

BDSRA 2009 Conference—St. Louis, MO

Many of you have been contacting the office wanting to know more about the 2009 Conference. Our annual Conference pack will be included with the April Illuminator. Until then, here is some of the basic information.

Dates: Thursday, July 16th thru Sunday, July 19th

Place: Marriott St. Louis Airport Hotel

10700 Pear Tree Lane

St. Louis, MO 63134

Phone: (314) 423-9700

Toll-free: (877) 264-8771

Fax: (314) 423-0213

Reservation line: 1-800-228-9290

Conference name: Batten Disease Conference

Room Price: \$89 a night plus tax

There are only 16 handicap accessible rooms available. Reservations for these rooms must be made through BDSRA by calling 1-800-448-4570.

Breakfast: \$10.50/person

Lunch: \$12.95/person

Dinner: \$21.95/person

Children 3 and under: FREE

Children 4 to 12: We are still negotiating these prices

There is a 22% service charge added to each meal per person

Shuttle Service is available to/from St. Louis Airport

2009 Dues are Due!

Please remember that your 2009 dues can be paid to BDSRA immediately. The cost is \$20 per family or per member who would like voting privileges. Paying your dues allows you to vote in the yearly Board elections. Each \$20 dues payment entitles you to 1 vote in the election. If you live in an area where there is an active chapter, please send your dues to the chapter. If you do not have an active chapter in your area, you can send your dues to:

BDSRA
166 Humphries Drive
Reynoldsburg, OH 43068

Paying your dues helps sustain the BDSRA operating fund and the existence of our main office. It also helps pay for the quarterly Illuminator and Lighthouse newsletters as well as our annual conference expenses and many other things. Please do your part to keep BDSRA operating at full capacity. PLEASE PAY YOUR 2009 DUES TODAY. Thank you.

Nick Wellner Meets NFL Superstar

Seven year old **Nicholas Wellner** (INCL) had a chance to meet one of his heroes: Arizona Cardinal's quarterback Kurt Warner. Nicholas and his family live in Waterloo, IA a town near Warner's hometown. Warner and his First Things First Foundation took the Wellner family to Disney World last June. They spent every day with Kurt Warner and his family traveling to each theme park and eating all meals with them. Nicholas said his favorite thing about Kurt Warner was the fact that he "screamed like a girl" on the Rock 'N' Rollercoaster. To see the entire news story on Nicholas and his trip to Disney World, please go to the website below and click on "Kurt Warner Gives Back" for video.

<http://www.kwwl.com/Global/story.asp?s=9699327>

Taylor Participates in 5K Jingle Jog

Ten year old **Taylor King** (INCL) from Charlotte, NC participated in her first Jingle Jog totaling 3.1 miles on Saturday, December 13th. Along with the help of another sighted jogger from Taylor's school, the pair finished the race in just over 55 minutes. Taylor has been a part of the group, "Girls on the Run" since August. "Girls on the Run" is a program dedicated to emphasizing self-respect and healthy living through running. Taylor is like so many other children with Batten Disease, always proving that this horrible disease will not stop them from living their dreams. To read the news article in the Charlotte Observer, please visit:

<http://www.charlotteobserver.com/104/story/414415.html>

Great job Taylor!

Jacob Scores the Winning Goal

Jacob Geer (age 6—unknown NCL) from Caledonia, MI, did something that most soccer players only dream of: he scored the winning goal to break a 5-5 tie during his final soccer game of the season. Jacob's team played the Division 1 boy's champion high school soccer team, East Kentwood, on November 8, 2008. They beat the high school boy's team 6-5. Jacob, who's been playing soccer on the VIP team set up by the local American Youth Soccer Organization, was very proud of his shining moment. His name was announced on the loud speaker and he was "high-five"ing everyone around him. His mom, Chris Geer says, "It was a very special moment for him!" The VIP soccer team has been a great thing for both Jacob and his family. To read the article about Jacob's winning goal, please visit:

<http://www.mlive.com/highschool/grpress/index.ssf?base/sports-0/1226512508307030.xml&coll=6>

Family Fundraising News**3rd Annual Festival of Hope—Raleigh, NC**

The Southeast Chapter held their 3rd Annual Festival of Hope Craft Fair and Silent Auction on November 15, 2008 at the New Community Church in Raleigh. The event saw over 230 attendees! Participants enjoyed a variety of crafts and goods for sale, a silent auction, live music and a Taekwondo demonstration. Clapper the Clown was there making balloon animals and entertaining children. Judy Hodges was nice enough to volunteer her face painting skills as well. All together the event raised approximately **\$5,000!** Great job SE Chapter and its families!

