

### **PARTICIPATE IN A DUKE CENTER FOR HUMAN GENETICS STUDY**

#### ***GENETICS OF CHIARI TYPE I MALFORMATION***

The Duke Center for Human Genetics is actively recruiting families who have TWO OR MORE family members with Chiari type I malformations (CMI), with or without syringomyelia. These family members must be related to each other by blood, and BOTH must be willing to participate. Our work is centered on determining whether or not there is a genetic cause to the development of CMI. Hopefully in the future this will lead to better ways to diagnose and treat CMI. If your family meets these criteria and wants to receive information on how to participate in this confidential study, please [email the study coordinator](#) or call 1-877-825-1694.

### **THIRD ANNUAL ARLINGTON RACE FOR THE CURE**

Join us at the Arlington Park Race Course in Arlington Heights, Illinois for the third annual Race for the Cure. Enjoy an afternoon of great food and good friends as we watch the exciting horse races and bid on fabulous silent auction items.

#### **[2010 Race for the Cure Sponsorship Opportunities](#)**

#### **[2010 Race for the Cure Invitation](#)**

#### **[2010 Race for the Cure Reply Card](#)**

***Some of the great silent and live auction items which will be available at this year's Race for the Cure:***

- **Golf Club foursome packages at golf clubs such as Barrington Hills Country Club, Chicago Golf Club, and Hawthorne Woods Golf Club**
- **Caddy for PGA golf pro Peter Jacobsen**
- **Two week-long credentials to 2011 US Open Golf Championships in Bethesda, Maryland. Includes AirTran vouchers and hotel accommodations.**
- **Set of Callaway golf clubs**
- **Chicago White Sox suite tickets**
- **United Center skybox tickets**

**THIRD ANNUAL ARLINGTON RACE FOR THE CURE (cont.)**

- **Bobby Jones Classic Gala tickets**
- **Party for 100 at Blackfinn American Saloon in Naperville, Illinois**
- **Jewelry and luxurious furs & leather coats**

**Chicago Blackhawks 2010 Stanley Cup champions signed red jersey** - This item is framed and matted with a certificate of authenticity. The Blackhawks have not won the Stanley Cup since 1961. This jersey is difficult to obtain since six of the players are now with other hockey teams. A real collector's item!

**Chicago Blackhawks 2010 Stanley Cup champions signed white jersey**

**U2 and Bono autographed guitar** - Outstanding group with world wide popularity. Bono is a great humanitarian throughout the world

**Joe DiMaggio and Muhammad Ali autographed photograph** - The Yankee Clipper and the Greatest shaking hands. Two icons in their respective sports. Limited edition item! This framed photograph is #3 of only seven such items.

**College jerseys signed by Larry Bird, Magic Johnson, and Michael Jordan** - All three jerseys are framed together with signatures of three of the top players of the last 40 years. Magic Johnson's Michigan State jersey, Michael Jordan's North Carolina jersey, and Larry Bird's Indiana State jersey. These players are NBA All-Stars, NBA champions, and USA Olympic team players.

**Movie collage from the Wizard of Oz** - Movie photographs with actual autographs from the following stars: Judy Garland (Dorothy), Bert Lahr (Lion), Jack Haley (Tin Man), Ray Bolger (Scarecrow), Billie Burke (Glenda the Good Witch). A very unique item that will only increase in value.

## **URGENT ACTION NEEDED!**



*"I need to alert our most compassionate donors of a serious situation: The current recession has resulted in a serious decline in the number of people who can support charitable Organizations such as CSF. But the need for research funding continues.*

*By conservative estimates, the number of people in the U.S. who are affected by Chiari (CM) and syringomyelia (SM) is 300,000 and the number continues to rise. Many live with daily pain. Many are children who miss countless days and weeks of school and just want to live a "normal" life – playing with friends, participating in sports. So many struggle to find answers when all they have are questions and frustration.*

*Your immediate help is critically needed."*

*--Dorothy Poppe, CSF Executive Director*

Read more about the Hazlett family (*pictured above*) in the Research Drive package arriving soon in your mailbox. Help us keep fighting the fight against CM and SM.

**Donate to the Research Drive [online!](#)**

### **FOURTH ANNUAL CHARITY BALL HONORING DR. DOMINIC MARINO**

Join us as we honor Dr. Dominic J. Marino, Chairman of the Department of Surgery and Chief of Staff of Long Island Veterinary Specialists, an internationally recognized veterinary specialty center with a staff of over 180. Dr. Marino is a member of the CSF Medical Research Board and has pioneered cutting edge operative techniques on dogs with Chiari-like malformation. His canine research focus will lead to a better understanding of Chiari and syringomyelia in humans and will hopefully lead to better surgical outcomes in children and puppies.

Click here for [Sponsorship](#) and [Journal advertising](#) opportunities.

