaid event sponsorship | 8,000 | 18,800 |
| **Total current liabilities** | 8,682 | 89,430 |
| **Net assets** | | |
| Unrestricted net assets | 1,091,464 | 796,367 |
| **Total net assets** | 1,091,464 | 796,367 |
| **TOTAL LIABILITIES AND NET ASSETS** | $ 1,100,146 | $ 885,798 |

# Summary of Activities

| SUPPORT AND REVENUE | |
|---|---|
| CONTRIBUTIONS AND GRANTS | $465,546 |
| PROGRAM SERVICE REVENUE | N/A |
| MEMBERSHIP DUES | N/A |
| NET INCOME FROM SPECIAL EVENTS | 494,546 |
| INVESTMENT INCOME | 19,308 |
| *TOTAL SUPPORT AND REVENUE* | *$979,400* |
| **EXPENSES** | |
| PROGRAM | $552,525 |
| ADMINISTRATION | 95,214 |
| FUNDRAISING | 119,879 |
| *TOTAL EXPENSES* | *$767,618* |
| NET INCOME | $211,782 |

# Bobby Jones CSF Events

Bobby Jones CSF Signature, Patient, Researcher, and Doctor Events are listed on our website here: bobbyjonescsf.org/events

International Night of Light Gala

Bobby Jones Classic


unite4answers

Cabs for Chiari

Dinner Dance for a Cure

Think Tank

Casino Night

Research Colloquium

# Contact Us

The Boards and Staff of the Bobby Jones Chiari & Syringomyelia Foundation wish to say thank you to the individuals and organizations who generously donated to our organization during the 2023 fiscal year. What Bobby Jones CSF accomplishes with these gifts is immense and we are grateful for your generosity.

We are achieving great things and it's thanks to all of you!

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