Bobby Jones® Chiari & Syringomyelia Foundation

RESEARCH
EDUCATION
AWARENESS
ADVOCACY

annual report 2019

SEAL OF TRANSPARENCY 2018 PLATINUM GuideStar

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Mission

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

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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.

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2019 Calendar of Events

Greater Metropolitan Washington Area
Educational Lecture
January 16, 2019 - Lanham, MD

New York, New York Educational Lecture
January 31, 2019 – New York, NY

Charleston, South Carolina Educational Lecture
February 07, 2019 - Charleston, SC

Sweetheart Dance
February 09, 2019 - Johns Island, SC

Boardwalk Casino Night
March 02, 2019 - Staten Island, NY

2nd Annual Mayo Clinic Advances & Innovations in Complex Neuroscience Patient Care: Brain & Spine
March 06 - 07, 2019 - Sedona, AZ

8th Annual Bobby Jones Classic
March 31, 2019 - April 01, 2019 - Atlanta, GA

CSF CDE/International Patient Registry Meeting
April 12, 2019 - San Diego, CA

Charleston, South Carolina Support Group Meeting
April 13, 2019 - Daniel Island, SC

CSF Think Tank Meeting
April 13, 2019 - San Diego, CA

Chicago, Illinois Educational Lecture
April 27, 2019 - Park Ridge, IL

Charleston, South Carolina Educational Lecture
May 23, 2019 - Charleston, SC

Chesapeake, Virginia Educational Lecture
May 29, 2019 - Chesapeake, VA

Sacramento, California Educational Lecture
June 04, 2019 - Sacramento, CA

NYC4CSF
June 04, 2019 - New York, NY

4th Annual CSF Disorders Symposium
From Canvas to Clinic June 15, 2019 - Providence, RI

Cincinnati, Ohio Educational Lecture
June 18, 2019 - Cincinnati, OH

Charleston, South Carolina Support Group Meeting
June 29, 2019 - Daniel Island, SC

5th International CSF Hydrodynamics Symposium
July 01 - 02, 2019 - Oslo, Norway

St. Louis, Missouri Educational Workshop – Harmony in Health: The Composition of a Balanced Care Team
August 10, 2019 - St. Louis, MO

Charleston, South Carolina Educational Lecture
August 15, 2019 - Charleston, SC

Johns Hopkins – Baltimore, Maryland Educational Lecture
August 28, 2019 - Baltimore, MD

Diagnosis & Management of Syndromes of the Craniocervical Junction & Roundtable Discussion
September 13, 2019 - London, England

The Chiari Consensus Project
September 26 - 27, 2019 - Bethesda, MD

Sioux Falls, South Dakota Educational Lecture
September 26, 2019 - Sioux Falls, SC

Cincinnati, Ohio Educational Lecture
October 07, 2019 - Cincinnati, OH

2019 Fall Research Meeting
October 18, 2019 - San Francisco, CA

2019 Research Colloquium
October 19, 2019 - San Francisco, CA

9th Annual Dinner Dance for a Cure
October 26, 2019 - Twinsburg, OH

2019 International Night of Light Gala
November 02, 2019 - New York, NY

Seattle, Washington Chiari Malformations Roundtable Discussion
November 06, 2019 - Seattle, WA

Charleston, South Carolina Educational Lecture and WEBEX
November 20, 2019 - Charleston, SC

Chicago, Illinois Educational Lecture
November 23, 2019 - Park Ridge, IL

Sweetheart Dance
February 9 – Johns Island, SC

unite@night walks
Various dates and locations

Bobby Jones Classic
March 31-April 1 – Atlanta, GA

NYC4CSF
June 4 – New York, NY

Dinner Dance for a Cure
October 26 – Twinsburg, OH

Night of Light Children's Gala
November 2 – New York, NY

Research

Research Grants

We have funded six individual research projects that have been published and a practical project that yielded a prototype adaptive golf car that allows children with paralysis and physical disabilities to engage in sports. This prototype was patented and is being manufactured by SoloRider, as part of Bobby Jones CSF's ongoing adaptive golf initiative to improve patients' quality-of-life. Excitingly, in early 2019, we published the Chiari I malformation Common Data Elements (CDEs) in the journal *Neurosurgery.* In addition, the seeds for future projects were planted in September for an exciting new research initiative.

Common Data Elements

Previously, Bobby Jones CSF had developed, accepted public comment and published CDEs for Chiari I malformation. As research and understanding of Chiari, syringomyelia and related disorders continues to evolve, we continue to recommend CDEs for future inclusion in the CDEs. Members of our medical board also sit on the revisions committee to continue pushing for improvements in research. Beyond 2019, we hope to develop additional CDEs for more related disorders such as tethered cord syndrome, among others.

