

### ANNUAL FUND DRIVE

By now you should have received your Annual Fund mailing. CSF thanks you for your continued support and we hope that you consider making a gift to this critical fundraising effort. Your gift can provide hope to those living with Chiari malformation and syringomyelia. There is so much to be done, and your gift will really make a difference.

Make your donation online at [www.CSFinfo.org](http://www.CSFinfo.org) and let's all work together to find a cure!

### 3<sup>RD</sup> ANNUAL CHARITY BALL A SUCCESS!

Two hundred people attended the 3<sup>rd</sup> Annual Charity Ball on March 13, helping CSF to gross almost \$100,000! We are grateful to our loyal supporters who, despite terrible weather and a slumping economy, came to show their dedication to our organization and its mission. Guests included more than 40 physicians from North Shore /LIJ Health System, Staten Island University Hospital, Long Island Veterinary Specialists, Doctors Community Hospital, Greenwich Hospital, and Cleveland Clinic.

Thanks to the Steering Committee members, Denise Aversano, Bob Rumphrey, Paul Farrell, and Dorothy Poppe, for all of their hard work and a special thank you to Denise for singlehandedly coordinating and preparing the Charity Ball raffle. Thank you also to our Charity Ball sponsors and to all the volunteers who help to make this a wonderful evening, year after year.

#### **Charity Ball Sponsors:**

Dr. and Mrs. Edward C. Benzel	Integra Foundation
Central National-Gottesman Foundation	Long Island Veterinary Specialists
The Cleary Family	Medtronic's Spinal & Biologics Business
Codman	North Shore/LIJ Health System
DLI Investments	Bob and Toni Rumphrey
The Farrell Family	Staten Island University Hospital
The Farrell Law Firm, LLP	

### **3<sup>rd</sup> ANNUAL CHARITY BALL A SUCCESS! (continued)**

#### **The Wind Was Blowing, But The Stars Still Shined...**

**By Sabrina Stabile** (*Charity Ball guest*)

#### **Despite monsoon-like weather, the 3<sup>rd</sup> Annual CSF Charity Ball and Silent Auction was a complete and utter success with a full house.**

There aren't many things I could do to help myself living with Chiari Malformation, but finding the Chiari & Syringomyelia Foundation may be the most important thing I could do at this point. I know that the medical world is not quite ready or prepared to deal with certain neurological issues such as mine; there simply isn't enough medical knowledge. I wouldn't say it's incurable, but the cure hasn't been found yet. Living with a "less known about" illness is life shattering, but when one aspect of your life is falling apart, you must compensate in other areas of your life. I find it spiritually uplifting to know and to see in action people's charitable ways; it gives me hope, especially with misunderstood illnesses. I have never been a selfish person, although this medical ailment can change perspective. Nevertheless, it does give me peace of mind to realize that people in the future, children and adults alike, may not have to suffer with what I go through daily, because of our efforts today. My son has juvenile diabetes, and I am so grateful to unnamed people from a century ago who did what CSF is doing now for these uncured conditions.

March 13, 2010 was a magical night. The goal of the night was awareness, and CSF met that goal. The venue and food was phenomenal, but better than that...even though the weather was atrocious, the turnout was outstanding – a full house. So many people donated time, money, and most of all, effort for months, yet the atmosphere was relaxing. I actually forgot I was a patient for most of the night. I sat with and was able to meet another Chiarian and her family. They are very nice people who, unfortunately, suffer as I do. Of course, the night was bittersweet. There was a remembrance for "Boots" Matelski, who recently passed away. Although it was upsetting, I was glad that the night's honoree, Dr. Edward Benzel, coined her the Chiari and Syringomyelia "athlete" for her perseverance and positive attitude, traits so many of us have to learn to acquire. Events like these are essential to meeting our ultimate goal – a cure. Without the neurosurgeons in the world that are willing to push the envelope, that goal may never be reached.

Thank you CSF!

## CSF STORE

Jim and Mary Ellen Feisthamel, CSF Utica Chapter Chairpersons, have set up their own merchandise fundraiser, The CSF Store, with a great selection of items featuring the CSF logo. All proceeds will benefit CSF.

In 2005, their only child, Megan, was diagnosed with Chiari malformation and has undergone two decompression brain surgeries with minimal relief. Jim and Mary Ellen have vowed to raise as much awareness and money as possible.

*“We love our daughter Megan and would do anything for her. The one thing we cannot do is stop her pain. No one should suffer in pain every day. We need to find a cure so that someday every child and adult can live a happy, healthy, productive life. This is our goal. If you would like to speak with us to talk or for assistance, please call us at 315-793-8823.”*

**Visit the CSF Store**

## CSF CHAPTERS

### **Utica, New York Chapter:**

#### **Valentine’s Day Dinner Dance**

Thank you to Mary Ellen and Jim Feisthamel, CSF’s Utica, New York Chapter Chairpersons for, once again, coordinating the Valentine’s Day Dinner Dance. Guests enjoyed a delicious cocktail hour, dinner, and dancing. Almost \$5,500 was raised for CSF!

**Save the Date! 5<sup>th</sup> Annual Benefit and Motorcycle Ride to Help Find a Cure for Chiari Malformation and Syringomyelia.** This annual event will be held on Saturday, August 21 in Upstate, New York. More information coming soon.

### **Greater Metropolitan Washington Area Chapter:**

The next educational meeting will take place on Tuesday, April 20<sup>th</sup> at Doctors Community Hospital in Lanham, Maryland. Dr. Robert Gerwin, Associate Professor at Johns Hopkins University, will be presenting and the topic will be “Pain Syndromes Associated with Chiari Malformation.” For more information, please visit our **Greater Metropolitan Washington Area Chapter page**.

## CSF CHAPTERS (continued)

### **Western Pennsylvania Chapter:**

If you live in Western Pennsylvania and are interested in becoming involved with a CSF Chapter in that area, please send your name, phone number, and email address to [info@CSFinfo.org](mailto:info@CSFinfo.org) and we will be in touch to discuss details.

If you are interested in attending an upcoming Chiari “Meet and Greet” in the Western Pennsylvania area, contact **Brandi Lipford**.

## 3<sup>RD</sup> ANNUAL RACE FOR THE CURE – SAVE THE DATE

Join us for an afternoon at the Arlington Park Race Course on Sunday, September 12, 2010 with good food and good friends, all for a good cause. Invitations will be mailed this summer. We hope you consider joining us for this fabulous event.

## CSF STRATEGIC PLAN THINK TANK MEETING

Members of the CSF Medical Research Board, Board of Directors and staff will attend the annual CSF strategic plan meeting, in conjunction with the American Association of Neurological Surgeons annual meeting, on May 1, 2010. The meeting agenda includes discussions on our continuing work with the NIH, an expansion of regional CSF chapters and lectures, and plans for an international gala in Washington DC in the Fall of 2010, along with the Bobby Jones Classic for CSF Golf Tournament in the Spring of 2011.

These annual “think tank” meetings are designed to chart the course for CSF’s future, bringing together some of the best minds in the business and medical communities.

## CONQUER CHIARI RESEARCH CONFERENCE

Building on the success of past conferences, CSF has partnered with Conquer Chiari, the University of Akron, and the University of Illinois-Chicago, which are organizing a two-day professional research conference to focus on new developments in Chiari research and to discuss controversies in diagnosis and care. The event, on November 11-12, 2010 at the Hyatt Regency O’Hare in Chicago, Illinois, will bring together the top physicians and researchers involved with Chiari malformation to share recent developments, discuss and debate controversial topics, and foster collaboration for future work. The proceedings will be made freely available to the Chiari community through a video web archive.