I'll admit it. I have a greeting card habit. On my latest run, in late March, in the snow, I made an impulse book purchase during my impulse card purchase. It's short - just 10 pages - of quotes on encouragement by Orange Art Miniatures.

My favorites?

- Lord, make me be the person my dog thinks I am. (refrigerator magnet)
- Great works are performed not by strength, but by perseverance. (Samuel Johnson)
- Half this game is ninety percent mental. (Yogi Berra)

All true. In the following pages you'll read about many more reasons to feel encouraged. Danielle Kerkovich updates us on the new research awards to scientists from around the world. Based on a new and refined protocol, BDSRA engaged a host of global donors to fund nearly $1M in projects. We hear from active parents, board members and donors who advocate, fundraise, engage and encourage. How will you get involved? Read more to find out how - and may you be the person your dog thinks you are.

2013 CONFERENCE
Nashville Brings Notes of Hope

It's hard to believe, but BDSRA's annual conference in Nashville is just a few months away. Below are some of the weekend events we are excited to share.

Thursday, July 18: Registration for both the conference and research studies opens at noon. Families new to the conference are invited to an hour orientation at 6:30 p.m. for an overview of weekend activities. The popular Sibs Pool & Pizza Party at 7:00 p.m. welcomes unaffected siblings of all ages. At 7:30, the Welcome Reception sets the scene for seeing old friends and meeting new ones.

Friday, July 19: The morning session welcomes folks to Nashville and provides a research overview. After lunch, the Sibs group heads out to the Nashville Zoo at Grassmere, and those who lost loved ones to Batten disease meet to go to the Country Music Hall of Fame. Afternoon sessions include symptom management, nursing and palliative care, fundraising strategies and a meditation workshop. A family concert offers entertainment following dinner.

Continued on page 2
2013 CONFERENCE (continued from pg 1)

Saturday, July 20: JNCL families can participate in a Q&A session with researchers, followed by separate break-out sessions for moms and dads to discuss issues specific to the juvenile form. Insights from researchers provide relevant updates on the science of the various forms of Batten disease. Therapy dogs delight as they mingle with affected children and Sibs. The Research Open House is our version of a science fair – posters describing various research processes, as well as one-on-one discussions with the scientists, keep families informed about progress for all forms.

After lunch, the Sibs group embarks on their outing to Nashville’s Adventure Science Center. The afternoon brings separate break-out sessions for mothers and fathers of children with INCL/LINCL to give them the opportunity to talk about matters related to these two disease forms. An expert panel consisting of a nurse, doctor and education specialist allows people to ask questions and catch up on some information they may have missed while attending earlier concurrent sessions. Otherwise, the afternoon is open to explore and enjoy Nashville before the dinner banquet.

The festive Kid’s Parade kicks off the evening’s events. Dinner follows, along with a presentation recognizing those who have contributed significantly to the Batten disease community. The DJ “turns the table” for the Sibs Dollar Dance and the dance floor becomes crowded with folks of all ages.

Sunday, July 21: A non-denominational prayer and memorial service is held to remember those lost to Batten disease. For new families, there is a decompression session with a psychologist to help process their weekend experiences. We then say our “farewells” and “until next year.”

If you have not yet made arrangements for conference or for your hotel room, there’s still time. Online registration and hotel accommodations can be found at http://www.bdsra.org/programs-services/annual-conference/. Hotel room reservations at the Nashville Airport Marriott can also be made by calling (800) 228-9290 (mention “Batten disease” or “BDSRA”). If you need ADA accessible accommodations, contact Lisa Weston at lisaweston@bdsra.org or (800) 448-4570, ext. 12. Please remember that the cut-off date for both conference and hotel reservations is June 25, 2013.

If you know someone who would like a printed copy of the preliminary program mailed to them, or if you have any questions regarding the conference, please contact us. A more comprehensive preliminary schedule will be available mid-April on BDSRA’s website.

Whether you’re a conference aficionado or novice, the weekend will offer everyone a chance to learn, share and communicate in a supportive and accepting environment.