International Patient Registry

We began building an international patient registry a few years ago. Broadly speaking, the goal is to provide an as-of-yet unprecedented dataset for Chiari, syringomyelia and related disorder populations, accessible to respected researchers around the globe. This will build the evidence base that is so desperately needed to more definitively link and/or distinguish Chiari to and from other conditions and better understand the natural history. Bobby Jones CSF has set an initial goal of recruiting 1,000 registry participants into this dataset. Big updates and research projects are being planned in 2020 and beyond. Get involved at bobbyjonescsf.org/keytoacure.

Research Colloquia and Symposia

By the end of 2019, Bobby Jones CSF had sponsored and hosted 35 national and international medical and scientific research conferences. Scientific meetings for 2019 included the CSF Hydrodynamics Symposium to understand basic science and fluid dynamics of these disorders (Oslo, Norway – Jul 1-2, 2019) and the 2019 Research Colloquium which focused on novel research in the field (San Francisco, CA, USA – Oct 19, 2019). In addition, Bobby Jones CSF participated in the **Diagnosis & Management of Syndromes of the Craniocervical Junction & Roundtable Discussion in London, England, in September.**

Proceedings from previous Research Colloquia have been transcribed and made available for purchase. The 2019 Colloquium Proceedings will be available in mid- to late-2020.

Education, Awareness & Advocacy

Educational Lecture Series

Bobby Jones CSF continues to offer free, educational lectures for patients, their families, and caregivers. These lectures are recorded and are made freely available online on our website in order to bring any pertinent information to millions of others around the globe who are searching for help. These videos have been accessed by almost 2.2 million people around the world. To date, we have hosted 526 individual lectures at patient- and provider-focused meetings.

NeuroConnect Alliance

The mission of the Neuro Connect Alliance is to connect non-profit organizations, specialists, advocates, and patients touched by these separate, but related disorders to share knowledge and forge partnerships that will advance collaborative research, unite advocacy efforts and improve health outcomes and increase overall quality-of-life through joint advocacy efforts.

Bobby Jones CSF stormed Capitol Hill at the beginning of May, to make a difference for people living with Chiari malformation, syringomyelia, dysautonomia, Ehlers-Danlos syndrome, and many other related disorders. Since we began our quest, Congress has passed important legislation like the 21st Century Cures Act which promises to fund more innovative medical research, especially for debilitating neurological disorders which are often overlooked for governmental funding.

unite@night Walks

unite@night is a one-mile casual evening walk, in various locations in the USA, during May - November that bring together people who are suffering with the devastating effects of Chiari malformation, syringomyelia, Ehlers-Danlos syndrome, and related disorders.

unite@night helps fund important educational programs and research projects. In 2019, we had approximately 1,000 people participate at 43 different walk sites and we raised almost $132,000. To see the list of walk sites, visit bobbyjonescsf.org/unitenight/walk-sites.

CHIARI & SYRINGOMYELIA FOUNDATION
STATEMENT OF FINANCIAL POSITION
As of December 31, 2019 with comparative totals as of December 31, 2018

		2019		2018
ASSETS				
Current assets				
Cash and cash equivalents	$	186,011	$	354,291
Prepaid expenses		3,900		25,937
Total Current assets		189,911		380,227
Investments portfolio		343,590		249,763
Property plant & equipment, net				
Computer equipment (Less Accum. Dep. $8,811)		2,785		2,785
Total Property plant & equipment, net		2,785		2,785
Intangible Asset				
Trademark patent legal fees		1,212		1,212
		1,212		1,212
TOTAL ASSETS		537,498		633,987

		2019		2018
LIABILITIES AND NET ASSETS				
Current liabilities				
Acounts payable		-		-
Credit card payable		28,109		1,660
Prepaid event sponsorship		19,500		6,000
Total current liabilities		47,609		7,660
Net assets				
Unrestricted net assets		489,889		626,327
Total net assets		489,889		626,327
TOTAL LIABILITIES AND NET ASSETS	$	537,498	$	633,987

2019 Summary of Activities

Support and Revenue		
Contributions, Gifts and Grants	$	195,484
Program Service Revenue		42,460
Membership Dues		0
Net Income from Special Events		556,368
Investment Income		52,528
Total Support and Revenue	**$**	**846,840**
Expenses		
Program	$	695,066
Administration		165,286
Fundraising		122,926
Total Expenses	**$**	**983,278**
Net Income	**$**	**-136,438**

Diamond ($100,000 and above)

Goldman Sachs Gives

Bobby Jones Society ($25,000 - $99,999)

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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 2019 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.

Bobby Jones®
Chiari & Syringomyelia
Foundation