



The Illuminator is now electronic! We're doing our part to "go green" and "save green" by reducing postage. If you have any future changes to your email address, please be certain to let us know so you don't miss an issue. Please feel free to share this newsletter with all of your local friends and supporters. We appreciate your feedback, but please be gentle, it's our first try. It will keep improving as we develop our skills.

Summary of contents:

- Creating Drug Discovery for JNCL
- INCL Research Meeting Review
- Programs Update
- New Zealand Update: After Earthquake
- And much, much more!



SPECIAL CHILD – AVEREE PIERCE

Averee was welcomed into the world on March 9th, 2004 weighing 8lbs 14ozs. The most precious little thing that you ever did see. Averee was a very active baby - she met all of her milestones at an early age apart from her speech, but we weren't really too concerned about it.

Averee had her first seizure on June 21, 2007. She was at a grocery store enjoying her bag of chips and talking to everyone that she saw. It was then that Averee started stumbling; I picked her up and she was unresponsive. We took her to the hospital and it was there that they sent her in an ambulance to a bigger hospital two hours away to get checked by the pediatrician. He said Averee was fine and sent her home but she would have to go back a few days later to have an EEG.

Averee had her EEG done but we didn't get the results until July 16, 2007. By this time Averee already had another staring spell so we knew there was something wrong. The doctor told us that she had an absence seizure. The pediatrician referred her to the Janeway Children's Hospital. The neurologist gave Averee another EEG and it was then he diagnosed Averee with epilepsy.

The neurologist started Averee on Tegretol. After about two weeks of taking this medication, Averee began to drop to the floor. Then she developed a really bad rash and we found out she was allergic to the medication. While Averee's condition was declining the nurse coordinator of the neurology department had mentioned Batten disease to us. We really didn't know much about it so we researched it and decided to get her tested in March of 2008 by a skin biopsy under her arm.

On April 3, 2008 we got the most devastating news ever, something that no parent should ever have to hear - that Averee had Late Infantile Batten Disease. There is no preparation for news like this but we have learned to take it one day at a time. Since being diagnosed, Averee has lost her ability to



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

walk, talk and is now being fed through a G-Tube. It's heartbreaking to watch your child go through something like this.

Averee is still the happy go lucky little girl that we have always had and loved and we enjoy spending every moment with her.



To learn more about Averee,
please visit *Averee's Purpose* at www.avereespurpose.ca



NOAH COUGLAN'S RUN FOR RESEARCH

By: Adina Ryan, Director of Development

On Monday, February 28, World Rare Disease Day, Noah Coughlan began a coast-to-coast run across the Southern U.S. to raise awareness and

funding for Batten disease. He has traveled over 250 miles to date to Phoenix, AZ.

Noah, 27, will run from Oceanside, CA, to Jacksonville, FL, averaging 25 to 30 miles a day in an effort to rally support for our families and to inform the general public about this disease. This journey will take Noah more than 2,400 miles and more than 4 months to complete.



WE NEED YOUR HELP! This is a big undertaking and there are ways that everyone and anyone can get involved. Here's what you can do:

- **Visit the website** <http://www.bdsra.org/noahrun.html> to learn more about the event and spread the word among your family and friends.
- **Host an e-mail fundraiser** or local walk/run to raise money for his journey. Take pledges per mile, or raise funds to pay for a day of his food, lodging or gas. All proceeds will benefit BDSRA.
- **Keep current with his journey**, visit the site often to check on his progress and send him e-mails with encouragement and thanks for his efforts on behalf of our children.
- **Share your story** and this amazing journey with your local media, get them involved, create a local buzz! We have press releases, advisories and video available...and you...you have your own personal story.
- **If you live in Southern CA, AZ, NM, TX, LA, MS, AL or FL**, call our office or e-mail us to see how you can get more involved and be of support when he arrives near you!

Visit www.BDSRA.org/noahrun.html for more information.

HOPE LOVE PATIENCE GRACE



BEYOND BATTEN DISEASE FOUNDATION: CREATING PLANS FOR DRUG DISCOVERY IN JUVENILE NEURONAL CEROID LIPOFUSCINOSIS (JNCL)

By: Danielle M Kerkovich, PhD, Principal Scientist of the Beyond Batten Disease Foundation

“Drug-able” targets in Juvenile Batten or other diseases are defined as a key molecules involved in cellular functions disrupted by disease. Since 1989, JNCL investigators have published over 400 peer-reviewed journal articles on the possible functions of CLN3 protein and the cellular and brain pathology resulting from *CLN3* mutations. While the function of CLN3 protein is still a “black box” in many ways, we do know a lot about the cellular functions disrupted by disease. We have targets; vulnerable cell populations, accumulated storage material to remove, dysfunctional pathways to resolve, and ultimately, a protein to replace or repair.

We also know that everything is works “up to a point.” For several years, a child with JNCL appears healthy so if something could tilt the balance in the early stages of the disease, that may be all it takes to make a difference. If we could bring the function of JNCL brain cell pathways back, closer to normal, we could drastically improve the lives of children with JNCL and their families.

On February 6-8, 2011, the Beyond Batten Disease Foundation (BBDF), together with BDSRA and NCL-Stiftung, our Germany-based colleagues sponsored 20 JNCL investigators from around the world to attend the *5th Drug Discovery in Neurodegeneration: An Intensive Course on Translating Research into Drugs* in San Diego CA. The purpose of the course was to teach basic scientists working on neurodegeneration principles in drug discovery, to provide a platform for the exchange of ideas, knowledge, and resources between biologists in academia and medicinal chemists in industry, and to stimulate collaboration that focuses and empowers each member of translation pipeline to excel in their areas of strength.