JOIN THE SIBS GROUP IN NASHVILLE

By Megan Knight, Sib Leader

A few therapy dogs and their handlers stopped in at the conference to mingle poolside with the Sibs during the 2012 conference.

Attention all SIBS! We are excited to invite you to attend the 2013 BDSRA Conference Sibs Program. Be ready for a fun pool/pizza/tie-dye party, informative sessions with doctors, support sessions with your fellow sibs, and two great outings: the Nashville Zoo and Adventure Science Center!

For those who have never attended a conference, the Sibs group provides a secure and open support system for unaffected siblings of those with Batten disease, and focuses on building and maintaining lifelong relationships between unaffected siblings through acceptance and open communication. We look forward all year to seeing one another, catching up, and providing support for those of us who need it. We would love for you to join us this year for a truly unique and exciting experience! Be ready to make life-long friends along the way!

If you have any questions, please contact Megan Knight, Sib Leader, at eknight510@gmail.com.

The Sibs gather for a group photo during one of their outings in Charlotte.
BATTEN DISEASE AWARENESS WEEKEND - JUNE 1-2, 2013

We all know how important awareness is to fight and cure Batten disease. Here are some ideas for you to share with family and friends to bring awareness to your community:

- Visit [www.bdsra.org](http://www.bdsra.org) for special posters and information for your Batten Disease Awareness Weekend activities.
- Help increase visitors to the BDSRA website by adding the link to your email account signature, which encourages others to view the link. Then send an email about Batten Disease Awareness Weekend to friends, family, co-workers and neighbors with the web address.
- If you have a Facebook account, update your status to encourage your FB community to learn about Batten Disease Awareness Weekend by visiting [www.bdsra.org](http://www.bdsra.org).
- Add BDSRA information to the small text box underneath your FB profile, and share your story.
- Ask members of your church, synagogue, community clubs or sports teams to join you in sending an email or FB message about Batten Disease Awareness Weekend with the link to BDSRA’s website.
- “Ten for Ten” – ask ten people to donate $10 to BDSRA – and ask them to ask friends to do the same – during Batten Disease Awareness Weekend.

BDSRA FAMILIES AND FRIENDS STEP OUT FOR RARE DISEASE WEEK - FEBRUARY 25 - 28

It was a great week of awareness sponsored by our Batten community. Facebook lit up. Batten families made visits to state capitals and to Capital Hill. Awareness events were held in schools, at work and houses of worship. Margie Frazier appeared on WOSU/NPR with NORD’s Mary Dunkle to talk about rare disease worldwide. Thank you for all you are doing to raise awareness in your community every day. Batten Weekend is coming! See how you can get involved.

*The Vise and Braddock Families visit Arkansas Governor Beebe on Rare Disease Day. From left: Donya Catlett-Vise, Scott Vise, Ali Vise, Governor Beebe (kneeling), Jason Braddock, Addie Braddock, Brody Braddock and William Braddock.*
THE NEW YEAR IN RESEARCH

It has been a year of exciting progress for Batten Disease Support and Research Association’s funded researchers, who are harnessing cutting-edge technologies along with new developments in gene therapy, enzyme replacement, and drug discovery to advance Batten disease research. To keep pace, BDSRA has transformed the way we identify and fund research with the highest treatment potential. Our new program reflects the highest standards associated with the U.S. National Institutes of Health and the European Research Commission, and it incorporates evaluation processes used by the pharmaceutical industry.

To identify drug targets in affected brain cells, BDSRA is funding research that explores the molecular basis of Batten disease [Chandra, Palmer]. To turn cellular problems into medical solutions, BDSRA is funding investigations into direct treatments such as enzyme replacement therapy [Hofmann], gene therapy [Stein], and drug discovery [Cooper, Gerst, Schultz]. To prepare for clinical trials, BDSRA is funding the expansion of a patient registry currently in use in several countries— including Germany, Finland, Italy, India, and the United Kingdom— into the United States, Brazil, Argentina, Turkey, France, Norway, and Denmark [Schulz]. Together with our funding partners, we are building a shared, trusted resource of patient history information and tools to identify patients eligible for potential clinical trials. Another notable grant supports the identification of biomarkers capable of measuring the efficacy of drugs in development for treating Batten disease, a key element to developing and testing effective medicines [Sleat].

