

# 2022

# Annual Report

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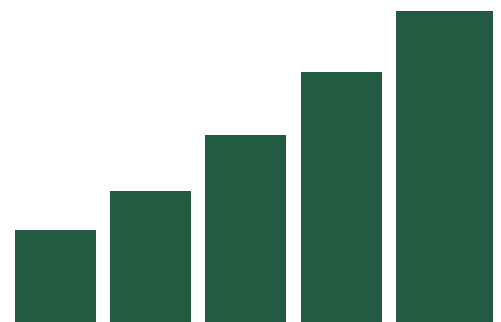
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# About Us

The Bobby Jones Chiari & Syringomyelia Foundation, Inc. is a national 501(c)(3) organization committed to disseminating accurate and current information about treatments for and best practices surrounding the management of Chiari malformation (CM), syringomyelia (SM) and related disorders. Many recognized world-class physicians, scientists and professionals agreed to collaborate and form a superior Scientific Education & Advisory Board (SEA Board).

The trusted and dedicated members of our Board of Directors and Board of Trustees include community and business leaders, educators, legal experts, families, and patients, who have been advocates in the CM & SM community for years. They have the skills and passion to create, fund, and direct programs and research that will change the lives of the over one million families affected by CM, SM, and related disorders.





# Vision And Mission

## 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 CM, SM and related disorders, and the driving force promoting ongoing programs and research focused on earlier diagnosis and better outcomes.

## Mission

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



Platinum  
Transparency  
2022

Candid.

# Meet Our Team



## BOARD OF DIRECTORS

**Paul J. Farrell** • Chair and Founding Member

James Rains • Vice-Chair

Pamela Fenner • Secretary

Dr. Catherine Loughin • Treasurer

Cameron Kim Dawson

Lory Watson • Founding Member

Marina White



## BOARD OF TRUSTEES

**Michael Mikula** • Chair

Adam Korn • Vice-Chair

Tyler Guettler

Cody Laird

Katherine Reid Laird

Lady Trish Malloch-Brown

Robert Walker Westbrook

Tygh Wyckoff, MD



## STAFF

**Dorothy Poppe** • Executive Director

Kaitlyn Esposito • Research and Programs

Andrea Grosz • Marketing & Development

Cathy Poznik • Chapter Coordinator

Mary Poppe • Programs and Events

# Medical Board



## SCIENTIFIC EDUCATION & ADVISORY BOARD

### Gerald Grant, MD - Chair • Duke University

John D. Heiss, MD - Vice-Chair • National Institutes of Health  
Ulrich Batzdorf, MD • David Geffen School of Medicine at UCLA  
Ari Blitz, MD • Case Western Reserve University  
Douglas L. Brockmeyer, MD • University of Utah  
Brian Dlouhy, MD • University of Iowa Hospitals and Clinics  
Richard G. Ellenbogen, MD • University of Washington  
Holly S. Gilmer, MD • Michigan Head & Spine Institute  
Jeffrey Greenfield, MD, PhD • Weill Cornell Brain & Spine Center  
Gabriel Haller, MD • Washington University School of Medicine  
Fraser C. Henderson, MD • University of Maryland  
Eric Jackson, MD • Johns Hopkins Medicine  
Petra M. Klinge, MD, PhD • Brown University  
Roger W. Kula, MD • Chiari Neurosurgical Center at NSPC  
David Limbrick, MD, PhD • St. Louis Children's Hospital  
Bryn Martin, PhD • Alcyone Therapeutics  
John Oró, MD • The Colorado Chiari Institute  
Sunil Patel, MD • Medical University of South Carolina  
Brandon G. Rocque, MD • Children's of Alabama  
Ilene Ruhoy, MD • EDS/Chiari Center At Mt. Sinai South Nassau Hospital  
Jennifer Strahle, MD • Washington University School of Medicine

### 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  
Bermans Iskandar, MD • University of Wisconsin Hospitals  
Myles Koby, MD • Doctors Community Hospital  
Mark Luciano, MD • Johns Hopkins University  
Cormac O. Maher, MD • Stanford University  
Arnold Menezes, MD • University of Iowa College of Medicine  
Misao Nishikawa, MD • Osaka City General Hospital  
Mark M. Souweidane, MD • Weill Cornell Medical College  
Marcus Stoodley, MD • Macquarie University Hospital



# One Year Review

## RESEARCH, EDUCATION, AWARENESS



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. By January, our international patient registry will also have completed data collection on 2 distinct projects, with analyses and publications expected in either 2023 or 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.

