



December 2015

Dear Friends,

With the joy of the holiday season upon us, we can reflect on the extraordinary accomplishments achieved in 2015 by the Chiari & Syringomyelia Foundation. Thanks to you and your generous gifts, CSF attained many of the short term goals we set for 2015, 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 2016.

On the education front, CSF continues to host free educational lectures for patients and physicians. To date, we have hosted over 200 lectures at 25 national and international venues. Each of these lectures are recorded and uploaded to our website. We are very proud to inform you that these videos have been viewed by almost a half million people in over 144 countries around the world. We also hosted two major medical meetings, the "Think Tank" in Washington DC and the CSF Colloquium in New Orleans. From lectures presented at the Colloquium, two books have been published. Regarding our chapters, we now have 30 chapters in 28 states, and we are working to grow this number both in the U.S. and internationally.

CSF continues to raise awareness and in 2015, CSF held 50 unite@night walks around the country, drawing over 2,000 participants and raising over \$120,000. A 5K CSF run is planned for Las Vegas in April 2016. CSF also continues to hold its four signature fundraising events – our Charity Ball/Casino night in March on Staten Island, the Bobby Jones Classic 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.

Regarding our research efforts, in July of this year, CSF hosted the third CSF Hydrodynamics Symposium in Amiens, France, featuring 25 speakers from around the world, including Dr. Thomas Brinker, who was the Keynote Speaker. We have partnered with the Brown University Institute of Brain Science, which received a \$1 million grant for a research project regarding controlling the production of cerebrospinal fluid in the brain, and plans to open a CSF research center. This is under the direction of SEA Board member, Dr. Petra Klinge. Continuing medical education, we also partnered with Johns Hopkins University on a CME Program, headed by SEA Board Vice-Chair Dr. Mark Luciano. We have also partnered with St. Louis Children's Hospital involving a \$2.8 million grant to study Chiari decompression surgeries. This will be conducted at 35 medical institutions and is headed by Dr. David Limbrick, a member of our SEA Board. Dorothy Poppe, CSF's Executive Director, sits on the Board for this project.

In addition, we are very proud to introduce our most ambitious project to date – the International Registry Project, which will enable doctors to better define Chiari malformation, which will lead to better diagnoses, better surgical options, better instrumentation, and better outcomes. This project is in its 2nd year, with CSF staff and members of the CSF SEA Board writing what the NIH calls common data elements (CDEs), common data instruments (CDIs),

and clinical research forms (CRFs) for CM and SM. We have collaborated with 35 medical institutions nationally, and have representation from 10 countries worldwide. The next step is to design an international database registry including these elements. In addition, we are waiting for a (PCORI) Patient Centered Outcomes Research Initiative grant for funding, and we 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, which won first place in the Georgia Tech Capstone Engineering project competition. We are currently meeting with E-Z Go Corp. to bring this cart to golf courses, to enable children who are handicapped to enjoy the sport of golf.

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, the Guidestar Gold Foundation, and the Health on the Net organization. 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, 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... 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