Run for Batten Disease—Pullman, WA

Charlene Jasper (in memory of sons Daniel & David, LINCL) is hosting a few fundraising opportunities for BDSRA. The first is a run in cooperation with a group of students from Washington State University. The run is scheduled for November 16, 2008 on the WSU campus. The anticipated turnout is looking to be big with over 200 entry forms already passed out. Charlene is also auctioning off a WSU signed football helmet in her coffeehouse. She is also setting up a Batten Disease Awareness Christmas tree in her coffeehouse and this will be auctioned off during December. We wish the best of luck to Charlene as she participates in her many fundraising efforts!

TGIFriday's Fundraiser—Reading, PA

Marcia Miller (son Ricky—JNCL) along with her employer, Penske Trucking, helped organize a fundraiser with their local TGIFriday's to raise money for BDSRA. Co-workers and friends passed out vouchers for Friday, November 28th. Each person who ate at TGIFriday's that day and presented their voucher allowed the restaurant to donate a portion of the bill's total to BDSRA. Over 50 vouchers were turned in and the event was able to raise **\$505.18!** Great job Marcia and your Penske Truck co-workers on a successful fundraiser.

Dave's Home Roasts—Chatham, IL

David Dahl (son Clifford—JNCL) has been roasting coffee for awhile now and even has his own coffee roasting business in Chatham. Dave recently found the Etsy.com website where people can sell their hand-crafted goods to a large spectrum of consumers. Dave's Home Roast special blends are only \$10/lb. Dave is donating all of the proceeds, including shipping and overhead costs, to the Juvenile Trial fund. This would make a great gift for any hard-to-buy person on your holiday shopping list. Visit his page and purchase his coffee today at <http://www.daveshomeroast.com>.

Taylor's Tale Unites Fans of Bitter ACC Rivals to Support Batten Disease Research—Charlotte, NC

About 150 University of North Carolina (UNC) and NC State University (NCSU) fans banded together at Blackfinn American Saloon in uptown Charlotte on the afternoon of January 31 to watch the in-state rivals' first match-up of the men's basketball season and support Taylor's Tale. The event was supported by the local UNC and NCSU alumni clubs and was covered by local media, including twice on the local CBS affiliate and three times on the ABC affiliate. Halftime festivities included a video featuring Taylor, door prizes and a raffle. Tip-off for Taylor raised nearly **\$2,500** for Taylor's Tale and Batten Disease research. Thanks to the Tip-off event committee, Blackfinn for partnering with us on this fantastic event and to all those who donated door prizes and raffle items!

Taylor's Tale will host a second Tip-off for Taylor event on March 8 when North Carolina and Duke meet in the last game of the regular season.

Fundraiser for Sarah's Hope—Crystal Lake, IL

Sarah Pfaller (age 16, JNCL) has great teachers and great classmates at her high school in Crystal Lake, IL. They are turning their love for Sarah into a fundraiser to help raise money for the Juvenile Trial. On February 19, 2008 during the varsity boys' basketball game, teacher Kerrie Kurth and Sarah's classmates will be selling t-shirts and bracelets, passing out information on Batten Disease, collecting money and playing half-time activities to help raise funds for the Trial. This will be a great opportunity for those in the Crystal Lake community to learn a little bit more about Batten Disease and how it affects a local family and an entire school community. For more information, please email Kerrie Kurth at kkurth@d155.org. Good luck to Kerrie and all of Sarah's classmates!