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.

More about what we do on our website here: [bobbyjonescsf.org/about-us/whatwedo](https://bobbyjonescsf.org/about-us/whatwedo)

# You Make it Happen

Every dollar you donate in support of the Bobby Jones Chiari & Syringomyelia Foundation is put to work *exponentially*. This page (front and back) highlights the work your donations have made possible in **just one calendar year!**

## Research

CHIARI SURGICAL  
SUCCESS SCALE

CHIARI CLINICAL  
RESEARCH  
CONSORTIUM

CRANIOCERVICAL  
INSTABILITY  
RETROSPECTIVE

CRANIOCERVICAL  
INSTABILITY  
PROSPECTIVE PREP

CRANIOCERVICAL  
INSTABILITY DELPHI

INTERNATIONAL  
PATIENT REGISTRY

5MM RULE STUDY

SYMPTOM BURDEN  
SURVEYS

CHIARI/POTS STUDY  
COMPLETION

CDI: PATIENT-FOCUSED  
FDA MEETING PILOT

TELEHEALTH STUDY

RESEARCH  
COLLOQUIUM MEETING

CNS CHIARI  
GUIDELINES

CDI: TRANSITION OF  
CARE PROJECT PREP

INTL CSF  
HYDRODYNAMICS  
MEETING

GENETIC ALLIANCE  
RESEARCH SYMPOSIUM

AMERICAN PUBLIC  
HEALTH ASSOCIATION  
MEETING

HEMOSTEMIX/PRECEV  
PRECLINICAL TRIALS

CHIARI RESEARCH  
AWARD

CHIARI RCT & P01  
GRANT AT WASH U

TETHERED CORD  
SYNDROME STUDY  
PREP

AANS/CNS JOINT  
SECTION NONPROFIT  
COUNCIL

THINK TANK MEETING

NINDS NONPROFIT  
FORUM PARTICIPATION

## Advocacy

UNITE@THEHILL

SOCIAL SERVICES  
CONNECTION:  
UNITEUS

ONGOING ADVOCACY  
FOR POLICY CHANGE

More about what we do on our website here: [bobbyjonescsf.org/about-us/whatwedo](http://bobbyjonescsf.org/about-us/whatwedo)



# You Make it Happen

## Education

ASK THE EXPERT  
VIRTUAL EDUCATION

IN-PERSON  
EDUCATION

CONSIDER CHIARI  
SEMINARS

CHIARI CHAMPION  
PODCAST

AANS/CNS JOINT SECTION  
MEETING STREAMING  
ACCESS FOR FAMILIES

## Support

ADULT SUPPORT  
GROUP VIRTUAL  
MEETINGS

PARENT/CAREGIVER  
SUPPORT VIRTUAL  
MEETINGS

YOUNG ADULT/TEEN  
SUPPORT VIRTUAL  
MEETINGS

CHILDREN'S SUPPORT  
VIRTUAL MEETINGS

IN-PERSON SUPPORT  
GROUP MEETINGS

INSPIRE.COM VIRTUAL  
SUPPORT FORUM

UNITE4ANSWERS  
WALKS & RUNS



More about what we do on our website here: [bobbyjonescsf.org/about-us/whatwedo](https://bobbyjonescsf.org/about-us/whatwedo)