As a result of our vetting processes and forward-thinking strategies, we were able to attract funding partners, raising the average award from $40,000 in 2011 to $100,000 in 2012. This shift accelerates the path to a cure by providing researchers access to the best resources and expertise— all part of BDSRA’s new strategy. The association is building upon its $6 million+ portfolio of evidence-based research with another million this year. Watch our video to see how we are investing in the next steps to reach our goals (http://www.bdsra.org/research/bdtras-role-in-research/).

We are proud of our successes, but our work is not done until we eliminate Batten disease. We are making headway, though. BDSRA’s researchers have excellent track records of publishing their findings (CLN1, CLN2, CLN3) in top-tier research journals and are leveraging their BDSRA-funded research with new grants (Davidson, Cotman).

So what’s on the research horizon for BDSRA? BDSRA recently issued its annual Request for Proposals (BDSRA RFP 2013) to over 3 million researchers around the globe. We are inviting researchers to continue to submit proposals in the basic biology of Batten disease and drug discovery. This year we are asking our medical community to submit proposals to create a set of practice guidelines sharing their valuable experiences with their colleagues; another step toward ending the diagnostic odyssey of families affected by Batten disease. Working with awardees and experts in sharing complex medical information, BDSRA will create a companion handbook for families and caregivers. We can’t wait to see what’s next.

### 2012 Grants Awarded

<table>
<thead>
<tr>
<th>Disease</th>
<th>Researcher</th>
<th>Project Title</th>
<th>Research Institute</th>
</tr>
</thead>
<tbody>
<tr>
<td>infantile, late infantile, juvenile, adult Batten disease</td>
<td>Angela Schulz, MD</td>
<td>The DEM-Child database network – an online NCL patient registry for clinicians, researchers &amp; parents</td>
<td>University Medical Center Hamburg-Eppendorf, Germany</td>
</tr>
<tr>
<td>infantile, late infantile, juvenile, adult Batten disease</td>
<td>David Sleat, PhD</td>
<td>Lysosomal biomarkers in Neuronal Ceroid Lipofuscinosis</td>
<td>University of Medicine and Dentistry of New Jersey</td>
</tr>
<tr>
<td>infantile Batten disease</td>
<td>Sandy Hofmann, MD, PhD</td>
<td>Enzyme Replacement Therapy for PPT1-Related NCL</td>
<td>University of Texas Southwestern Medical Center</td>
</tr>
<tr>
<td>juvenile Batten disease</td>
<td>Jeffrey Gerst, PhD</td>
<td>Development of a cell-based assay for identifying down-stream effectors of CLN3 and in drug screening</td>
<td>Weizmann Institute of Science, Israel</td>
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<tr>
<td>juvenile Batten disease</td>
<td>Colleen Stein, PhD</td>
<td>Does restoration of CLN3 to endothelial cells alleviate neurological symptoms in JNCL mice?</td>
<td>University of Iowa</td>
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<tr>
<td>juvenile Batten disease</td>
<td>Jonathan Cooper, PhD</td>
<td>Cell based systems for drug discovery in JNCL</td>
<td>King’s College London, UK</td>
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<tr>
<td>juvenile Batten disease</td>
<td>Mark Schultz, BS</td>
<td>CLN3 regulation of Cdc42 and drug screening for JNCL</td>
<td>University of Iowa</td>
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<tr>
<td>juvenile Batten disease</td>
<td>David Palmer, PhD</td>
<td>Molecular dissection of neuroinflammation in ovine Batten disease</td>
<td>Lincoln University, NZ</td>
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<tr>
<td>adult Batten disease</td>
<td>Sreeganga Chandra, PhD</td>
<td>Molecular basis of DNAJC5-mediated neuronal ceroid lipofuscinosis</td>
<td>Yale University</td>
</tr>
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</table>
FOCUS | ON | FAMILIES

The DiCapuas Share Perspectives on Carrier Testing

Families affected by Batten disease provide an amazing network of support for each other. The perceptions, experiences and advice that are shared through Facebook, e-mails, phone calls, etc. offer families and friends unique resources in addition to the care received from medical professionals.

