

CSF CLEVELAND CHAPTER MEETING

Speaker: Dr. Mark Luciano, MD, PhD - Cleveland Clinic



Topic: "Chiari: Are children just little adults?"

Join us for this free education and awareness program which is designed to educate and inspire physicians and healthcare providers; patients, their friends and family; and the public about CM and SM and encourage them to become advocates for CSF.

Date: Wednesday, November 4, 2009

Time: 6:30pm-8:30pm

Location: Cleveland Clinic Main Campus, Bunts Auditorium (TT Building, located on E. 90th Street between Carnegie and Euclid), Cleveland, Ohio. Parking available in Lot #4

Please reserve your place by contacting Cathy Poznik at cpoznik@CSFinfo.org or 330-425-8476.

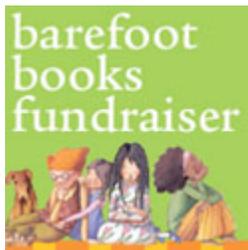
About Dr. Luciano: Dr. Mark Luciano is board-certified in general neurosurgery and in pediatric neurosurgery. He is Head of Congenital and Pediatric Neurosurgery and Co-Director of the Pediatric Neurology Center at Cleveland Clinic. His patients are children and adults with neurological congenital anomalies, hydrocephalus, cerebral cysts, tumors, craniofacial anomalies, tethered cord, Chiari malformation and cerebral palsy.

Dr. Luciano also directs the Neuroendoscopy and CSF Disorders program. He has an established clinical program, research and educational work in neuroendoscopy, a form of minimally invasive neurosurgery. Dr. Luciano has directed Cleveland-area, national and international courses in neuroendoscopy and has developed new techniques in minimally invasive neurosurgery.

As a result of his recognized leadership in hydrocephalus, Dr. Luciano has been on the National Hydrocephalus Association advisory board and has appeared in the local and national press and television including the *Wall Street Journal*, *Woman's Day*, and the *Today Show*.

In addition to national publications, peer-review and editorial activity, Dr. Luciano is an internationally invited speaker in neuroendoscopy, hydrocephalus and pediatric neurosurgery. He was the "Brahm Prakash Memorial Orator" in New Dehli, India, and has been invited as visiting professor and speaker in India, China, Egypt and Europe. He has initiated an international cooperation between Cleveland Clinic and Peking Union Medical Center in Beijing, China, for education in neuroendoscopy. In addition, he has served as host and thesis mentor for international MD research fellows from Egypt and Sweden.

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WEDDING FUNDRAISER



Camilla and David Martin reside in New York City and were recently married in Dublin, Ireland. Camilla is from Stockholm and David is from Dublin, so they decided to have their wedding reception there. Camilla was diagnosed with Chiari malformation about three years ago and had surgery in December 2006. Unfortunately, it was not successful but she does her best every day. She and David have been running Fi, an internet company which delivers premium interactive services and media platforms, for the past ten years. In lieu of wedding gifts, the couple decided to ask their guests to donate to CSF, in their honor. CSF has received almost \$1,400 from their family and friends. Thanks Camilla and David and best wishes from CSF!

UNITED WAY AND UPS SUPPORT CSF



“I was born with a Chiari malformation. Throughout my life, I have dealt with many medical problems, ranging from allergies and chronic infections to more recent and serious problems. To date, I suffer with about 90% of symptoms. Because of its degenerative nature, not only do I have Chiari, but I also have spinal canal stenosis, kyphosis, obstructive sleep apnea, COPD, and degenerative disc disease, to name a few, so far. Unfortunately, it was only until young adulthood that I was accurately diagnosed with Chiari malformation. In turn, I may be suffering from latter illnesses that may have been prevented, if more education were available. When I was diagnosed, I was a single mother attending college while casually dating my current boyfriend, Matthew McHenry. Ten years ago, we really had no idea what kind of beast we were facing. Chiari malformation, and its related disorder, syringomyelia, could be a very debilitating illness in which permanent damage occurs. Because of their location near the hindbrain, too often enough, symptoms could be disabling. Unfortunately for myself and people who are in my situation, some symptoms will be permanent.”

