

CSF END OF YEAR UPDATE



As the end of another year approaches, we take the opportunity to reflect on the progress and achievements the Chiari & Syringomyelia Foundation made in 2013. Thanks to your generous gifts, support and participation, we accomplished many of the goals we set for 2013, and we continue to establish new and exciting events. As one of our most productive years draws to a close, I'd like to update you on the significant achievements we accomplished in 2013.

Read more on the CSF website.

CLEVELAND CHAPTER EDUCATIONAL MEETING

Join us on Thursday, November 21, 2013 from 6:30 to 8:00 PM at Cleveland Clinic's Bunts Auditorium for an educational lecture entitled "Sleeping with Chiari - The Role of the Sleep Lab" The featured speaker, Jyoti Krishna, MD, is a pediatric sleep specialist at the Cleveland Clinic who specializes in pediatric sleep disorders. We will allow plenty of time for questions from the audience.

Also, prior to the lecture, please join Cathy Poznik, CSF Chapter Coordinator, for a Meet and Greet session at 5:30 in the lobby of Bunts Auditorium.

To register please call Cathy at 330-998-6195 or email her at cpoznik@CSFinfo.org.



About Dr. Krishna: Jyoti Krishna, MD, D-ABSM, was born in Calcutta, India. He attended medical school in New Delhi, India. During his Pediatric residency at Texas Tech University Health Sciences Center, Lubbock, Tex., (1993-1996) he served as Chief Resident and was voted Outstanding Resident.

As a practicing pediatrician, he became interested in childhood sleep disorders. In 2004 he completed a two-year Sleep Fellowship at the Kosair Children's Hospital and the University of Louisville, Ky.

Following this, he continued to serve as Assistant Professor of Pediatrics in the Division of Pediatric Sleep Medicine at the University of Louisville.

CLEVELAND CHAPTER EDUCATIONAL MEETING (continued)

In August 2007, Dr. Krishna joined Cleveland Clinic as Staff Physician and Head of Pediatric Sleep at the Sleep Disorders Center. He is board-certified both in sleep medicine and pediatrics.

Dr. Krishna has presented more than 25 national and international lectures and published more than 20 scientific abstracts and peer reviewed papers. He has been actively teaching residents, medical students, and fellows, and he has participated in community programs teaching children the importance of education and staying in school.

2013 THINK TANK MEETING

The 2013 Think Tank Meeting took place in New Orleans, Louisiana on April 27, 2013. The thought leaders and investigators in Chiari malformation, syringomyelia & related disorders were present and the meeting itself was a huge success. We will be sharing several of the Think Tank talks over the next few months. This month, you can view Dr. Paolo Bolognese's talk on the diagnosis and surgical management of CMI Associated with Anterior Pathologies.

UNITED WAY



If you are an employee of a company that conducts its own employee workplace-giving fund drive, you may be able to double or even triple the impact of your gift. In order to encourage charitable giving, the companies will often "match" your gift- thereby doubling your gift to CSF. Some will even "double-match" your donations to triple the impact of your original donation. To have CSF included in your company's campaign, please request an application for CSF or call us at 718-570-0057 so that we can apply to be included in your campaign. Many employers sponsor corporate matching gift programs and will match any charitable contributions that their employees make. Some companies also match gifts made by retirees and/or spouses.

United Way Donor Designation

If you participate in a United Way giving campaign that allows donor designations, you may be able to select CSF as the beneficiary of your United Way gifts. If CSF is not listed as a member agency, please contact the campaign coordinator to see if you can

UNITED WAY (continued)

write in CSF to be considered for your gift. If you are able to write CSF in as your choice, please use our complete, spelled-out name (Chiari & Syringomyelia Foundation) and provide the following information: CSF's address (29 Crest Loop, Staten Island, NY 10312) and federal tax-identification number (26-1316274). As procedures do vary with each local or regional campaign, please verify that you have completed your designation correctly.