Peggy and Fred DiCapua live with their family in Middlesex, NJ. Their children, Melissa and Christopher, were born 17 months apart. Things were going great until April 1998, a week before Christopher's 3rd birthday when he had a seizure. He was first diagnosed with epilepsy but there were too many other delays to believe it was only epilepsy. After 14 months of testing and doctors, Christopher was officially diagnosed in June 1999 with Late Infantile Batten disease. Life changed forever for the DiCapua family - but with such tragedy came many blessings. Two wonderful doctors who helped keep Christopher's seizures under control. A loving, caring school staff who received Christopher into their program at age 4 while he was still able to run and eat and get into trouble, and who remained with him through the progression of Batten disease right up until his death at age 8. Christopher is missed every single day but the DiCapuas continue to help fight to find a cure for Batten disease with the hope that other parents will never have to endure the same tragic loss.

BDSRA: There are families who want to encourage their relatives to be carrier tested for Batten disease. What motivated you to reach out to your relatives about carrier testing?

Peggy: Right after Christopher’s diagnosis, my mom, daughter, husband and I went for carrier testing. We found out my daughter was a carrier at age 6. I had two children and one was affected and one was a carrier; neither was spared completely and it broke my heart to know that it could even be possible for the same thing to happen to my daughter when she has children. Fred and I each have five siblings and a total of 13 nieces and nephews. None of our siblings were ever tested. The internet was not as popular or common in the 90s and I think the written information available was overwhelming for them. I don’t think they moved beyond what was going to happen to Christopher and I also think in their eyes they thought they were clear because none of their kids had Batten disease, and they were all beyond having more kids themselves. I’ve always known that one day I would need to have some frank conversations with all the nieces and nephews. They are now ages 20 - 28 and I knew I had procrastinated too long as my oldest niece already had two boys. She had brought up testing to her doctor (she was in the Navy at the time) and he told her that it was rare and not likely and not to worry about it. I realized that not only would I have to encourage them to test, but that I might also have to advocate for them to the doctors to express the seriousness of the chances of them being carriers. I reached out to a few other families online to ask if their siblings had been tested and when I heard their statistics (4 of 6 siblings were carriers, 3 of 6 nieces and nephews were carriers, and so on), I knew that my hunch was right that Fred and I could not possibly have been the only carriers in our families. I sat down on the 9th anniversary of Christopher’s death and addressed one letter to all the kids, explaining the genetics of Batten disease in simplified terms, and basically told them I loved them too much to see them end up in the same situation as Fred and I if there was any possibility of preventing it - or at least having the tools to make an informed decision about having kids. In the letter I told them that after I was finished writing I would be visiting Christopher’s grave, hoping it would have an impact on them.

BDSRA: How did you communicate the importance of carrier testing?

Peggy: I told them that it was very possible that their parents were carriers and that they could also be carriers and not even know it. I explained that although Batten disease is rare, it was no longer rare in our family. I wrote about other chapter members in the NY/NJ area who tragically have multiple affected children. Most of all, I tried to express to them that I did not want to see this horrible disease ever strike their own families because they were carriers and didn't know it.

BDSRA: What barriers did you experience as you approached family members?

Peggy: I think the biggest barrier is denial and the “it can’t happen to me” view. Another barrier was not so much their lack of a clear understanding of the genetics of Batten disease, but more so the inability

Continued on page 6
to face the uncomfortable feelings of actually asking us for more information. I think people are afraid to talk about it because it's not a comfortable subject. They think bringing it up will make you cry, but deep down I think they are afraid of their own feelings that will surface when talking about it. It's a difficult subject. I chose the route of going directly to Christopher's cousins because I felt it might have a greater impact coming from me than from their own parents. They might think it's just one more thing their parent is nagging about, or even being paranoid about. I took the chance that if the subject was brought up by me, unexpectedly addressed directly to them, it would have more impact. The other barrier is plain old unresponsiveness.

