

THE BOBBY JONES CHIARI & SYRINGOMYELIA FOUNDATION

29 Crest Loop | Staten Island, NY 10312 | www.bobbyjonescsf.org



Dear [Sample A. Sample],

We are proud to announce that the Chiari & Syringomyelia Foundation has officially joined the family of Bobby Jones and launched the Bobby Jones Chiari & Syringomyelia Foundation (Bobby Jones CSF). Our mission to find a cure, fund research and to educate the medical, allied science and lay public about Chiari malformation, syringomyelia and related disorders remains the core of all we do. Now, we are able to make these complex and difficult-to-say disorders more recognizable with the legendary name of Bobby Jones.

WHAT YOUR GIFTS HAVE DONE...

Through your generous gifts, we, like Jones, have had many great accomplishments. Just in the past 10 years we...

- Funded **5 basic research grants**
- Published **6 research papers** in major medical journals
- Pioneered the **Common Data Elements Project** with NIH/NINDS. This project will establish one common language for researchers and physicians worldwide as we search for a cure.
- Funded **35 medical research meetings**
- Hosted **419 patient and professional educational lectures**. Lecture videos are available for free viewing on our website and have been accessed by over 2 million people around the world.
- Launched the **PEER International Patient Registry**, the first ever international registry for patients with Chiari and syringomyelia
- Participated on the board of the PCORI-funded \$2.8 million **randomized surgical trial** to determine whether posterior fossa decompression (PFD) alone or with duraplasty is a more effective surgery.

We are continuing to work to grow and improve our programs. With the launching of our new and enhanced website for patients, researchers and medical professionals, we are making it easier for all of our online visitors to access the information they need. Visit our new site at bobbyjonescsf.org.

OVER, PLEASE>>



WHAT'S NEXT...

Bobby Jones CSF is sponsoring the **5th International Hydrodynamics Symposium** in Oslo, Norway on July 1-2, 2019. This biennial international meeting of physicists, engineers, bioengineers and mathematicians allows researchers to come together to discuss the pathology of cerebrospinal fluid flow disruption and fluid dynamics, related to CSF flow in patients with Chiari and syringomyelia.

This Fall, Bobby Jones CSF will host a **symposium in London** for United Kingdom medical professionals to improve diagnosis and treatment of Chiari, syringomyelia and related disorders.

The Chiari Consensus Meeting taking place in September will bring together some of the most brilliant minds in the field. The goal is to create a guide for physicians to use in determining the best treatment for Chiari.

WHY BOBBY JONES...

Bobby Jones was regarded by many as the greatest athlete of the 1920's. An amateur golfer from Atlanta, Jones won thirteen national championships between 1923 and 1930. He is also the only man in history to win golf's Grand Slam, all four national championships in the same calendar year. He co-founded the Augusta National Golf Club and the Masters Tournament. He was also a highly-educated man, holding degrees from Georgia Tech and Harvard, and passing the bar after less than two years in law school. He and his father co-founded a law firm that is now one of the most prominent in the country. He married his childhood sweetheart and had three children whom he adored. Bobby Jones had it all: family, fame, fortune...and syringomyelia. In Bobby's day, there was no treatment for syringomyelia and, today, it's not much better. That's where you can make a difference. With your support, you can join the Bobby Jones family to find the cure. Just as Bobby Jones proved years ago, together, **anything is possible.**

How Do We Find the Answers?...



We need to continue on our successful path to fund research to find the cure for over 3,000,000 patients in the United States alone.



We need to continue educating and serving people in 194 countries around the world with current and accurate information about symptoms, diagnosis and treatment.



We need to continue to lead the medical world with projects like the CDE's to make standardization of measurements and language translate from one database to another.



We need to continue to fund the PEER International Patient Registry so researchers can find the answers that are currently locked away.



Your gift provides the key. Please consider a gift to end the suffering, give hope and find the cure. Your membership card is enclosed. Thank you!



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