Emma's Bayou Bash—Baytown, TX

Emma's Hugs, created by friends and family of Emma Dunnam (INCL) are hosting their first ever Emma's Bayou Bash on Saturday, March 21, 2009. The event is being held at the Eastside Honda from 11:00-6:00pm. Activities include a live and silent auction, children's games and live music by Mean Gene Kelton. There will also be delicious BBQ food served up between 11:30-1:30pm. For more information about the event, please visit the Dunnam blog at <http://emmadunnam.blogspot.com/>.

Korry and Rachael’s Research Roundup Crop for a Cure—Vacaville, CA

Who doesn’t love a day of scrapbooking; and who doesn’t love scrapbooking when they know they are also raising money for a worth cause? Amy Sharp (aunt to Korry and Rachael, CLN5) is hosting a 12 hour crop on National Scrapbook Day which is May 2, 2009. The event will last from 10:00am to 10:00pm. This all day event will include food, a silent auction, door prizes, a raffle and more scrapbook fun than most can handle! Tickets for the event are \$. For more information, please visit the Roundup Crop for a Cure website at <http://www.researchroundup.org> or contact Amy Sharp at 707.453.1049 or sharpshouse4@comcast.net. Good luck to Amy and the entire Sharp family!

Race for a Miracle/Cook for a Cure—Mandeville, LA

This fundraiser is being hosted by the Mary Payton’s Miracle Foundation which was formed in March of 2008 in honor of Mary Payton Vigil (LINCL). The fundraiser will be held on Sunday June 7, 2009 in recognition of National Batten Disease Awareness Day. This will be a 5K race along the Mandeville Lakefront followed by a 1 mile fun run for children and a ‘Roll and Walk’ for children with special needs. The races will be followed by a jambalaya cook off and children’s festivities at the Mandeville trailhead. Sponsorship opportunities are available. For more information, please visit the Mary Payton’s Miracle Foundation website at <http://www.marypaytonsmiracle.com>.

Cookie Lee Jewelry—Dallas, TX

Jessica Griffith, (in memory of sister Kari Anderson-JNCL) is a Cookie Lee fine fashion jewelry consultant. Jessica has graciously offered to donate a portion of her profits made from her Cookie Lee jewelry sales to BDSRA. To view Jessica’s jewelry, visit her website at www.cookielee.biz/jessicagriffith. When you place an order, be sure to mention “Batten Order” to ensure BDSRA and the Juvenile Trial receives the profits. Jessica is also selling a special line of pink jewelry in memory of Kari. The proceeds raised from this jewelry will also benefit BDSRA. If you have questions, please email Jessica at jessicagriffith@cookielee.biz.

TheBattenProject.com – Les & Deb Ham

Just like many of you our efforts to launch **thebattenproject.com** is very personal - because we want to honor our son Daniel Yanak (JNCL Vancouver Washington) and do our part to give hope to children with Batten Disease. To that end we began this journey with the commitment to donate the gross profits of a product (Perfect Empowered Drinking Water) that we sell to the Juvenile Trial – we are still doing that but the vision has grown. We can’t do this alone and we hope that you are willing to help us move this fundraising effort forward. We need help with the following:

- Please visit www.thebattenproject.com watch the video (the video is on youtube as well) then please share the website with everyone you know and ask them to share it. Post it on Facebook, My Space any networking group the more the better. Around the first of March a new video will be added which actually tells Daniel’s story – again as a way of building a compelling message and drawing attention to the need for funding.
- We need pictures of children that have already passed way from JNCL that we can post on the website. We want to create a photo montage – but we need your pictures and I need them soon. Please email them to Debbie at ham.debra@gmail.com.
- Please check out the Partner Link on the website – that is where you and your friends and family can purchase the Perfect Water. Each case that is sold we will donate \$6.96 (29 cents per bottle) to BDSRA for the Juvenile Trial. This may not seem like much but you know the water they sell at Starbucks? They donate 5 cents per bottle and have raised millions of dollars – it’s the same concept only the Perfect Water will help our kids. The Partner link will continue to evolve we have other business that want to join the effort so check back often.

Thank you for your help. Please don’t hesitate to contact us if you have any questions and please send us those pictures.