BDSRA: Any advice to offer others as they consider taking this step?

Peggy: I think you have to approach it with a simple explanation and emphasize that it is no longer rare within the family. We don't have large family gatherings anymore, but for those who have family BBQs or similar get-togethers, the subject can be approached with the benefit of reaching many at one time. It could spark a lot of questions and conversations so be sure to have some of the carrier testing information ready to hand to them. You should also be willing to help them navigate through it if needed. Also, be prepared to respect their decision of "what will be will be." You don't have to agree with them, but you can rest at night knowing you did the best you could to help them make an informed decision. So far three nieces and one nephew have contacted me interested in finding out how to have the testing done.

BDSRA: What role did BDSRA play in your decision to advocate for carrier testing?

Peggy: BDSRA sponsored me to go to a gathering for rare diseases in Albany, NY, a few years back. Three of our NY/NJ Chapter members attended on behalf of BDSRA and met with the NY State Health Department and discussed rare diseases and testing along with representatives of other rare diseases. They were very interested in testing of newborns for rare diseases. I was sitting next to a gentleman, who like me, thought the emphasis should instead be focused on carrier testing. We had a private conversation after the meeting and I left feeling a sense of wonder as to why so many family members don't take the carrier screening seriously. If BDSRA had not asked for our support to attend that meeting, I would not have met that gentleman, and may not have found the strength to advocate for the testing with my family. I saw so many other parents and representatives from other rare disease organizations who united and found power in numbers. We have that same power in numbers if we stand united and continue

9th Annual WORLD Symposium
Orlando, Florida - February 12-15, 2013

BDSRA was well represented at the annual Lysosomal Disease Network annual conference. Board members Tony Ferrandino and Tracy VanHoutan, along with David Kennicott, Miguel Peruyero, Margie Frazier and Julie Conry, were all on hand to network with research, university and pharmaceutical partners. Of special interest was a meeting held for all LDN patient advocacy groups (of which there are many) to hear from the NIH/National Institute of Neurological Disorders and Stroke (NINDS) about current Congressional appropriations and its impact on funding for programming like LDN.
Road to a Cure Fundraiser Supports Batten Disease Research

Veteran fundraisers Gregg and Paula Froio welcomed nearly 350 friends, supporters and community members to their 2013 Road to a Cure Monte Carlo Night on February 23 in Berlin, NJ, marking the 14th year they have organized and sponsored a large scale event through the Melissa Froio Foundation to raise funds for Batten disease research honoring their late daughter Melissa. In March 2009, Melissa lost her 10 year battle with Late Infantile NCL at the age of 14. From the time their daughter was diagnosed, in 1999, the Froio family enlisted volunteers, family, and friends to devote hundreds of hours to support their efforts to generate research funding. Their foundation annually supports research initiatives of the national office of BDSRA.

The success of their annual event has been a process of learning, trial, and error, according to the Froios, with being open to changing what doesn’t work. Trying new approaches with the details every year has refined aspects of the event to constantly improve it, they added. Their current model, they said, was created partly from their willingness to move on from years of sponsoring a golf tournament during the summer.

“We have learned a few important things over the years,” Gregg said. “Forming a fundraising committee is crucial to staying organized and improving the process, because the work that goes into an event is more than one can imagine. A family cannot perform all of the work associated with a successful fundraiser without help.” It’s also important, he noted, to “be flexible, not be afraid to delegate, and listen to advice from others who have attended other events or have experience hosting events.” On his list of “do’s and don’ts” is to always send thank you notes to participants and donors, keep a tracking system of donors on a database of some kind, such as Excel, organize early, and don’t overprice sponsor opportunities or overcharge for the event.

He and Paula also joined their local chapter of the Association of Fundraising Professionals (AFP), and joined their educational classes and meetings to network with other fundraising professionals and learn tips and techniques to improve their events. AFP chapters are located in most major cities and provide a variety of programming and classes.