The course was immediately followed by a ‘think tank’-style one-day conference focused solely on drug discovery for JNCL. Researchers from academia who had just been primed with current information on the principles of drug discovery met face-to-face with industry-trained leaders in drug discovery from the federal funding sector, the pharmaceutical industry, and newly formed academic hybrids. To prepare for the day-long ‘brainstorming session’, these drug discovery experts had been introduced to JNCL via a three-part webinar series presented by experts in Batten disease research**.

Together investigators and drug discovery experts discussed JNCL-specific drug targets, prioritized which targets could have the greatest impact on health, and suggested strategies for developing effective screens and how to streamline current processes and work together to find treatments for JNCL. This was the first time JNCL investigators, clinicians, and industry experts gathered together to create a drug discovery action plan to apply emerging findings in JNCL basic science to the science of drug discovery. As one of our JNCL scientists put it, it’s “like speed-dating for scientists”, getting together people who wouldn’t otherwise meet to stimulate collaborations and speed the path to drug discovery.

Today the BBDF is maintaining the momentum of the course and conference by working with various experts in Batten disease, drug discovery, public policy, and rare disease to explore the development of collaborative projects between drug discovery centers across North America. For more information, please see the upcoming BBDF May newsletter.



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

* The Alzheimer's Drug Discovery Foundation, which developed and hosted the *5th Drug Discovery in Neurodegeneration: An Intensive Course on Translating Research into Drugs* is the only public charity solely dedicated to rapidly accelerating the discovery and development of drugs to prevent, treat and cure AD. The ADDF expanded their efforts in 2006 to share drug discovery education and awareness with academic researchers studying PD, MS and ALS. BBDF is proud and thankful for our partnership with ADDF, which adds Lysosomal Storage Disease to this list.

** To obtain access to pre-meeting, course or conference materials or updates on this and other BBDF-sponsored scientific activity, please contact Danielle M Kerkovich, PhD, Principal Scientist of the Beyond Batten Disease Foundation at dkerkovich@beyondbatten.org or 202/812-6462.

2011 REQUEST FOR PROPOSAL (RFP)

The Batten Disease Support and Research Association (BDSRA) is pleased to announce that limited funds are available to promote research and/or assist in a promising research project/s primarily for, but not limited to, development of novel therapeutic approaches for treatment of NCL. The BDSRA specifically seeks proposals aiming to:

- Identify bioactive compounds and characterize cell-based therapeutic strategies
- Utilize proteomic and genomic approaches to improve understanding of NCL
- Explore the neurobiology of NCL disease to determine the molecular pathogenesis in the CNS
- Gain an improved understanding of the cell biology of the NCL proteins/enzymes
- Characterize the substrate and/or storage material
- Identify biomarkers
- Identify the function of the CLN3 transmembrane protein

Proposals will be considered for all forms of NCL, with emphasis on CLN1, CLN2, and CLN3.

Deadline: Submissions will be received in pdf format attached to email dated no later than 11:59 PM EDT, May 15, 2011.

NEW BOOK ON BATTEN DISEASE NOW AVAILABLE

Authored by Sara Mole, PhD, Ruth Williams, MD and Has Goebel, PhD, *The Neuronal Ceroid Lipofuscinoses (Batten Disease)* is the latest book that covers all the forms of Batten disease.

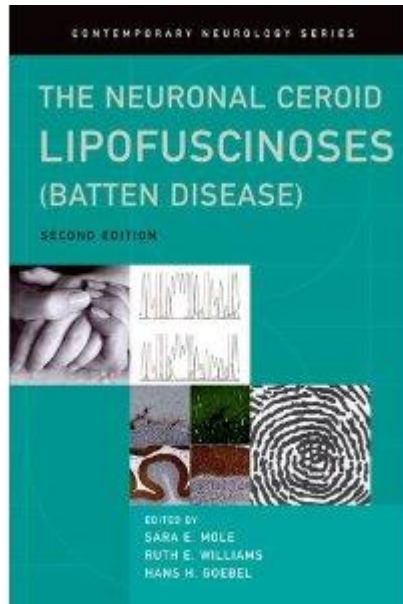
Review: This new edition will be the definitive reference work for the next decade for consultation by clinicians, research scientists, diagnostic laboratories, families affected with the disease and industry planning translational research. The format is similar to the original book, and includes invaluable



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

advice on the genetic, clinical, diagnostic, morphological, care and treatment options available. All chapters have been updated and new chapters have been written by experts in their respective fields.



Dr. Mole has put on her website a 20% voucher that you can use to order direct from OUP. Or you can order at a 7% discount from USA Amazon at <http://www.ucl.ac.uk/ncl/Resources.shtml>.



BATTEN DISEASE
SUPPORT & RESEARCH ASSOCIATION

BDSRA ANNUAL CONFERENCE

July 14-17, 2011

Hosted by the Minnesota Chapter
Minneapolis Airport Marriott
2020 American Boulevard
East Bloomington, MN

We are very excited about this year's Annual Conference, graciously being hosted by the Minnesota Chapter. They are planning all kinds of great things and we thank all the committee members for their time, energy and ideas. Registration packets will be mailed the second week in April, but don't forget that conference and registration information are also available online at <http://www.bdsra.org/conference11.html>.



INCL RESEARCH MEETING

By: Lance Johnston, Executive Director

This is a summary of the recent INCL research meeting held March 5, 2011 in St Louis, Missouri, organized and hosted by BDSRA.

Attending:

Sandra Hofmann, PhD, University of Texas Southwestern

Mark Sands, PhD, Washington University in St Louis

Eric & Christine Thelen, Hayden's Hope Batten Foundation

Sharon King, Taylor's Tale Foundation

Lance Johnston, Executive Director, BDSRA

Kim Zellmer, Esq., BDSRA Vice President (by telephone)

Purpose of meeting was to update everyone on current status of research into Infantile Batten disease and how to advance to human trials.