“On August 18, 2009, Matthew McHenry, as an employee representative to UPS, invited Dorothy Poppe, CSF’s Executive Director to present UPS with a United Way Fundraiser. Thanks to the efforts of Dorothy and the love of my life, Matt, UPS definitely came through to not only fund research, but to be made aware of these disabling conditions. They were willing to sacrifice time out of their very intense and hectic workday, and for that alone I commend them. But for designating the CSF as their United Way contribution I consider them to be my heroes. I personally cannot thank them enough for all they did for this fundraiser. The guys at UPS are wonderful!”

“With support like this, maybe one day, we will live to see pain free days!”

-Sabrina Stabile

Thanks to the UPS employees for donating \$6,500 and for their support. **Read the Staten Island Advance article**

AUTUMN BBQ IN LITTLE ROCK

Unseasonably cool weather in Little Rock didn’t dampen the spirits of Richelle & Ed Daniel’s guests who attended the first CSF Autumn BBQ fundraiser. The art of barbecue is an endeavor that Ed takes very seriously, as he has his own smoker and a secret rub recipe. Dorothy Poppe, CSF’s Executive Director, had the opportunity to see the amount of work that goes into a true southern BBQ event! Richelle was busy preparing the slaw, beans, and fixins’ while Ed and friends prepared racks of mouthwatering ribs, chicken, and sausage. It is an unbelievable undertaking.

AUTUMN BBQ IN LITTLE ROCK (cont.)

The event was attended by about 60 guests who had the opportunity to learn about Chiari malformation, syringomyelia and CSF through brochures and a presentation given by Dorothy, along with Paul Farrell, CSF's Board Chairman. The Daniel's are not strangers to Chiari malformation as their nephew, Dax was diagnosed and treated with decompression surgery.

This event raised almost \$2,500, but more importantly, CSF established a base in Arkansas to generate awareness, support, and education. A big thank you to Ed and Richelle and all the families that participated in this "one of a kind" event.

CSF GOES TO WASHINGTON—AGAIN!



In a continued effort to establish and grow strongholds in key geographic areas around the US, earlier this month marked another trip to the capital city for CSF. Our relationship with Dr. Fraser Henderson and his wonderful staff at Doctors Community Hospital in Lanham, MD, continues to flourish. On Oct 13, approximately 60 people attended our second meeting with doctors, patients and caregivers, all of whom either contributed to the discussion about CM and SM or took some valuable information away.

Mackenzie Mathis, one of Dr. Henderson's patients, spoke on her life changing journey with Chiari malformation. Mackenzie and her family are starting the first CSF Carolina Chapter and encourage anyone who would like to be involved to contact them.

Attendees enjoyed an interesting presentation by keynote speaker, Dr. John Heiss (*pictured*) of the NIH/NINDS (National Institute of Neurological Disorders and Stroke), who's talk was entitled "The Revision Surgery for Chiari Malformation". His prospective findings on the re-operation results of failed Chiari patients underscores the importance of finding a surgeon who has a high level of skill and success rate with their particular style, regardless of the actual technique. In addition to hearing Dr. Heiss, audience members also viewed the latest CSF DVD, *Can You Spell That For Me?* and their responses to the film were positive.

The next event in DC, again in conjunction with Dr. Henderson, will be held on Jan 19, 2010 and will focus on the topic of genetics, with guest speaker Dr. Clare Francomano, of the Harvey Institute for Human Genetics at Greater Baltimore Medical Center. Please spread the word to your contacts in that area and we look forward to seeing you there.

For more information about upcoming events or to register, please visit the CSF Greater Metropolitan Washington Area Chapter page.

DENVER CHAPTER MEETING

The Denver Chapter gathered on October 14th for their first educational event as a new CSF Chapter! There were some new faces in the audience who are willing to help spread the word! Dr. Oro's new presentation was very well done, as always. We appreciate all he does for CSF and are so grateful that he's able to spend time with our group. Bryan Downey, the Chapter Chair, began laying the foundation for a successful Chapter with a recap of CSF's mission and vision, as well as new Chapter needs. The Denver chapter needs to harness the energy we know is available in Colorado, and your help is greatly appreciated!