

## COUNTDOWN TO THE RACE FOR THE CURE



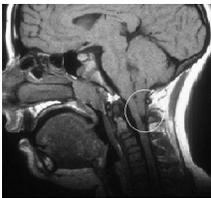
The Third Annual Race for the Cure at the Arlington Park Race Course in Arlington Heights, Illinois is fast approaching. Be a part of this exciting event and join us on Sunday, September 12. Enjoy a delicious lunch, open bar, and silent auction. Formal invitations will be mailed this month or you can access the invitation on our website. If you are unable to attend, please consider making a donation online.

We are seeking items for the Race for the Cure silent auction such as jewelry, artwork, trips, and gift certificates. If you or your employer is able to donate an item for the event, please contact us.

### Event Sponsorships Are Available

See you at the races!

## RESEARCH UPDATE



CSF is planning the 1<sup>st</sup> CSF International Hydrodynamics Symposium to be held in Switzerland on July 1<sup>st</sup> and 2<sup>nd</sup>, 2011 at the Swiss Federal Institute of Technology in Zurich (ETH). 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 symposium is being organized by Dr. Frank Loth (University of Akron), Dr. Dimos Poulidakos (ETH), and Dr. Vartan Kurtcuoglu (ETH).

In the coming months, we will be featuring the biography of each of the symposium organizers. Look for the first one coming next month.

## **TWO NEW CSF CHAPTERS BEING FORMED**

CSF is in the process of forming the Southeast Regional Chapter at Duke University and the Northwest Regional Chapter at the University of Washington/Seattle Children's Hospital. Thank you to Dr. Allison Ashley-Koch and Dr. Rich Ellenbogen and for lending their expertise in helping to organize these chapters.

**More details to be announced**

## **GREATER METROPOLITAN WASHINGTON AREA CHAPTER NEWS**

**Next Education and Awareness Event:**

**Tuesday, July 20 - 6:30pm**



**Expert Speaker: Dr. Riad Dakheel, Pulmonary Disease, Sleep Specialist, Doctors Community Hospital, Lanham, MD**

**Topic: Sleep Disturbances in Chiari Malformation**

Professional Office Building  
8116 Good Luck Rd  
Ground Floor Conference Room

Lanham, Maryland

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

Space is limited so please register soon. And bring a family member!

**Next Support Group Meeting:**

**Wednesday, August 11 – 6:30pm**

Professional Office Building  
8116 Good Luck Road  
Ground Floor Conference Room  
Lanham, Maryland

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

## UTICA CHAPTER NEWS



### Next Fundraising Event:

**5th Annual Benefit and Motorcycle Ride to Help Find a Cure for Chiari Malformation and Syringomyelia**

**Saturday, August 21, 2010 - 2pm - 6pm**

Midstate-Marcy QWL Building  
(At the intersection of Rt. 291 and Fox Road)  
Marcy, New York

### ***Event Information:***

Food, drinks, beer, raffles, Chinese auction, sports memorabilia

Door Prize - Apple iPod Touch - Magic Show by "Magic Bill" - Live Music by "Sour Mash" blues band

This year's honoree is Justin Blinn.

Donation: \$20 per person; Kids under 10 years old are free

This benefit will be preceded by a motorcycle and classic car run of approximately 115 miles.

Registration is from 8am-10:30am on August 21.

Ride starts at 10:45am and will begin and end at the Midstate-Marcy QWL Building (Fox Road, Marcy, NY 13403)

### **For tickets, please contact:**

Jim Feisthamel 315-793-8823  
Becky Thompson 315-542-3845  
Jim Thompson 315-542-3459  
Jerry Hitchcock 315-336-1673  
Krissann Lozipone 315-750-6368  
Bob Tenbrink 315-269-5005

## CLEVELAND CHAPTER NEWS

### Education and Awareness Event Recap:

Dr. Ed Benzel, Dr. Judith Scheman and Dr. Ed Covington spoke at the June 23<sup>rd</sup> Education and Awareness Event held in the Bunts Auditorium at the Cleveland Clinic. The physicians spoke on the topic of “Chiari and Syringomyelia: The Many Faces of Pain”. Dr. Benzel discussed Chiari malformation, syringomyelia, and pain specifically associated with these disorders; Dr. Scheman spoke about Chiari malformation, fibromyalgia and overlapping symptoms; and Dr. Covington discussed the mechanisms for pain, how pain is perceived in your body, and alternative methods to deal with pain.

This engaging panel discussion will be broadcast on our website, so CSF can educate not only those in attendance, but also anyone interested in viewing the meeting can do so online.

**Coming Soon! Be sure to check out the CSF website to view the panel discussion.**



**About Dr. Scheman:** Judith Scheman, PhD, is a psychologist at the Cleveland Clinic's Department of Psychiatry and Psychology, Section of Pain Management. Dr. Scheman specializes in chronic pain rehabilitation. Dr. Scheman graduated Cum Laude, with honors in psychology, at the University of Washington, Seattle, WA. She earned an MA and PhD at Kent State University, Kent, OH.

Dr. Scheman is a member of the American Psychological Association and American Pain Society. She is the author of several articles and has presented at many national and international conferences.



**About Dr. Covington:** Edward Covington, MD, was trained in psychiatry at the Mayo Clinic. He is certified by the American Board of Psychiatry and Neurology in psychiatry, with added qualifications in addiction psychiatry and pain management. He is also certified by the American Board of Pain Medicine.

Dr. Covington founded the Chronic Pain Rehabilitation Program at Cleveland Clinic in 1979 and has served as its Director since that time. He developed a hospital pain consultation service for the diagnosis and management of problematic acute, chronic and malignant pain.

Dr. Covington has published articles and chapters on subjects related to the psychology, physiology and pharmacology of chronic pain. He is a reviewer for the *Clinical Journal of Pain*, and a member of the Editorial Review Board for Pain Medicine and lectures nationally and internationally on subjects related to chronic pain.

He has been active in medical organizations and served as President of the Ohio Psychiatric Association and the American Academy of Pain Medicine. He serves as Secretary of the American Board of Pain Medicine and is a longtime member of the Board of Directors of the American Chronic Pain Association.

*Covington, 56, is helping to pioneer a more comprehensive - and, experts say, effective - approach. "Ed is a leader in his field," says Dr. Jeffrey D. Rome, Medical Director of Pain Rehabilitation at the Mayo Clinic in Rochester, Minn.*

*The Cleveland program is one of a handful in the U.S. that attack intractable pain not only with carefully calibrated pharmaceuticals but also with exercise, biofeedback, self-hypnosis, psychological counseling and family therapy. That regimen is based on a growing body of research showing that pain is "intensely affected by emotions, fears and beliefs," says Covington, and that treating it as a mere symptom is not always enough. In chronic cases, says Covington, pain can cause permanent neurological changes. "Pain becomes an evolving, perpetuating problem," he explains. "A disease."*

## THE CSF STORE



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

*"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."*

## DONATE TO CSF THROUGH YOUR LOCAL UNITED WAY



If you participate in a United Way giving campaign that allows donor designations, you may be able to select CSF as the beneficiary of your United Way gifts. If CSF is not listed as a member agency, please contact the campaign coordinator to see if you can write in CSF to be considered for your gift. If you are able to write CSF in as your choice, please use our complete, spelled-out name (Chiari & Syringomyelia Foundation) and provide the following information: CSF's address (29 Crest Loop, Staten Island, NY 10312) and federal tax-identification number (26-1316274). As procedures do vary with each local or regional campaign, please verify that you have completed your designation correctly.