1. Sandra Hofmann did update on her research into ERT. ERT shows that it can extend life span of mice. Mice treated at birth do the best and their liver and spleen showed significantly less storage material vs. untreated. Soon ready to be moved to a pharma company. Need to have a large company be able to produce enzyme quantity useable for humans. Because of lack of funding from NIH, etc., she will be giving up mouse colony and likely one person out of her lab.
2. Mark Sands updated on latest information on his work with INCL mice. CNS-directed gene therapy by itself shows significant biochemical, histological and clinical improvements. Bone marrow transplant (BMT) by itself provides no benefit. However, the two treatments together show great synergy and reveal that life span of mice can be doubled. Most significant improvement in life span and rotorod performance is with mice treated immediately after birth. Unknown if BMT is providing systemic enzyme. Likely have to do an ERT to peripheral body. Dr. Sands is confident that this is a good therapy and needs to go to human trials.
3. Discussion ensued regarding how to get to human trial:
 - a. Results must be published. Dr. Sands believes submission for publication will be in a few weeks.
 - b. After publication, need to make face-to-face meeting with FDA to discuss toxicology studies. Currently expecting to have to do nonhuman primates (monkeys). Maybe able to do a different large animal, i.e., rabbit or dog. Also have to make certain FDA accepts his mouse data as small animal toxicology study. Cannot move further until tox studies are completed.
4. FDA – help or roadblock? Discussion about how to approach FDA and get them to be help and not hinderance. Kim Zellmer will talk to Drs. Landis and Tagle to gather any insight and,



- perhaps, support. It was agreed that BDSRA and family foundation reps need to accompany Dr. Sands to FDA. Anybody we can get should be a help.
5. It is determined that there is a need for identification of biomarkers and a natural history in order to have clinical end points.

FROM THE NURSES CORNER

By: Nancy Carney, RN

Scoliosis

Scoliosis is defined as a sideways or lateral curvature of the spine or backbone. The bones that make up the spine are called the vertebrae. Some people who have scoliosis require treatment and others, who have milder curves, may only need to visit their doctors for periodic observation.

Who gets scoliosis?

In most cases, the scoliosis is idiopathic (80% of cases), meaning that it is not known what has caused the curvature to occur. It is not caused by having poor posture or carrying a heavy book bag and, in most cases, if detected early, can be treated and does not cause any permanent problems or disabilities. Scoliosis is usually painless. Adolescents are the most common age group to have idiopathic scoliosis, and it usually begins between the ages of 10 and 14. While it occurs about equally in both boys and girls, girls are much more likely to have a progression of the curve that requires treatment. Only about 10% of children with scoliosis require corrective treatment with bracing or surgery. The rest (90%) will not require treatment and will have no long lasting effects or symptoms from the curve.

In every 1,000 children, 3-5 may develop a spinal curve large enough that needs treated. Scoliosis can run in families, so if one child has it, it may be wise to have your other children checked yearly at young ages. Early onset usually occurs younger than 3 years of age. This type is seen more in Europe than in the United States. Juvenile scoliosis is seen in children between the ages of 3 and 10.

What causes scoliosis?

In 80-85%, the cause is unknown. It also could be due to an injury or infection, or a nonstructural or structural condition. A nonstructural condition is a spine that appears curved possibly by a difference in leg length, muscle spasms or inflammatory conditions, such as appendicitis. Doctors treat this type of scoliosis by treating the underlying problem. A structural curve could be one such as an inherited connective tissue disease as Marfan's syndrome (in which you see a tall, lean body with long extremities, including fingers and toes), or cerebral palsy, muscular dystrophy, birth defects, certain infections or tumors, metabolic diseases, rheumatic diseases or idiopathic scoliosis.

How does the doctor diagnose scoliosis?

The doctor will do a thorough history to look for causes of a curvature and do a physical examination. Should he find a curve or asymmetry, he may refer you to an orthopedic spinal specialist. Either doctor can order x-rays to confirm the diagnosis. If a curve is present, they can measure the angle of the curve to measure the degrees of the curve. If greater than 20 degrees, they will discuss treatment with you. Doctors group curves by their location, shape, pattern and cause. The location is where the vertebrae within the curve is the most off-center. The shape is either a S or C shaped. And the pattern



follows patterns that have been studied in previous patients. The larger the curve, the more likely it will progress (depending on the amount of growth remaining).

Does scoliosis have to be treated? What are the treatments?

The doctor will suggest treatment for each child based on the child's age, how much more he or she is likely to grow, the degree and pattern of the curve, and the type of scoliosis. The doctor may recommend:

- Observation – doctors follow children every 4-6 months when the child is still growing and has an idiopathic curve of less than 25%
- Bracing – doctors advise children to wear a brace to stop a curve from getting any worse when the child:
 - is still growing and has an idiopathic curve that is more than 25–30 degrees;
 - has at least two years of growth remaining, has an idiopathic curve that is between 20-25 degrees, and if a girl has not had her first menstrual period; or
 - is still growing and has an idiopathic curve between 20-29 degrees that is not getting worse
- Surgery – doctors advise children to have surgery to correct a curve or stop it from worsening when the child is still growing, has a curve that is more than 45 degrees, and has a curve that is getting worse
- Chiropractic manipulation
- Electrical stimulation
- Nutritional supplementation
- Exercise – exercise alone will not stop progressive curves, but you may want to have your children do exercises for the effects on their general health and well-being.

These last four have not shown any prevention of curve progression or worsening of the curves.

If the doctor recommends surgery, which procedure is best?