SAVE A LIFE AND SUPPORT CSF!



In a medical emergency situation, the availability of essential medical information could be the difference between life and death. What medication is the patient taking? What medical conditions do they have? Do they have any allergies? First Responders can provide the best possible care by knowing all of this information. With QR LifeSupport they have access to so much more essential information than the traditional one or two word bracelets. They will have immediate access to your essential health information through a secure, state-of-the-art technology platform; information that could save your life.

The founders of QR LifeSupport, having family members suffering from medical conditions including Chiari malformation and syringomyelia, recognized the need for this type of bracelet and **will generously donate a portion of sales from every bracelet to CSF.**

For more information or to order your bracelet, [click here](#).

CSF ON THE GO!

We recently launched an optimized mobile version of our website to allow for easier sharing of information about Chiari malformation, syringomyelia and related disorders while on-the-go! Now you can spread awareness at a moment's notice by using your mobile device!

CSF VISITS WASHINGTON



The CSF Faces of Chiari letter writing campaign was a huge success and we visited Capitol Hill last month to meet with several members of Congress to express your views on the importance of research. Even more exciting, Executive Director Dorothy Poppe and Chapter Coordinator Cathy Poznik personally helped to deliver YOUR letters to the Hill!

BECOME AN ADVOCATE

Living with a debilitating disorder or disability can make anyone feel powerless. But we at CSF want to help you understand that you are much more powerful than you may know.

You have the very real ability to affect the outcome of legislation by becoming an advocate. The idea of speaking out — either by writing letters or physically meeting with your representative(s) — seems scary at first, but with a little help, it's a snap!

How Do I Become An Advocate?

CSF HONORED AS 2013 TOP-RATED NONPROFIT



CSF has been honored with a prestigious 2013 Top-Rated Award by GreatNonprofits, the leading provider of user reviews about nonprofit organizations.

The Top-Rated Nonprofit award was based on the large number of positive reviews that CSF received – reviews written by volunteers, donors and clients. People posted their personal experience with the nonprofit. For example, one person wrote, “I’ve attended many functions over the past years sponsored by this Foundation and they have all been educational, informative and help bring awareness to these conditions. I have supported this group and will continue to do so as they work to sponsor research necessary for the future to combat these conditions. The Foundation is professionally managed and organized with a clear focus on its Mission. The goals of this Foundation are crucial, important and noble.”

CSF HONORED AS 2013 TOP-RATED NONPROFIT (continued)

While the Top-Rated Awards ran through the end of October, CSF was part of the inaugural group to qualify for the year.

“Savvy donors want to see the impact of their donations more than ever,” said Perla Ni, CEO of GreatNonprofits, “People with direct experience with CSF have voted that the organization is making a real difference.”

MAYFIELD CENTER CHIARI WEBINARS

The Mayfield Chiari Center in Cincinnati will be offering free webinars as follows. More information can be found here.

January 18, 2014 @ 2pm EST
Diagnosis & Treatment of Chiari
Robert Bohinski, MD, PhD
Neurosurgeon, Mayfield Chiari Center

April 12, 2014 @ 2pm EST
Improving Symptom Control Through Nutrition and Wellness
Stefanie Stevenson, MD
Clinical Director, Integrative Medicine, UC Health

SAVE THE DATE FOR THE 2014 BOBBY JONES CLASSIC



Join us on Sunday, May 18 and Monday, May 19, 2014 for the Third Annual CSF Bobby Jones Classic at East Lake Golf Club in Atlanta, Georgia. Limited to 100 golfers, the event's activities are as follows:

Sunday, May 18: Private tour of Bobby Jones landmarks, Alexa Stirling Putting Challenge, Cocktail Reception at East

Lake Golf Club

Monday, May 19: Bobby Jones Classic for CSF Tournament, Award Dinner

More details to follow For more information, visit www.bobbyjonesclassic.com.