For their current event, a Monte Carlo night that features a buffet dinner, gaming activities and dozens of raffle prize gifts, the Froios start organizing in October, and they ask for gift basket donations prior to the holiday season so people can add basket items to their shopping lists. The most important item, they note, is for people to have fun, so they will return in future years and invite others to participate.

Gregg and Paula welcome any questions, and are happy to brainstorm with friends and supporters of BDSRA on fundraising events. They can be reached at greggpaulal1@comcast.net.
Metro NY/NJ Chapter of BDSRA Bowls Over Hurricane Sandy

The 12th annual Metro NY/NJ BDSRA Chapter Bowl-a-Thon scheduled for November 3, 2012 may have encountered hurricane sized challenges this year, but the volunteers, sponsors and families rallied after their event was initially cancelled because of storm damage from Hurricane Sandy. The Staten Island bowling alley, Rabs Country Lanes, the event site, had significant water damage after the storm hit the island October 29. Staying loyal to their long-time location, event volunteers shifted gears and created a holiday celebration when the date was shifted to December 15, 2012.

According to Janet Surrey, chapter member, the Bowl-a-Thon has raised nearly $200,000 for Batten disease since it began in November 2000. The event is sponsored by the New York State Society of CPAs, the Cicero and LoVerde CPA firm, and the NY/NJ BDSRA Chapter. Nearly 40 bowling lanes are utilized during the event, which also features raffle prizes and gift baskets.

Running for Batten Disease

BDSRA was the 2013 recipient of the proceeds from the Charlotte, NC, Run the Creek 5K race held March 16. Volunteers for the BDSRA booth included North Carolina resident Chris Hawkins and his sons, Brandon and Jeremy, and Julie Conry, Senior Director of Advancement and Outreach for the national office.

Nearly 400 individuals ran the course, with awards given in several categories and a children's one-mile race that followed after the adults completed the course.

Spring and Summer Event Season Brings New Community Partnerships

With the many spring and summer fundraising events for Batten disease soon filling the calendar, many first-time organizers and volunteers encounter a range of questions regarding how to best coordinate and manage their events and donations. We’ve included a few of the most common questions to provide information. We encourage calls or emails to the national BDSRA office for any questions, concerns, or comments: (800) 448-4570 or email jconry@bdsra.org.
**FREQUENTLY ASKED EVENT MANAGEMENT QUESTIONS**

As we assemble a new and revised website tool-kit for fundraising, we invite suggestions from veterans and first-time organizers. Events and fundraisers are an important community partnership for BDSRA to help the research and family services mission of the organization. We appreciate all the gifts of time, talent and skill to help expand the resources available for research and family support. Our goal is to help each and every event be successful and seamless for organizers and volunteers.

**Q: How does the national BDSRA office help with third-party event fundraisers?**

**A:** The national office can offer advice and resource guidance on event planning and the process for accepting donations as well as help promote the event with the BDSRA website and Facebook links. Educational and awareness materials are available and can be shipped to the event location, and the office will also provide permission and promotional guidelines for use of the BDSRA name and logo. Event ideas and referrals to event mentors who have experience with certain formats are also available. Pre-event publicity and post-event information and photos can also be shared and coordinated through the national office to let BDSRA families know what great work is being done on their behalf.

**Q: What are the financial guidelines and what is the process to receipt event donations?**

**A:** The BDSRA national office follows all financial and tax regulations required by the Internal Revenue Service (IRS) of 501(c)3 nonprofit organizations associated with third-party fundraisers and events. Detailed accounting of event revenues and donor gifts is important for tax purposes. All donations received made payable to and received by the national BDSRA office will receive a written acknowledgement for tax purposes acknowledging the donation. All donor contact information, amount of gift, and date of the event is necessary for the national office to provide gift acknowledgement letters. This information can be emailed via a list or spreadsheet to jconry@bdsra.org, or sent in the U.S. mail to BDSRA, 1175 Dublin Road, Columbus, Ohio 43215.

Under federal income tax law, if goods and services are received by a donor in return for a donation (raffle tickets, meals, gifts, golfing), the portion of the donation that is tax deductible for tax purposes is limited to the amount by which the donation exceeds the value of the goods or services received.