Many surgical techniques can be used to correct the curve of scoliosis. The main procedure is correction, stabilization and fusion of the curve. Fusion is the joining of two or more vertebrae. Surgeons can choose different ways to straighten the spine and also different implants to keep the spine stable after surgery. Implants are devices that remain in the child after surgery to keep the spine aligned. The decision about the type of implant will depend on the cost; the size of the implant, which depends on the size of the child; the shape of the implant; its safety; and the experience of the surgeon. Each child/parent should discuss their options with experienced surgeons. Parents who are thinking about surgery may want to ask the following questions:

- What are the benefits from surgery for scoliosis?
- What are the risks from surgery for scoliosis?
- What techniques will be used in surgery?
- What devices will be used to keep the spine stable after surgery?
- Where will the incisions be made?
- How straight will my child's spine be after?
- How long will the hospital stay be?
- How long will it take to recover from surgery?
- Is there chronic back pain after surgery for scoliosis?
- Will my child's growth be limited?
- How flexible will the spine remain?



- Can the curve worsen or progress after surgery?
- Will my child be able to do all the things he or she wants to do following surgery?

Can children exercise with scoliosis?

Exercise does not make scoliosis worse. In fact, it is very important for all those with scoliosis to exercise and remain physically fit. Girls have a higher risk than boys of developing osteoporosis (a disorder that results in weak bones that can break easily) later in life.

What are researchers trying to find out about scoliosis?

Researchers are looking for the cause of idiopathic scoliosis. They have studied genetics, growth, structural and biochemical alterations in the disc and muscles, and central nervous systems changes. The changes in the disc and muscles seem to be a result of the scoliosis and not the cause. Scientists are still hopeful that studying changes in the central nervous system in children with idiopathic scoliosis may reveal a cause for the disorder. Researchers continue to examine how a variety of braces, surgical procedures and surgical instruments can be used to straighten the spine or to prevent further curvature.

How does scoliosis relate to Batten disease?

In the Clinical Database that I keep, I have 68 children that have reported some form of scoliosis. That seems like a high number in Batten disease but it did state in one of the references that it was higher in metabolic diseases. We do not know why. Scoliosis is fairly equal in Infantile, Late Infantile and Juvenile children. It seems like the majority of children developed scoliosis around the ages of 6-12, although there were some at 18 months to 3 years of age and some from 16-27 years of age. Six children that I know had surgery ranging in curvature from 50 degrees to 140 degrees, some that the curvature was greater than 40 degrees had special wheelchairs made, one used a wedge, two had braces, and one used rods for stabilization during surgery. Five were listed as "bad" and two were listed as "severe" and, to my knowledge, did not have surgery to correct the curvature.

How does scoliosis affect the body?

If the curvature becomes great enough, the respiratory system can become compromised and breathing can be very difficult by the vertebrae pushing on the diaphragm. Then surgery almost becomes mandatory. It all depends on how quickly the curvature is widening in degrees and how much the respiratory system is being involved.

If you would like to have any more statistics about scoliosis and Batten disease, you may contact me at the office at 877/642-5512 or nancycarney@bdsra.org.

Helpful Product

Resource Breeze is a product that was introduced to me by one of our families that can be very helpful for our children with Batten disease. It is for those children who do not yet have a G-tube but are experiencing trouble with eating. This mom is using it for her two boys with LINCL with good success. Here are some of its features:

- ❖ Nestle Corporation/Boost Product
- ❖ Natural Product
- ❖ Medicaid will cover the cost
- ❖ Edgepark.com – 8:30 a.m. to 5:30 p.m.
- ❖ UPS shipping to your door in 4 days from date of order; 3-4 cases \$300/month



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

- ❖ Juices with different flavors - Peach, Wildberry, Cranberry, Orange
- ❖ Lactose-free, fat-free
- ❖ Three boxes/day (with straw on back) – chill it
- ❖ Already nectar thick

If anyone needs further information or has questions, please contact me at the office at 877/642-5512 or nancyarne@bdsra.org.

SOUTH AMERICAN CHAPTER



From Left: **Rosilene** – mother of Jennifer, 12 years old; **Raquel** - mother of Gustavo, 31 years old; **Margarete** - mother of Mateus, 12 years old & Felipe (who died at 9); **Sirlene** - mother of Débora, 12 years old; *Pictured in foreground is Gustavo.*

Uma pessoa especial...“A Special Person”

March 19, 2011

Four mothers who live in Belo Horizonte, Brazil, and have children with Batten disease, gathered at the home of Raquel de Faria, President of BDSRA's South America Chapter.



EDUCATION SUPPORT UPDATE

By: *Wendy Bills, PhD, Education Specialist for BDSRA*

On June 12-14, in Park City, Utah, we will hold a special training for Batten Disease Education Consultants. Trained BDSRA consultants have been invited to meet again for further training on conducting functional behavioral assessments, writing behavior intervention plans, and communicating with parents, teachers, and administrators. We will also cover thoroughly how to review IEPs and make suggestions to improve goals for our special students. Our goal is to provide families with professionals who can help them navigate the school system. Please inform your children's schools that this service is available.

IT'S ALL ABOUT YOU: BDSRA PROGRAM UPDATES

By: *Lisa Weston, Program Director*

Sibs Support

At the 2010 conference, each sibling was challenged to raise \$100 before the 2011 conference. Adina Ryan, BDSRA's Director of Development, spoke to sibs ages 14 and up during one of the sessions, offering different fundraising ideas. The challenge was announced at the dinner Saturday night. To date, the Sibs' fundraising efforts have brought in almost \$1,200 since August 1, 2010. We appreciate those efforts and continue to encourage the sibs to meet that 2010 challenge as we get closer to the 2011 Annual Conference!

Equipment Exchange

Don't forget that BDSRA has quite a bit of gently used equipment available to our families. If you need, or have, any equipment or supplies, please contact either nancycarney@bdsra.org or me at lisaweston@bdsra.org. We are happy to assist with delivery and pick-up arrangements. Your donation of equipment is tax deductible.

