



December 2016

Dear Friends,

With the joy of the holiday season upon us, we can reflect on the extraordinary accomplishments achieved in 2016 by the Chiari & Syringomyelia Foundation. Thanks to you and your generous gifts, CSF attained many of the short term goals we set for 2016, and we have laid the groundwork for many new and exciting long term projects. I'd like to update you on the progress we made this year, as we look forward to an exciting and productive 2017.

CSF continues to raise awareness and in 2016, we held 62 unite@night walks around the country, drawing almost 3,000 participants and raising over \$165,000. A 5K CSF run was held in Las Vegas in June 2016. We also hosted our unite@thehill advocacy event in September, in which letters from families were personally delivered to Congress by CSF staff and volunteers, who met with their congressmen and women to present a message of support for federal research funding and to support the 21<sup>st</sup> Century Cures Act.

CSF continues to hold its four signature fundraising events - our Charity Ball/Casino night in March on Staten Island, the Bobby Jones Classic for CSF Golf Tournament at East Lake Golf Club in Atlanta in May, the Dinner Dance for a Cure in Cleveland in October, and the Night of Light Children's Gala in November. This year we also added a new event in Chicago, the CSF Shine A Light on CSF Dinner Dance, in October.

On the education front, CSF continues to host free educational lectures for patients and physicians. To date, we have hosted 257 lectures, 56 this year alone, at over 100 national and international venues. Each of these lectures is recorded and uploaded to our website. We are very proud to inform you that these videos have been viewed by over 750,000 people in over 90 countries around the world. Regarding our chapters, we now have 37 chapters in 28 states, and we continue to work to grow this number both in the U.S. and internationally.

Regarding our research efforts, we hosted four major medical meetings, the "Think Tank" in Chicago, the CSF Colloquium in San Diego, the Consider Chiari Symposium in Cleveland, and the First Annual Cerebrospinal Fluid Symposium at Brown University. In July of 2017, CSF will host our fourth CSF Hydrodynamics Symposium at Georgia Tech University, featuring 25 speakers from around the world, including engineers, physicists, mathematicians, neuroradiologists, and neurosurgeons.

In addition, we have made tremendous progress with our most ambitious project to date - the International Patient Registry Project, which will enable doctors to better define Chiari malformation, which will lead to better diagnoses, surgical options, instrumentation, and outcomes. This project is entering its 3<sup>rd</sup> year, with CSF staff and members of the CSF SEA Board having published what the NIH calls Common Data Elements (CDEs), Common Data Instruments (CDIs), and Case Report Forms (CRFs) for CM and SM, which, among other things, will provide a universal method for determining the presence of a Chiari,

potentially allowing for more consistent diagnoses. We have collaborated with 37 medical institutions nationally and have representation from 10 countries worldwide. We have begun designing an international database registry using these elements. We received funding from the Robert Wood Johnson Foundation through the PEER (Platform for Engaging Everyone Responsibly) White Label Project to design the initial module, which will launch in January 2017. We will apply for a Patient-Centered Outcomes Research Institute (PCORI) grant for funding, and are also seeking private donors for this most important project.

Finally, we have completed our children's handicap accessible golf cart project with Georgia Tech University, and we have partnered with E-Z Go Corp. to bring this cart to golf courses, to enable children who are handicapped to enjoy the sport of golf. Our first cart was recently delivered to the DiSalvo family of Staten Island, New York.

CSF is proud to be the pre-eminent charitable organization for Chiari malformation, syringomyelia, and related disorders, and we are the only charitable CM, SM and related disorders organization that has met the standards of the Better Business Bureau and the Health on the Net organization, and is a Guidestar Platinum Participant. We are very proud of our progress, which could not have been possible without your support. Thank you!

It's been quite a productive year, as we continue to set our course for the future. Visit our website at [CSFinfo.org](http://CSFinfo.org), click on *Sign Up Now* and we will add you to our mailing and email contact list. You can also keep tabs on all our ongoing research, by visiting our website to watch lectures and annual colloquium proceedings.

***Please consider making your year-end tax-deductible contribution to CSF by donating online at [www.CSFinfo.org](http://www.CSFinfo.org)... just click the DONATE button. If you prefer to mail your gift, please send to:***

Chiari & Syringomyelia Foundation, 69-39 Yellowstone Blvd. # 216, Forest Hills, NY 11375

Thank you so much for your support of CSF! Have a healthy & happy New Year!

Paul J. Farrell



Chairman