If donations from an event are deposited into a separate account outside BDSRA and donated in a single amount to BDSRA (i.e., one check), only the individual, organization, foundation, or other entity whose name appears on the check is eligible to receive a tax acknowledgement for the donation. It is the responsibility of the event sponsor, when appropriate, to inform donors their gift cannot be acknowledged as a tax deduction to BDSRA. Credit card gifts charged to an independent bank account outside BDSRA also cannot be provided with a tax deduction from the national office. Cash gifts must be entered on a list with the donor’s name, amount of cash donated, and contact information when transferred to the national BDSRA office.

Proceeds from an event listing BDSRA as the nonprofit gift recipient, with checks made payable to BDSRA, cannot be split between the organization and any other group or individual if BDSRA is providing a tax acknowledgement to the donor. BDSRA cannot provide a Tax I.D. number or nonprofit 501(c)3 status to any event that is a fundraiser for private individuals or families.

Additional details and IRS requirement guidelines to acknowledge charitable donations are available at http://www.irs.gov and Publication 526 of the Internal Revenue Service or by calling 800-829-3676.

**Q: What are the guidelines for event expenses and banking?**

**A:** Event organizers are responsible for expenses associated with third-party events, and the national office cannot process any bills or invoices associated with third-party fundraisers. Any insurance liability coverage, and federal, state, or local taxes associated with an event is the responsibility of the event organizers. The national BDSRA office cannot compensate for an event in which the expenses exceed the proceeds.

**Q: Will thank you letters be sent from the national BDSRA office to event participants?**

**A:** The national BDSRA office will send a thank you letter to event participants if the office is provided with a list or spreadsheet with the names and contact information of the participants. This can be emailed or mailed to the office. A gift acknowledgement letter with the appropriate charitable deduction documentation will be sent to event donors whose gifts are documented and transferred to BDSRA within the IRS requirements noted above. The national BDSRA office will work with each event or fundraiser in advance to determine what letter can be issued to donors by BDSRA within the tax and organizational guidelines. Thanking event participants and donors is an important step in helping supporters feel their gifts are important and have an impact. It also encourages people to attend again and share their experiences with others.

**Q: What if there are special situations or questions about an event or fundraiser?**

**A:** Call BDSRA at (800) 448-4570 or email jconry@bdsra.org.
I live in Grand Rapids, MI, where I do business development for IT project based solutions and staffing with Kelly Services. I have been happily married for 17 years to Chris Geer and have four children: Nick - 14, Jacob - 10 (Batten - Unknown), Sophia - 7 and Joshua - 4. I graduated from the University of Michigan (GO BLUE!), enjoy getting away for small breaks with my wife, traveling, social media, craft beer and technology.

Jacob was adopted at birth. We were unaware of what was soon to be ahead of us. Jacob’s medical issues began as an infant. His first diagnosis was Cerebral Palsy and had a feeding tube at 20 months old. At age 4½, Jacob began to have seizures and diagnosed with generalized epilepsy. Knowing something else was very wrong, we pushed the doctor into further testing, including a skin and muscle biopsy that revealed fingerprint inclusions and a diagnosis of NCL.

Since then, we have tested all known genes to determine which form of NCL he is affected with. Further testing in Boston is being done to identify a new gene relating to NCL. Since his diagnosis, progression of the disease has been slow and he continues to amaze us every day.

I have been on the board for three years, currently serving as First Vice President. I have assisted with social media set up including Facebook and Twitter, the BDSRA website, technology questions, and the recruitment and interviewing process for our Executive Director, Margie Frazier.

**SUPPORT SERVICES FOR FAMILIES**

Several resources are available for families seeking financial assistance in pharmaceuticals and equipment not covered under their health care plans. These services and resources can be accessed directly by families.