Tissue Donation

The Batten Disease Tissue Program provides families with information about the importance of tissue donation, as well as provides support to families having to make such difficult decisions. This is an effort to keep vital research moving forward that will ultimately produce better lives for children and young adults with Batten disease. If you are interested in knowing more about this program, please contact me and I can provide you with details and our recently updated materials. Your gift may literally change the course of Batten disease research and lead to the ultimate goal of saving the lives of children.

Sibling Carrier Testing

The purpose of the Sibling Carrier Testing Program is to make available to siblings of individuals affected with Batten disease the opportunity to be tested for carrier status. The program will also cover carrier testing for qualified spouses or fiancées and diagnostic testing for children of siblings. For more information regarding testing protocol, eligibility, costs and available funding, confidentiality, etc., please feel free to contact me.



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

FRIENDLY REMINDER:

Please pay your BDSRA membership dues by May 1 if you have not already done so. We very much appreciate your support!

BOARD OF DIRECTORS NOMINATIONS

We have four (4) board positions available for a three-year commitment to serve the organization beginning at the July conference in Minneapolis. Nominations for Board of Directors will be received up to April 25, 2011. Please send nominations to Rob Geer at geer@umich.edu. Ballots will be mailed to all current paid members on May 1 and ballots must be received by 11:59 p.m. on May 15. If you have not sent in your 2011 membership dues, they must be paid in order to vote. Results of the election will be announced the third week in May. Questions may be addressed to geer@umich.edu, bdstra1@bdstra.org or 800-448-4570.

MEGAN

By: *Mike Soccol*

She would walk on the field
A smile ear to ear

Her sickness wouldn't yield
But she played year after year.

The on deck circle was the place to be at
For Megan knew well she was next up to bat.

The pitcher would wind up and throw her a ball
Though Megan was blind, she would hit one and all.

If you ever see a star twinkling bright in the night,
It's Megan taking batting practice with all of her might.

For now she's on God's team and plays second base,
And no one on earth can take Megan's place.

Mike Soccol was Megan Harriman's baseball coach. Megan played for the Rohde's Wildcats Challenger Baseball team in Clifton, NJ.

HOPE LOVE PATIENCE GRACE



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

KID'S CORNER

By: Donna Gunn, Office Manager

BDSRA gives a BIG "Hip, Hip Hurray!" for the young people within the Batten families who are willing to give of their time and generosity of heart to help in the fight against this disease. And so we want to graciously thank:

- Miss Leah Kennedy for giving a donation in honor of her classmate, Lily Hurt. Leah, you are truly a great friend!
- Misses Reese & Abby Tucker, who held a lemonade stand fundraiser in their drive way to raise money in honor of Jake Medley. Way to go, girls!

We thank these young people from the bottom of our hearts!

TIME IS LIMITED FOR THE MEMORIAL

Dear Parents: If you would like to have a photo of your child placed on the Memorial DVD for conference this year, the photo must be received by the BDSRA office, 166 Humphries Dr., Reynoldsburg, OH 43068, no later than May 1, 2011. For those families who lost a precious child this year, we must also have the permission form (that was sent to each family) returned by the same date.

NEWS FROM SERBIA

BDSRA is thrilled to announce that Dr. Ruzica Kravljanac has accepted Dr. Katherine Sims invitation to come to the U.S. this spring as a visiting fellow to observe and participate in clinics at Massachusetts General Hospital (a Batten Disease Center of Excellence) and Children's Hospital Boston. This is an excellent opportunity for Dr. Kravljanac to see patients, establish a collaborative relationship and further her NCL and Batten disease knowledge. She will also spend time in Columbus, OH, attending a Clinic Day at another Center of Excellence, Nationwide Children's Hospital, touring the hospital and meeting with the Batten disease medical team. Dr. Kravljanac's whirlwind itinerary includes a visit to the BDSRA office, to meet the staff, and to learn about the organization and our family support programs and services.

A recent e-mail from Stevan Čović, President of Child Rare Disease Support and Research Association "LIFE" (*Zivot*) in Serbia, included this picture and note:

"We are proud to inform you that "Life" was invited to hold a presentation at the first Pharmaceutical



FUNDRAISING EVENTS IN OHIO

By: Ann Salladin, Parent Volunteer

Benefit Held in Vaughnsville, OH for Benroth Family

Family and friends of the Benroth family held a benefit on February 27 in Vaughnsville, OH, to raise awareness and support for Katie's gene therapy treatment she received March 1 in New York City., Katie's sister, Lauren, whose birthday is March 10, was able to join Katie in New York and celebrate her birthday for the final week of Katie's stay in the hospital. Between 500-600 community residents of all ages enjoyed a variety of well-planned events. The benefit, held from 2 p.m. - 8 p.m., featured a bake sale, DJ, Bingo, a 50/50 drawing, silent auction, Euchre tournament, face painting, and opportunities to visit while enjoying plates of delicious food. The cost of \$15 for an individual, or \$30 for an entire family, included entertainment, food, soft drinks and five raffle tickets. The *Putnam County Sentinel* published a front page story featuring the Benroth family and Batten disease prior to the event. BDSRA's office was represented by Nancy Carney, RN, and Ann Salladin, Parent Volunteer.

Pancake Dinner in Columbus, OH

March 8 was the date chosen by the AWARE youth group of near-teens and teens of St. Stephen's Episcopal Church and University Center, which adjoins the Ohio State University campus, to sponsor a Shrove Tuesday Pancake Dinner fundraiser for Batten disease. Hometown Honorees Celia Betz and her family, some of whom attend St. Stephen's, were present.

A group of enthusiastic and energetic young people under adult guidance and supervision planned and worked the event. A meal of freshly made pancakes, breakfast meats, a fruit cup and beverage was served for \$5.00, and donation baskets were placed on each table. A total of \$1,041.00 was raised for Batten disease. Additional awareness was promoted with a table display providing information about Batten disease, and a five-minute DVD, "The Batten Journey," was available for people to watch at their convenience. BDSRA ribbon magnets, bears and awareness bracelets were available for sale. The home office was represented by Ann Salladin, Parent Volunteer.