# Bobby Jones CSF Events



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



# Financial Position

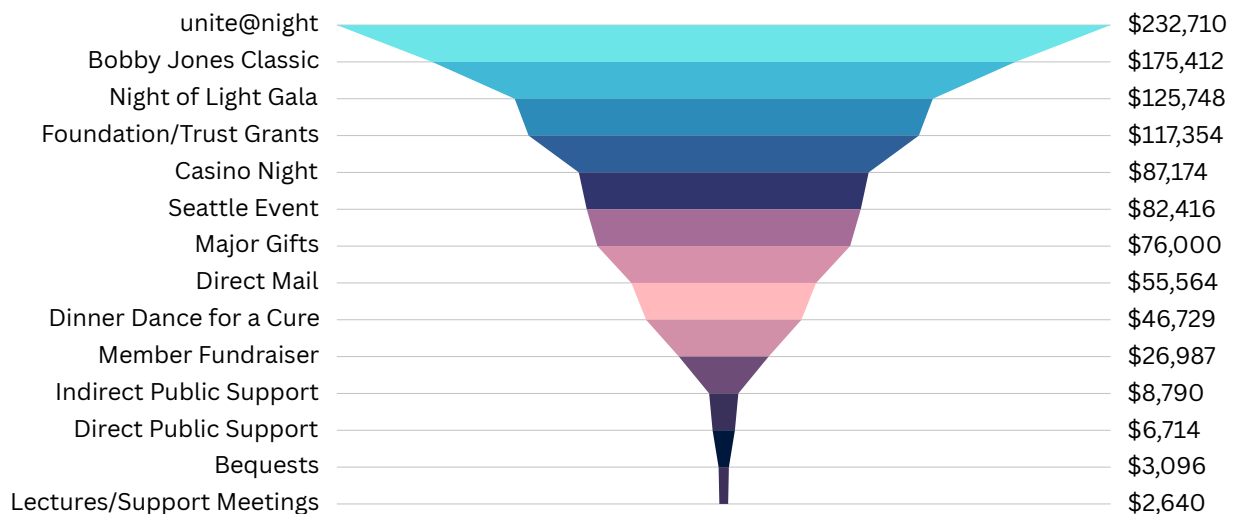
## CHIARI & SYRINGOMYELIA FOUNDATION STATEMENT OF FINANCIAL POSITION

As of December 31, 2022 with comparative totals as of December 31, 2021

	2022	2021
<b>ASSETS</b>		
<b>Current assets</b>		
Cash and cash equivalents	\$ 242,951	\$ 302,244
Prepaid expenses	28,725	8,529
<b>Total Current assets</b>	<b>271,676</b>	<b>310,773</b>
<b>Investments portfolio</b>	<b>610,125</b>	<b>582,448</b>
<b>Property plant &amp; equipment, net</b>		
Computer equipment (Less Accum. Dep. 58,811)	2,785	2,785
<b>Total Property plant &amp; equipment, net</b>	<b>2,785</b>	<b>2,785</b>
<b>Intangible Asset</b>		
Trademark patent legal fees	1,212	1,212
	1,212	1,212
<b>TOTAL ASSETS</b>	<b>885,798</b>	<b>897,218</b>
<b>LIABILITIES AND NET ASSETS</b>		
<b>Current liabilities</b>		
Accounts payable	70,630	11,687
Prepaid event sponsorship	18,800	4,000
<b>Total current liabilities</b>	<b>89,431</b>	<b>15,687</b>
<b>Net assets</b>		
Unrestricted net assets	796,367	881,531
<b>Total net assets</b>	<b>796,367</b>	<b>881,531</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$ 885,798</b>	<b>\$ 897,218</b>

# Summary of Activities

SUPPORT AND REVENUE	
CONTRIBUTIONS, GIFTS AND GRANTS	\$300,053
PROGRAM SERVICE REVENUE	0
MEMBERSHIP DUES	0
NET INCOME FROM SPECIAL EVENTS	458,035
INVESTMENT INCOME	11,119
<b>TOTAL SUPPORT AND REVENUE</b>	<b>\$769,225</b>
EXPENSES	
PROGRAM	\$499,049
ADMINISTRATION	105,296
FUNDRAISING	156,037
<b>TOTAL EXPENSES</b>	<b>\$759,037</b>
<b>NET INCOME</b>	<b>\$9,843</b>







# By the Numbers



3.6

We serve **3.6 million patients** in the United States and in countries around the world.



34

In 2022, we held **34 monthly support group meetings, 6 bi-monthly physician/researcher meetings, and 18 twice-monthly virtual “Ask the Expert” lectures** to disseminate information and support and educate patients, physicians, and scientists.



6.6

We've funded **\$6.6 million** in educational programs and research.



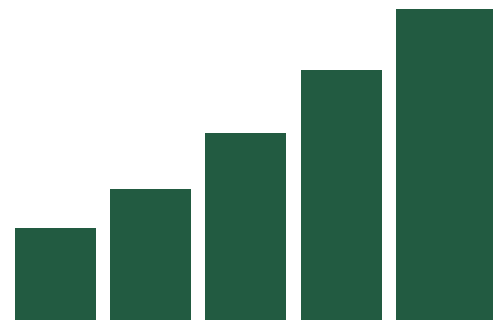
5.5

Our educational lectures have received over **5.5 million views**, with a growth rate of **10 thousand views** per month.



25

**25 unite@night walks, 13 solo walks, and 5 national and international fundraising 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.



# Contact Us



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

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 2022 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.