### **NEW CSF CAROLINAS CHAPTER**

CSF has established a Carolinas Chapter at Duke University, in North Carolina. The official Chapter kick-off will take place in October 2010, in conjunction with the dedication of a memorial garden in honor of Dr. Marcy Speer. Dr. Speer's contributions as a Duke University scientist dramatically advanced our understanding of Chiari and syringomyelia.

Dr. Speer spent nearly 15 years establishing a genetic repository in order to identify specific genes associated with risk for developing Chiari. Her patient population remains one of the few Chiari genetic data sets in the entire world. In fact, she published the first genetic screen on Chiari malformation which identified several chromosomal regions that contain genes implicated in the development of Chiari. She was internationally recognized as an expert in the syndrome. On August 4, 2007, Dr. Speer lost her valiant fight with cancer.

**Thank you to the Carolinas Chapter Chair, Shannon Clarke, and the Chapter Founders** - Dr. Allison Ashley – Koch, Dr. Herbert Fuchs, Dr. Gerald Grant, Shannon Clarke, Mr. & Mrs. Shane Gray, Candace Morse, Lisa Mathis, and Mackenzie Mathis

*Pictured above in front of the Marcy Carlson Speer memorial stone: Shannon Clarke, Candace Morse, Shane Gray, and Dr. Allison Ashley-Koch*

### CSF AT THE HAMPTON CLASSIC

CSF will be at the 35<sup>th</sup> Hampton Classic Horse Show, in Bridgehampton, New York, to exhibit and present information. Join us on Sunday, August 29 and Monday, August 30, in conjunction with Long Island Veterinary Specialists and Dr. Dominic Marino, member of the CSF Medical Research Board.

The Hampton Classic features world-class hunter, equitation, and show jumping competition.

Visit [www.hamptonclassic.com](http://www.hamptonclassic.com) for more information.

### CSF HYDRODYNAMICS SYMPOSIUM

This symposium will take place on July 1 and 2, 2011 at the Swiss Federal Institute of Technology (ETH Zurich) in Zurich, Switzerland and is organized by Dr. Frank Loth (University of Akron), Dr. Dimos Poulidakos (ETH Zurich), and Dr. Vartan Kurtcuoglu (ETH Zurich)

This will be an engineering/physics focused symposium on the motion of cerebrospinal fluid (CSF). Approximately 20-30 invited speakers from around the world will speak about their research that involves either experiments or computational methods to better understand diseases related to cerebrospinal fluid motion such as hydrocephalus, Chiari malformation, and syringomyelia

*This month's featured symposium organizer: Prof. Dr. Dimos Poulidakos*

Dr. Poulidakos received his degree in 1978 in mechanical engineering from the National Technical University, Athens, and studied at the University of Colorado at Boulder where he earned his M.S. in 1980 and his Ph.D. in mechanical engineering in 1983. Before joining ETH Zurich, he was full professor of mechanical engineering at the University of Illinois at Chicago. He received numerous awards including the White House/NSF Presidential Young Investigator Award in 1985 and the

**CSF HYDRODYNAMICS SYMPOSIUM (cont.)**

James H. Potter Gold Medal in Thermodynamics in 2000. He is the editor in chief of the Journal of Experimental Heat Transfer and an editor of several other journals.

For more information or to register, please contact Administrative Co-Director, Anita Savage at (301) 654-9390.

**NORTHWEST REGIONAL CHAPTER**

**WEDNESDAY, SEPTEMBER 22, 2010 - 6:00pm**

Harborview Medical Center, Research & Training Building, 300 Ninth Avenue - Room: R&T 121, Seattle, WA, 98104

**Expert Speaker: Dr. Richard Ellenbogen**, University of Washington-Dept of Neurological Surgery, Harborview Medical Center, Seattle Children's Hospital

**Topic: Questions You Were Afraid To Ask About Chiari and Syringomyelia.**

This program will focus on the various types of treatments, failed treatments and pain (such as chronic, acute, neuropathic, somatic, depression), their relationship to each other and their implications for treatment.

Space is limited so register early. And bring a family member or friend!

To register or to receive more information, please contact [Sheena LaShomb](#) via email or call Sheena at 253-278-7378 or Dorothy Poppe at 718-966-2593.



**CSF CHAPTERS – GET INVOLVED!**

CSF has established Chapters in Cleveland, Ohio, Denver, Colorado, Washington DC, Utica, New York, and North Carolina. If you live in any of these regional areas and would like to be involved in a CSF chapter, please contact [Cathy Poznik](#) for more information.

**HELPFUL LINK**

**Patient AirLift Services (PALS):** This 501(c)(3) organization arranges FREE flights for individuals in need of medical diagnosis and treatment. Visit their website at [www.palservices.org/](http://www.palservices.org/).