NEW ZEALAND - UPDATE AFTER EARTHQUAKE

By: Lisa Weston, Program Director

Ra Timms, the president of the newly-formed New Zealand Chapter, recently wrote to let us know how she and other families affected by Batten disease are managing after a 6.3 magnitude earthquake struck the Canterbury region of New Zealand's South Island, near the country's second largest city, Christchurch, this past February. Ra reports that they "felt it very strongly here," experiencing damage and cracks around the exterior of their house. She said there was some trouble contacting and locating the four or five LDNZ (Lysosomal Disease) families in the direct vicinity of the



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

quake, as well as getting necessary supplies to them. Although he is fine, Professor David Palmer apparently had a lot of damage to his own home.

Ra said she “was up in Christchurch last weekend [March 5-6, 2011] and felt [a] 5.0 aftershock. The fear of it totally immobilized me but we were all ok. What you see on TV is nothing compared to the destruction in some areas. Other areas, you wouldn’t know there had been an earthquake at all. It is unfathomable to see a house that is nothing but rubble whilst those around it are ‘ok’. Some houses looked as though they were a giant’s play-thing and had been carelessly tossed aside. There were some that were twisted and contorted.”

“We have a lot of ‘quake refugees’ in Timaru. You can tell by the look on their faces; tired and stressed. Some of my family have picked up, packed up and left Christchurch. Many people are weary of ‘the moon man’s’ further predictions of there being another on March 20-23 and a bigger one in April...I don’t blame them. We, in Timaru, are already preparing ...just in case...as there are many things you can’t get off the supermarket shelves in an event like this.”

We ask all the families and friends of BDSRA to keep our New Zealand families in your thoughts and prayers as they work to rebuild from the impact of this devastating natural event.

REMINDER ABOUT A WAY TO HELP BDSRA!

When you fly on American Airlines, American Eagle® or AmericanConnection® carriers, Batten Disease Support and Research Association (BDSRA) can earn points while you who travel still earn your personal AAdvantage miles. So everyone gets rewarded! Make sure to encourage your family and friends to include BDSRA’s Business ExtrAA account number **823093** in their reservations and in their personal AAdvantage accounts. This will make earning points for BDSRA effortless when booking travel online at AA.com. If you use a travel agency, make sure they have the number, too.

When you purchase a ticket from American Airlines, American Eagle® or AmericanConnection® there will be a space close to the bottom of the page that asks:

Business ExtrAA Account Number _____

Just enter **823093** and BDSRA will earn points and so will you if you have a personal frequent flier account with American.



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

♥ *In Loving memory* ♥

NIELS LAUWEN, son of Marie-Louise Lauwen, Rucphen, Netherlands

Born: 12-17-91 ♦ Died: 12-05-10 ♦ Juvenile

KOURTNEY HARMON, daughter of Donna Fogle, St. Augustine, FL

Born: 01-17-02 ♦ Died: 12-29-10 ♦ Late Infantile

THOMAS ONEIL SOMERS, son of Tim & Sherry Somers, Fort Fairfield, ME

Born: 01-26-00 ♦ Died: 12-31-10 ♦ Late Infantile

CHRIS GAINES, son of Becky Lucas, Jemison, AL

Born: 12-11-74 ♦ Died: 01-03-11 ♦ Juvenile

SAOIRSE HEFFERNAN, daughter of Tony & Mary Heffernan, Castlemaine, Ireland

Born: 06-04-05 ♦ Died: 01-18-11 ♦ Late Infantile

JEMYNI BEAN, daughter of Cynthia & Robert Bean, Spokane, WA

Born: 05-27-00 ♦ Died: 01-24-11 ♦ Infantile

NICHOLAS PAUL JEWETT, son of Paul & Patsy Jewett, Burt's Corner, New Brunswick

Born: 12-15-79 ♦ Died: 02-21-11 ♦ Juvenile

MATTHEW STEWART, son of Kevin & Diane Stewart, Palm Springs, CA

Born: 05-15-87 ♦ Died: 03-06-11 ♦ Juvenile





APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

FIRST QUARTER DONOR GIFTS

(as of March 15, 2011)

Batten Disease Support and Research Association has been remembered many times in the past three months by families and friends of children with Batten disease. To all of you, we express our deepest appreciation for your generous gifts. We sincerely apologize if there are any omissions or misspellings; please alert us to any changes. We kindly ask that with any future gifts, you specifically indicate whether the donation is in "Honor of" or in "Memory of."

In Honor Of:

BDSRA

Ms. Pamela Christensen

KATE BENROTH

Ms. Phyllis Willer

CHRISTIANE BENSON

Dad & Mom

CELIA BETZ

Ms. Stephanie Bailey

Mr. & Mrs. Adam Betz

Mr. Christian Coyle

Ms. Amber Epling

Mr. & Mrs. George Epling

Ms. Holly Epling

Mr. & Mrs. Joe Kessmeier

Mr. & Mrs. Michael King

Mr. & Mrs. Edward Midkiff

Mr. & Mrs. Joseph Oliverio

Mr. Bryan Shelton

Ms. Jamie Smith

Mr. & Mrs. Cory Vaudt

AIRON & CAMERON BOLEY

Ms. Cassandra Rousseau

JONATHON BROWN

Mom

ZICHAELA CAFFEY

Ms. Michelle Caffey

HOLLY & DANIELLE CARBREY

Grandpa & Grandma Carbrey

NAOMI CAUGHEY

Ms. Jeanne Jacobson

Ms. Dawn Morrison

Mr. & Mrs. John Shantz

Ms. Katie Swinson

Ms. Margaret Warmke

BECCA COLLINS

Ms. Dori Barker

Ms. Deneen Leone

In Memory Of:

