

3RD ANNUAL CHARITY BALL - SAVE THE DATE

Join us on Saturday, March 13, 2010 at the Hilton Garden Inn, Staten Island, NY for a fabulous evening of dinner, dancing and auction, as we honor **Dr. Edward C. Benzel**, Chairman, Department of Neurosurgery and Director, Center for Spine Health, at the Cleveland Clinic and member of the CSF Medical Research Board.

Formal invitations will be mailed in January 2010.

Visit our [website](#) for more information, if you are interested in sponsoring this event or advertising in the Charity Ball journal. If you would like to be on a Charity Ball committee, please [contact us](#).

WELCOME TO CSF'S NEW BOARD OF TRUSTEES MEMBERS



We would like to extend a warm welcome to CSF's new Board of Trustees members, **Simon J. Archibald, PhD**, Chief Scientific Officer and Vice President Clinical Affairs at Integra LifeSciences Corporation; **Richard E. Kuntz, MD**, Senior Vice President of Medtronic, Inc. and President of Medtronic Neuromodulation; and **Sean Lilienfeld, MD**, Vice President, Clinical Research & Medical Affairs at Codman & Shurtleff, Inc, and at DePuy Mitek, which are Johnson & Johnson companies.

CSF SPONSORED FELLOWSHIP

CSF, along with the Congress of Neurological Surgeons (CNS), is sponsoring a \$10,000 Monkton Institute Fellowship. The CNS/Chiari & Syringomyelia Foundation and Monkton Institute Fellowship is meant to assist neurosurgeons in the clinical investigation or basic science research of Chiari malformation, syringomyelia and related disorders.

Sponsored fellowship awards represent a strategic investment by the Congress of Neurological Surgeons on behalf of the field of Neurosurgery. The Congress of Neurological Surgeons offers several fellowship awards for residents, neurosurgeons who have recently completed training, and established neurosurgeons alike. The awards are meant to defer some of the costs fellows incur during their research and studies and to enhance the education of neurological surgeons at all stages of their careers.

Visit the [CSF website](#) to link to the list of 2010-2011 CNS Fellowships.

CSF CHAPTER NEWS

Cleveland Chapter

November 4 Educational Lecture

On Nov. 4, more than 50 people attended the first educational lecture at the Cleveland Clinic Main Campus with doctors, patients and caregivers. Dr. Mark Luciano, MD, PhD from the Cleveland Clinic was the keynote speaker. His topic, "Chiari: Are Children Just Little Adults?" was very informative. Dr. Luciano is board-certified in general neurosurgery and in pediatric neurosurgery. He is Head of Congenital and Pediatric Neurosurgery and Co-Director of the Pediatric Neurology Center at Cleveland Clinic. His patients are children and adults with neurological congenital anomalies, hydrocephalus, cerebral cysts, tumors, craniofacial anomalies, tethered cord, Chiari malformation and cerebral palsy.

In addition to hearing Dr. Luciano's lecture, audience members also viewed the latest CSF DVD, *Can You Spell That for Me?* and their responses to the film were positive.

This marks the first educational lecture for the CSF Cleveland Chapter. The next lecture will be held on February 24, 2010 and Dr. Edward C. Benzel, M.D. will be the keynote speaker. Dr. Benzel is Chairman, Department of Neurosurgery and Director, Center for Spine Health, at the Cleveland Clinic. We look forward to seeing you there.

For more information about upcoming events or to register, please visit the CSF [Cleveland Chapter page](#).

November 18 Hour of Hope



Dr. Frank Loth from the University of Akron was the keynote speaker at the Chiari & Syringomyelia Foundation's Hour of Hope on November 18. Dr. Loth engaged the audience with a presentation about Chiari & syringomyelia, including an update on CM and SM research. In addition, there were individual presentations by graduate students who work with Dr. Loth - Dipankar Biswas, George Poppe, and Nick Shaffer. The three young men discussed their research projects. Dr. Mark Luciano and Dr. Ed Benzel, both from the Cleveland Clinic, were also able to join us this year.

We are happy to have raised over \$11,000 this year, with 125 people in attendance. 2009 is the fifth year that this event has taken place and, once again, it was held at the Hilton Garden Inn in Twinsburg, Ohio. Event sponsors included Key Bank and Porter Wright Morris & Arthur. We are also grateful for the support that we received from the Twinsburg Hilton Garden Inn, Twinsburg AC Soccer, Twinsburg High School Staff, Twinsburg Dairy Queen and Client Strategy Group.



Dorothy Poppe, CSF's Executive Director welcomed everyone to the Hour of Hope. Calvin Poznik, age 15, gave a touching discussion as he spoke about what it's like to live with CM & SM on an everyday basis. He talked about how he never knows when CM & SM will get in the way of his plans, that he has had to deal with head pain 24/7 for over 8 years now, and that he actually was fighting for his life in August of this year when a stent blocked up and shut down

his system.

We welcomed back many familiar faces and we were happy to see some new ones. Jake Nees, now an 8th grader at Chamberlin Middle School, was back for his 5th event and he, once again, made a \$100 donation out of his own allowance. We also appreciate the support from some of our other young kids in attendance including Matt Andrews and Sean Clunn.

Thanks to everyone who attended and to all those, without whose support and dedication, an event like this would never be possible.

Greater Metropolitan Washington Area Chapter

Join us at the next meeting on Tuesday, January 19, 2010 at 6:30pm

Expert Speaker: Dr. Clare Francomano (Harvey Institute for Human Genetics at Greater Baltimore Medical Center)

Doctors Community Hospital
8118 Good Luck Rd, Ambulatory Surgery Building, DSE Room, Fifth Floor
Lanham, Maryland

Light refreshments will be served

For more information and to register, visit the [Greater Metropolitan Washington Area Chapter page](#) on the CSF website.

Utica Chapter

Valentine's Day Dinner Dance
Saturday, February 13, 2010
Radisson Hotel, 200 Genesee Street, Utica, New York

For more information about the Dinner Dance, contact James or Mary Ellen Feisthamel at 315-793-8823.

LETTER FROM THE CHAIRMAN

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!" Click [here](#) to read Board of Trustees member bios.

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

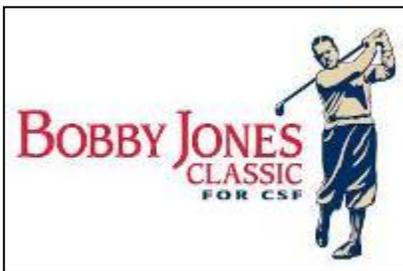
plans include opening additional chapters in 2010 in Chicago, Washington State, Pittsburgh, and the Carolinas.

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. View our [Awareness video](#) page.

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. Read CSF [Advocacy News](#).



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, click on [Sign Up Now](#), add or update your information, and you will receive the CSF eNewsletter.

And please consider making your year-end tax deductible contribution to CSF. [Donate now online](#).

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

Paul J. Farrell
Chairman