



December 2009

Dear Friends,

At this joyous time of year, we reflect on the many blessings 2009 held for the Chiari & Syringomyelia Foundation. Thanks to you and your generous gifts, we accomplished many short term goals in 2009, established the framework for many exciting long term projects, and now we look forward to a fruitful and productive 2010. CSF is comprised of many dedicated and exceptionally goal-oriented people who are committed to seeing our vision of finding a cure for CM and SM become a reality. I'd like to update you on the progress we made in 2009.

Regarding our fundraising efforts, our core events continue to provide us with the needed revenue to continue on to our goals, even in these difficult economic times. Your continued generosity is inspiring!

Our second annual *Charity Ball*, held on March 28, in Staten Island, New York, was a huge success, and on September 13, our second *Race for the Cure* at the Arlington Park Race Course near Chicago generated more excitement, awareness and funds. These two events raised over \$265,000. September 21 also marked our second *Conquer for Kaya Golf Tournament* in San Antonio, Texas, hosted by the Culver family, which raised money for research, and on September 12, the *Motorcycle Ride For A Cure* took place in Utica, New York. This is the second year that Board of Directors member-elect Jim Feisthamel and his wife Mary Ellen have hosted this event to benefit CSF. The Feisthamel's also hosted the first CSF *Valentine's Day Dinner Dance* in Utica on February 14, and on October 10, an Education & Awareness event was held for the first time in Little Rock, Arkansas, at an *Autumn BBQ* party hosted by Ed and Richelle Daniel.

Our Strategic Planning meetings in 2008 have truly paid off. We are extremely proud to announce the appointment of our newest Board of Trustees members, Dr. Simon J. Archibald, Chief Scientific Officer, Integra LifeSciences Corporation; Dr. Richard E. Kuntz, Sr. Vice President and President, Medtronic Neuromodulation; and Dr. Sean Lilienfeld, Vice President Clinical Research & Medical Affairs, Codman & Shurtleff, Inc. This partnership with industry leaders will provide additional intellectual and business capital that are "priceless!" Please review their bios on our website, www.CSFinfo.org.

At the end of last year, our "wish list" included establishing our first CSF chapters, completing a series of informational and educational DVDs, taking our cause to the National Institutes of Health, and laying the groundwork for our most ambitious project yet, a

spectacular Pro-Am golf tournament to be held in the Atlanta area, the *Bobby Jones Classic for CSF*. I am pleased to report that we made exceptional progress on each of these goals.

Through the comprehensive and tireless work of Jennifer Cleary, Board of Directors member Cathy Poznik, Bryan Downey, Andrea Grosz and Dorothy Poppe, I am proud to announce the incorporation of our first four CSF chapters, located in Cleveland, Denver, Utica and Washington, DC. Our Education and Awareness series has already directly impacted over 250 families this year and included respected keynote speakers Dr. John Heiss, Dr. Fraser Henderson, Dr. Mark Luciano, and Dr. John Oro'. CSF's plans include opening additional chapters in 2010 in Chicago, Washington State, Pittsburgh, and the Carolinas.

Earlier this year, we completed the filming and editing of a new set of nine educational and informational videos, which were made possible by a very generous gift from the Jordan Family Foundation, through Board of Trustees member Burt Jordan. Special thanks to our Emmy award winning video team, Bob Bagley and Sterling Johnson, for their efforts in bringing this project to completion. You can view these videos on our website.

In July, Dorothy Poppe, Board of Directors member Lory Watson and I met with representatives of the National Institute of Neurological Disorders and Stroke in Bethesda, Maryland to discuss the procedures for receiving funding for NIH sponsored research into CM and SM. We will continue to pursue this valuable resource on May 1, 2010 with a "Think Tank Meeting" of our Medical Research Board, scientists, Board of Directors, Board of Trustees and the NIH.

This year, CSF, in collaboration with the Monkton Institute, is sponsoring a Research Fellow from the Congress of Neurological Surgeons. Research is a priority for our organization and CSF is in the planning stages of an International Engineering Symposium under the guidance of Dr. Frank Loth, to be held in Switzerland in 2011 to further cooperation on current research.

Finally, it is with great pleasure that I introduce the *Bobby Jones Classic for CSF*, tentatively scheduled for April 2011. We have partnered with Peter Jacobsen Sports, a full-service sports and entertainment marketing firm that specializes in golf tournaments involving professional golfers to benefit charitable organizations such as CSF. This tournament is only made possible with the blessing of the Jones family - in particular Board of Trustees member Bob Jones IV, grandson of the legendary golfer, and by the driving force behind the event, Board of Directors member Steve Kragrud. Please continue to visit our website for important updates on this groundbreaking event.

It's been quite a productive year, as we continue to build a solid foundation and set our course for the future. Join the CSF community and stay up-to-date on upcoming news and events with periodic email updates. Just visit our website at www.CSFinfo.org, click on *Sign Up Now* on the left side of the site, update all of your information, and we will add you to our email contact list.

And please consider making your year-end tax deductible contribution to CSF by donating online at www.CSFinfo.org. Just click the *Donate Now* button and fill out the form. 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

A handwritten signature in black ink that reads "Paul J. Farrell". The signature is written in a cursive style with a large, prominent initial "P".

Chairman