KARI ANDERSON

Dad & Mom

CURTIS ANTHONY

Great Grandpa & Grandma

Anthony

WHITNEY BARROW

Ms. Renee Jordon

AMY & MIKE BOER

Dad & Mom

Mr. Robert Merkle

RACHEL BONNELL

Mr. Thomas Bonnell

ABBY BORTZ

Mr. Ryan Bornbach

DANIEL BREUER

Dad

LULU CALDERON

Dad & Mom

Ms. Georgina Griego

Ms. Joanna Harper

Mr. Joseph Oseguera

GARRETT CAMPBELL

Dad & Mom

HANNAH CAULFIELD

Dad

ALLY CHANCE

Dad & Mom

ELIAS CORTES, JR.

Ms. Adriana Carbajal

MEGAN DEPEW

Mr. & Mrs. Greg Stacey

EMILY DUGGER

Mr. & Mrs. James Brown

JOHN BRIAN DUNLAP

Ms. Bobbie Hudgins

JACOB EHRISMAN

Grandma Lauver



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

CLIFFORD DAHL

Dad & Mom
Friends of the Chatham Library
(Café)

Mr. George McIntyre
Mr. & Mrs. David Richert
Mr. Eddie Rodriguez

THE DOCKTER FAMILY

Mr. & Mrs. John Mitchell

KEN DOCKTER

Mr. & Mrs. Arthur Mezzano

ADIA ELFERT

Mr. & Mrs. Philip Elfert

THE FAIR FAMILY

Ms. Barbie Peace

THE FARET FAMILY

Mr. & Mrs. Francis Casta, III

RYAN FARET

Dad & Mom
Ms. Clare Casale
Mr. & Mrs. J.D. Gassman
Mr. & Mrs. Sorenson
Mr. & Mrs. Dean Thomas
Mr. & Mrs. James Thomas

DREW FERRANDINO

Dad & Mom

KELSEY FULLER

Mr. & Mrs. Vince Walsh

DANIEL GERARD

Ms. Valerie Paolucci

KELSIE HARDIN

Mr. & Mrs. John Hardin
Ms. Kathleen Moore
Mr. & Mrs. Bryan Williams

THE HAWKINS FAMILY

Ms. Sarah Hart/UpGrade Lifestyle

AUSTIN HEIN

Dad & Mom
Grandpa & Grandma Fink
Ms. Paulita Pranschke

JENNA HILL

Mr. & Mrs. William Bessette

ERNIE HOUGHTBY

Ms. Beth Kordt

LILY HURT

Miss Leah Kennedy, Lily's
classmate

CHRISTOPHER ISNARD

ERIK & JON EVENSON

Mr. & Mrs. Thomas Swanson

TRAVIS JACK FAIR

Mr. & Mrs. Greg Fair
Mr. & Mrs. Michael Muetzel
Mr. & Mrs. John Packard
Ms. Barbie Peace

JOHN FAVORITE

S.Q. Allhiser
Ms. Lorraine Brasket
Mr. & Mrs. Gerald Brytowski
Mr. & Mrs. Blair Bury
Mr. Richard Carlson
Mr. & Mrs. Mark Degonda
Ms. Janis Favorite
Mr. Thomas Gallagher
Mr. Joseph Getty & Ms. Anne
Loney
Mr. & Mrs. Raymond Gleason
Mr. & Mrs. Thomas Gleason
Mr. & Mrs. William Hall & Ms.
Katherine Blanchard
Ms. Susan Hart
Health Fitness
Mr. & Mrs. Charles Heimark
Mr. & Mrs. Michael Hussey
Mr. Clifford Johnson
Mr. & Mrs. James Jordan
Ms. Elin Krueger
Mr. Richard Krueger
Mr. & Mrs. Patrick Loney
Mr. & Mrs. David Longren
Mr. & Mrs. David Lund
Mr. & Mrs. Greg Mook
Ms. Helen Palmer
Ms. Barbara Plummer
Mr. Thomas Quirk
Mr. & Mrs. Robert Radde
Mr. Lee Radermacher
Ms. Gretchen Rasheed
Mr. & Mrs. Timothy Reiner
Mr. John Swift
Marilyn Thomas & Steven
Doimer
Mr. & Mrs. John Volkert
Ms. Laurie Volkert

AMANDA FITZGERALD
Ms. Valerie Johnson



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

Ms. Karen Adelman
Mr. & Mrs. Paul Bennett
Black River Middle School
Ms. Mary Boyce
Mr. & Mrs. Scott Cohen
Mr. Frederick Corona
Ms. Marion Dubow
Ms. Barbara Grace
Mr. & Mrs. Timothy Jeffers
Mr. & Mrs. Jay Noble
Mr. & Mrs. Christian Pechmann
Ms. Lynne Swanbeck
Mr. & Mrs. Patrick Turner
Ms. Katherine Vazquez

NOAH & COURTNEY JOHNSON

Grandpa & Grandma Depoi
Mr. & Mrs. Randall Latham
Mr. & Mrs. Mark Roberts

LANCE JOHNSTON

Mr. & Mrs. David Ryan

CHARLES JORDAN

Mr. Richard Meyer

RYAN KENNEDY

Ms. Blanche Kennedy

ZACHARY KILLINGER

APA Benevolent Fund

TAYLOR KING

Mr. & Mrs. William Hackney

JUSTIN LAVEN

Dad & Mom

NOLAN LEIS

Mr. & Mrs. Jim Klippel

ASHLEIGH & ALISHA LENNON

Ms. Sally Whitaker

ERIC LOWDEN

Mr. David Williamson

EDDIE MAJESKI

Mr. & Mrs. Stanley Rybicki

JOHN PATTERSON MANGUM

S.Q. Allhiser
Ms. Lorraine Brasket
Mr. & Mrs. Gerald Brytowski
Mr. & Mrs. Blair Bury
Mr. Richard Carlson
Mr. & Mrs. Mark Degonda
Ms. Janis Favorite
Mr. Thomas Gallagher
Mr. Joseph Getty & Ms. Anne
Loney