**The UnitedHealthcare Children’s Foundation:** The foundation recently announced new grants are available to help children who need critical health care treatment, services or equipment not covered by their parents’ health benefit plans. UHCCF provides grants to families to help pay for services such as speech therapy, physical therapy, occupational therapy, and medical equipment such as wheelchairs, orthotics and eyeglasses. Parents and legal guardians may apply for grants of up to $5,000 each for child medical services and equipment by completing an online grant application. To be eligible for grants, children must be 16 years of age or younger, and families must meet economic guidelines, reside in the United States and be covered by a commercial health benefit plan. For an application form and further details, contact:

UnitedHealthcare Children’s Foundation  
9700 Health Care Lane  
MN017-W400  
Minnetonka, MN 55343  
Phone: (855) 698-4223  
Email: UHCCF SUPPORT  
www.uhccf.org

**Bridges to Access Program of GlaxoSmithKline:** Bridges to Access is the patient assistance program of GlaxoSmithKline that provides GSK non-oncology medicines at no cost to qualified patients. Products available are those manufactured by GSK, particularly epilepsy medications and respiratory medications. Patients can apply directly to Bridges to Access for assistance. Enrolling in the program can be done by fax or mail, or, if medication is needed the same day, by having a patient advocate such as a social worker, case worker or nurse enroll the patient via phone. A completed application and income documentation is needed to determine eligibility in the program. For further details to enroll contact:

Bridges to Access  
P.O. Box 29038  
Phoenix, AZ 85038-9038  
Phone: (866) 728-4368  
www.bridgestoaccess.com
IN LOVING MEMORY

CHELSEY JANE WORSTER, daughter of Paula & Jay Worster, Lee, ME
Born: 08-06-95    Died: 03-21-13    Juvenile

BRYAN OOSTERVELED, son of Kees & Helga Oosterveld, Wolvega, The Netherlands
Born: 11-06-03    Died: 03-19-13    Infantile (Variant)

MARCI HASSELL, daughter of Jodi & Jerry Holtzman, Evansdale, IA
Born: 03-14-91    Died: 03-09-13    Juvenile

DYLAN CLASPILL, son of Monica Stoney, Abilene, TX
Born: 09-24-03    Died: 03-02-13    CLN5

SKIP SMEDEMAN, son of Henk and Judy Smedeman, Hellevoetsluis, The Netherlands
Born: 07/26/95    Died: 02-26-13    Late Infantile

CASEY MUELLER, daughter of Mike Mueller, Minier, IL, and
Terri & Steve Kellum, Baltimore, MD
Born: 05-01-84    Died: 02-23-13    Juvenile

DEON AMOSAH, son of Phil & Tanya Amosah, Oxbow, SK, Canada
Born: 04-14-03    Died: 02-14-13    Late Infantile

JEREMY FIELDS, son of Cecelia Fields, Siler City, NC
Born: 01-12-88    Died: 12-09-12    Juvenile

SYED ABDULLAH, son of Ayaz Kaleem & Farah Hakim, Corona, Ca.
Born: 10-20-95    Died: 12-01-12    Juvenile

HANNAH DAVIS, daughter of Bill & Peg Davis, Bovey, MN
Born: 07-19-81    Died: 11-18-12    Juvenile

CHRISTOPHER D'ORSAY, son of Robert & Wendy D'Orsay, Barrie, Ont., Canada
Born: 10-04-87    Died: 11-13-12    Juvenile/Grods

BDSRA takes great care to memorialize those individuals who have passed away from Batten disease.
If a person is omitted from this page, it is because BDSRA was not notified of the death,
did not have permission to publish, or did not have confirmed information.
The Batten Disease Support and Research Association has been remembered many times in the past three months by families and friends affected by Batten disease. Thank you for your generous contributions. This support for the vital mission of research and services for families is crucial to finding a cure. We are also grateful to those supporters who have participated in events and volunteered their time to advance our efforts for Batten disease research and family services. We also acknowledge in this donor list all the generous contributions made through the 2012 Annual Fund Campaign.

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Catie and Annie’s Cops
Vacaville Police Officers Association
KELLY ALLIO
Julia Mitchell
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Continued on page 13
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Honor of Brandon and Jeremy Hawkins
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Honor of Kelsey Fuller
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Please direct any questions or concerns regarding this list to Tracy Kirby at tkirby@bdsra.org or (800) 448-4570, ext. 13. Thank you for your continued support.