



*Happy Holidays*

December 2017

Dear Friends,

As 2017 comes to an end, and with the joy of the holiday season upon us, we can reflect on the extraordinary accomplishments achieved this year by the Chiari & Syringomyelia Foundation. Thanks to you and your generous gifts, CSF attained many of the short-term goals we set for 2017, 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 2018.

CSF continues to hold its four signature fundraising events – our Charity Ball/Casino night in March in Staten Island, New York, 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 added two new events: the NYC4CSF event in New York City in July, and the Gin, Jazz & Generosity Casino Night in Naperville, Illinois in September.

Regarding education and awareness, in 2017 we held 56 unite@night walks around the country, drawing almost 1,800 participants and raising over \$130,000. We also hosted our unite@thehill advocacy event in June, in which we marched to Capitol Hill. CSF continues to host free educational lectures for patients and physicians. To date, we have hosted 330 lectures, 72 this year alone, at over 110 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 1.8 million people in 98 countries around the world. Regarding our chapters, we now have 41 chapters in 30 states, and we continue to work to grow this number both in the U.S. and internationally.

On the research front, we again hosted four major medical meetings, the "Think Tank" in Los Angeles, the CSF Colloquium in Boston, the Consider Chiari Symposium at Johns Hopkins, and the Annual Cerebrospinal Fluid Symposium at Brown University. In addition, in July of 2017, CSF hosted our fourth CSF Hydrodynamics Symposium at Georgia Institute of Technology, featuring 25 speakers from around the world, including engineers, physicists, mathematicians, neuroradiologists, and neurosurgeons.

In addition, we have made significant progress with our most ambitious project to date – the International Patient Registry Project, which will enable doctors to better define Chiari malformation, and will provide a universal method for determining the presence of a Chiari malformation, potentially allowing for more consistent diagnoses. Through the PEER (Platform for Engaging Everyone Responsibly) White Label Project, the registry was soft-launched earlier

this year and with no formal introduction by email or other means, already has 29 respondents with the current surveys at 70% completion. We have collaborated with 37 medical institutions nationally and have representation from ten countries worldwide. We hope that when the registry is fully rolled out, there will be significant participation. Each registry survey has been (and will continue to be) translated into at least seven languages (Spanish, French, German, Italian, Chinese, Japanese and now Russian) to facilitate international participation and cultural competency of research participants.

In conjunction with the registry project, CSF worked for over two years developing Common Data Elements (CDEs), which have been submitted to the NIH via the NINDS for Chiari I malformation (and syringomyelia). These were published on the NINDS CDE website late last year. There will be an ongoing committee (formed by the NINDS, not CSF) that re-evaluates these CDEs on an annual basis. CSF will remain tangentially involved, recommending CDEs, as further research is performed and new concepts develop. Recommendations will come from CSF research meetings such as the Think Tank and the Colloquium.

Finally, as we reported to you last year, we have completed our children's handicap accessible golf cart project with Georgia Tech, and we have partnered with E-Z-GO to bring this cart to golf courses, to enable children who are handicapped to enjoy the sport of golf. We have received word from the U.S. Patent and Trademark Office that our design will be granted a U.S. Patent, and we are continuing our efforts to place these carts with children and adults who need them.

CSF is proud to be the pre-eminent charitable organization for Chiari malformation, syringomyelia, and related disorders, and 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 use the enclosed envelope and 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