

# eNewsletter of the Chiari & Syringomyelia Foundation September/October 2009



## GIVE YOUR KIDS THE GIFT OF READING AND HELP CSF

Explore. Imagine. Create. Connect. Give Back. That's what Barefoot Books is all about.

It's exploring other cultures, our planet, ourselves. It's making time for make-believe and letting imaginations run wild and free. Most of all, it's about using the power of stories to nourish the creative spark in everyone and strengthen connections with family, the global community, and the earth.

Simply visit the **Barefoot Books website**, make a purchase and 30% of the sale will go directly to CSF. Feel good knowing that not only will your purchase help CSF, but will also enrich the minds of children at the same time.

To kick off the busy holiday shopping season, Barefoot Books will be offering free shipping, for purchases over \$35, through October 31, 2009. Click here to start shopping.

\*\*Barefoot Books is offering a discount to CSF members. Enter Special Offer Code SCSHTE at checkout to receive 10% off your purchase. This offer code is valid until December 31, 2009 for a one time use per customer.

About Barefoot Books: Barefoot Books is an award-winning children's book publishing company dedicated to bringing high-quality art and story to children from all walks of life. For sixteen years, Barefoot Books has been committed to nurturing a love of reading in a way that encourages children to explore their creativity and discover the diversity of the world's many cultures and traditions. Barefoot Books began with two mothers who wanted their children to have books that would feed the imagination, while instilling a respect for diversity and a love of the planet. Today, Barefoot Books is a world-wide community of writers, artists, storytellers, musicians, and others who are committed to providing timeless stories and captivating art that can help children become happy, engaged members of a global society.

# 4TH ANNUAL BENEFIT AND MOTORCYCLE RIDE TO HELP FIND A CURE FOR CM AND SM

Thanks to Mary Ellen and Jim Feisthamel for helping to raise over \$12,000 for CSF. About 50 motorcyclists took to the roads on Saturday morning, September 12 to raise awareness about CM and SM. The riders alone raised nearly \$1,000 for the CSF Utica Chapter. This is the fourth year of the Ride for a Cure, and the organizers say it has a deep meaning to them. "My daughter has this disease, so it's very important to me. It's close to home, and hopefully everybody that has this disease someday will have a cure," said Jim Feisthamel. **See Utica's Channel 10 News story**.



# **CONQUER FOR KAYA GOLF TOURNAMENT**

Thanks to everyone who helped put this event together, made donations or participated. This year's Conquer for Kaya Tournament raised over \$22,000 and, in the last four years, has raised over \$110,000 for research of Chiari and syringomyelia. We celebrate this success with new friends to the tournament and with the ones we see every year, which make this tournament even more special.

"I have talked to three parents of kids with CM & SM, which makes me even more determined to raise money for research so people don't have to suffer because of these disorders."

Thank you from the bottom of our hearts, The Culver's & Grover's

## **KAYA'S STORY**

Visit CSF's **Awareness Video page** to see "Kaya's Story". Kaya was diagnosed with a Chiari malformation and syringomyelia in June 2006, shortly before her second birthday. Soon after she was diagnosed, she underwent her first brain surgery in November

2006. Unfortunately, the benefits of this operation did not last, and Kaya has had to endure even more surgeries. Her family and friends pray that each one will be the last!

Each month we will feature a different video story, so check back regularly!



### ARLINGTON RACE FOR THE CURE A SUCCESS!

Well, it's that time of year again. Fall is definitely upon us—especially in chilly Chicago. For most, while this means back to school and back to the grind, for a group of families in Naperville, IL (along with a dedicated New York City area contingent), it also means back to hosting our annual Arlington fundraiser. This year was the 8<sup>th</sup> year since its inception and the second year that CSF was the beneficiary of the proceeds from this great day.

Given the state of the economy, it's fair to say that the host families were more than a bit concerned about what our turnout and proceeds would be in this year of financial turmoil for many people. We're honored that old friends and new faces traveled from around the country (Washington DC, Arkansas, New York, Minnesota, Florida, Virginia, Michigan, Oklahoma, Maryland, Indiana) to join us at the Arlington Park Race Course on September 13<sup>th</sup>. Now that the dust has settled and the numbers have been tallied, we are thrilled to report that the generosity of our friends and family has prevailed even in these trying times. The one-day event raised over \$190,000 for CSF! Needless to say, the organizers of the event are very pleased.

Many dedicated people worked very hard to make Arlington so successful this year. As always, Jerry Kyle did an unbelievable job with his sports memorabilia room. A favorite of the guys, Jerry's items alone grossed almost \$35,000 for CSF. Jerry is an amazing man and a wonderful supporter of our charity.

Another special thanks goes out to Dr. Fraser Henderson, Chief of Neurosurgery, and Scott Gregerson, Vice President of Business Development, both of Doctors Community Hospital in Washington DC, who made the journey all the way to Chicago for the event. Dr. Henderson helped to educate our audience about Chiari and syringomyelia and many people approached the host families after his speech to comment on how impressed and moved they were. He truly has dedicated himself to CSF and our endeavors in order to help his patients combat the devastating side effects of CM and SM. We are lucky to call him our friend.

Finally, late in the day, another very moving tribute was given by one of the hosts, Joe Fitzpatrick. Joe's son Liam has been suffering a great deal lately and his elegant plea for support brought many people to tears. These contributors, along with the nearly 300 friends and family members who attended and generously donated towards the event did much to give us another successful Arlington.

We hope you consider joining us next year for another amazing day!

# CSF GREATER METROPOLITAN WASHINGTON AREA CHAPTER MEETING

Join Dr. Fraser Henderson for the 2<sup>nd</sup> meeting of the Greater Metropolitan Washington Area Chapter on Tuesday, October 13, 2009 at 6:30pm.

Doctors Community Hospital 8118 Good Luck Rd. DSE Room, Fifth Floor Lanham, Maryland

### Light refreshments will be served

For more information and to register for these quarterly events, please contact Administrative Co-Directors Anita Savage at (301) 654-9390 or Avelene Mahan at (301) 654-9390, or Clinical Co-Directors Inge Molzahn BSci. and Brittney Renehan BA at (240) 723-6515.

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

#### THANK YOU TO OUR NATIONAL CORPORATE SPONSORS

Visit our **website** to see a listing of CSF's national corporate sponsors. Thank you to those organizations and individuals who help us in our mission. Please support those who support CSF.