Les and Debbie Ham (1-877-691-0437)

Family Fundraising Contributions

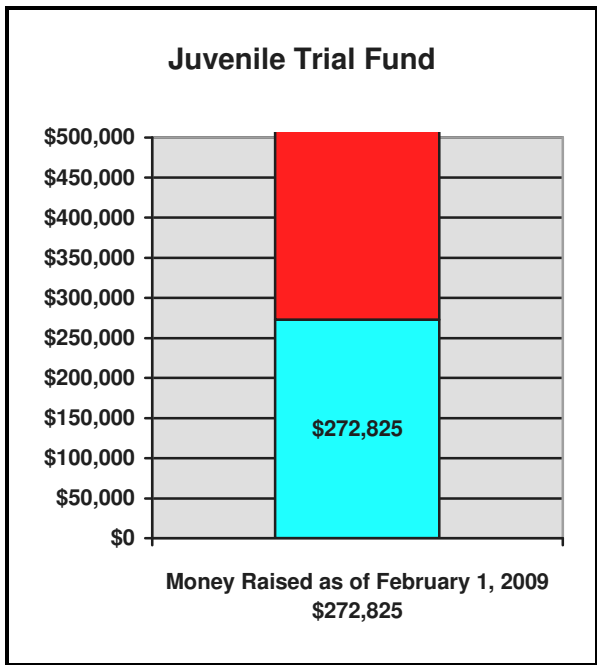
Did you (or will you) have a successful fundraising event that you would like featured in the monthly BDSRA News Flash? Please send a description along with the date and location of the event to kirka@bdsra.org. Raising money for Batten Disease research and support is an amazing feat and deserves recognition. Submit your event today!

With a little help, special kids score!

The Cat5 Canes Hockey Team in Raleigh, NC is not your regular youth hockey team. This team is especially for those children who face special needs. However, they love to shoot the puck and move around the ice like any other hockey player. The Cat5 Canes team started in the summer of 2007 with just seven children, and today the team has grown to thirty! One of those thirty players includes **Eric Lowden (JNCL)**. Eric loves playing hockey and has been ice skating since he was three! The Cat5 Canes hockey team is the perfect sport for him. Mom, Danielle, loves that Eric gets to hang out with the other players and enjoy the camaraderie. To read the entire article about the Cat5 Canes Hockey Team, please visit:

<http://www.newsobserver.com/news/story/1393002-p2.html>

Juvenile Trial Fund—Where are we?



Request for Conference Feedback

For those of you who have attended the Annual BDSRA Conference in recent years, we want to hear from you! In an effort to keep the Conference fresh and informative we want to know what you, the families, find the most helpful and most interesting.

- What sessions would you like to see?
- What topics would you like covered?
- Is there a program or aspect you have an idea for?
- What do you want to see change?

No matter what your comment or suggestions is, we want to hear it. Please understand that not all comments or suggestions will be put into place immediately, but all will be read and considered. Please send all feedback to Amy at kirka@bdsra.org or call 1-888-379-2546. Of course you can always send it through the U.S. Mail to the BDSRA office at 166 Humphries Drive, Reynoldsburg, OH 43068. Thank you everyone for your time and we appreciate hearing from you.

In Loving Memory

Michelle Newell, daughter of Robert & Marjorie Newell, Maple Valley, WA
Born: 11/30/88—Died: 11/3/08 JNCL

Lucas Nitzschke, son of Richard & Marta Nitzschke, Sunbright, TN
Born: 8/22/86—Died: 11/6/08 JNCL

Elaine Johnston, wife of Lance Johnston, mother of Lorena & Lee Johnston (deceased), Reynoldsburg, OH Died: 12/8/08

Abby Bortz, daughter of Terry & Mary Bortz, Portage, WI
Born: 10/30/86 – Died: 12/30/08 JNCL

Curtis Anthony, son of Paul Anthony & Donna Kapper, Dublin, PA
Born: 9/17/02 – Died: 1/18/09 LINCL

Megan DePew, daughter of Phyllis DePew, Stanwood, MI
Born: 5/22/87 – Died: 1/22/09 JNCL

Tom Schultz, son of John & Caryll Schultz, Leawood, KS
Born: 6/16/96 – Died: 2/10/09 INCL