TONYA & BRANDEN FONTENOT

Mom

MELISSA FROIO

Dad & Mom
Ms. Carol Snyder

JIM FRYE

Ms. Dru Glenn, Niece

CHRIS GAINES

Ms. Lisa Bucklin
Mr. & Mrs. Ralph Cash
Mr. & Mrs. Dennis Dahl
George Emfinger
Shirley Emfinger
Friends at Huddle House in

Montville

Mr. & Mrs. Jimmy Goins
Mr. & Mrs. Hatchett
Mr. & Mrs. Kevin Hevze
Imm's Industrial Coating
Mr. & Mrs. Charles Leffler
Mr. & Mrs. Don Morlan
Mr. & Mrs. Tony Phillips
Piggly Wiggly No. 53
Employees

Mr. & Mrs. Stephen Thompson
Numerous, Numerous Friends

LUPE QUINTERO HARLOS

Mr. James Harlos, Grandson

KOURTNEY DANIELLE HARMON

Ms. Linda Fordem
Mr. & Mrs. Bill Ortino

MEGAN HARRIMAN

Dad & Mom
Mr. & Mrs. Thomas Gallenstein
Mr. Lewis Milrod

DANIEL HOUGHTBY

Dad & Mom

BOB IRELAND

Dad & Mom

BLAKE JAEGER

Dad & Mom

IRENE JERSHA & JAMIE JERCHA

Mr. & Mrs. Donald Blank
Mr. & Mrs. Mark Jercha
Mr. & Mrs. Anthony Tomich
Mr. & Mrs. John Wright

NICHOLAS PAUL JEWETT

Anglican Parish of Bright
Mr. Leo Beausoleil



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

Mr. & Mrs. Raymond Gleason
Mr. & Mrs. Thomas Gleason
Mr. & Mrs. William Hall & Ms.
Katherine Blanchard
Ms. Susan Hart
Health Fitness
Mr. & Mrs. Charles Heimark
Mr. & Mrs. Michael Hussey
Mr. Clifford Johnson
Mr. & Mrs. James Jordan
Ms. Elin Krueger
Mr. Richard Krueger
Mr. & Mrs. Patrick Loney
Mr. & Mrs. David Longren
Mr. & Mrs. David Lund
Mr. & Mrs. Greg Mook
Ms. Helen Palmer
Ms. Barbara Plummer
Mr. Thomas Quirk
Mr. & Mrs. Robert Radde
Mr. Lee Radermacher
Ms. Gretchen Rasheed
Mr. & Mrs. Timothy Reiner
Mr. John Swift
Marilyn Thomas & Steven
Doimer
Mr. & Mrs. John Volkert
Ms. Laurie Volkert

JONATHAN McCOLLUM

Mr. & Mrs. Paul Williams

CHRISTOPHER McDONOUGH

Mr. & Mrs. Jack Caveney
Ms. Maureen Rodgers
Mr. & Mrs. Charles Tindall

JAKE MEDLEY

Abby & Reese Tucker

THE MILANI FAMILY

Mr. & Mrs. Jeff Van Spankeren

JOEY MILANI'S 18th BIRTHDAY

Mr. & Mrs. Victor Karl
Mr. & Mrs. John Milani

JEFF MONTAVON

Compton Volunteer Fire
Department
Ms. Angela McConnell

STEVEN MUNKRES

Ms. Stephanie Ohnigian

ASHER NIKOLAJEVS

Ms. Connie Brewer
Ms. Nancy Brewer
Ms. Ruth Brewer
Mr. Tom Brewer
Mr. & Mrs. Keith Bull
Laurie & Cathy Burt
Ashley & Margaret Cummings
Mr. David Doimo
Ms. Pauline Foster
Ms. Wendy Haines
Mr. James Hallett
Mr. & Mrs. Paul Jewett
Ms. Wendy Jewett
Ms. Denise Jones
Mr. & Mrs. Ulric-Robert Jones
Mr. & Mrs. Wayne Jones
Mr. Joseph Kelemen & Ms.
Jane Grinstead
Mr. & Mrs. Harold Lawrence
Ms. Dawna Leger
Mr. Jack Lucas
Ms. Priscilla MacDonald
Mr. Robert McNeil
Mr. & Mrs. James Monteith
Mr. Frank Morehouse
Ms. Heather Olmstead
Mr. & Mrs. Joseph Pelham
Ms. Eleanor Phillips
Mr. Robert Poore
Ms. Carolyn Price
Ms. Jacqueline Rioux
Terry Sargeson
Mr. & Mrs. Ronald Smith
Ms. Susan Stockford
Mr. Derek Squire
Mr. & Mrs. Brian Wall
Mr. Robert White
Ms. Cheryl Wiezel

ELISABETH JOHNSON

Dad & Mom

ELAINE, LORENA & LEE JOHNSTON

Mr. Dean Wyse, Brother &
Uncle

CHARLES & LORETTA KELLUM

Ms. Diana Wright

DANIEL KERNER

Ms. Muriel Moster

BRET KILLEN



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

Mr. Sanford Black
THE PFOHL FAMILY
Mr. Bruce Bell
Belmark Inc.
Ms. Norma Griswold
CHRISTINE RATZ
Mr. & Mrs. Philip Hovis
Ms. Kate Oshima
**MR. & MRS. DEL SCHLESINGER'S 70th
ANNIVERSARY**
Mr. & Mrs. Brad Ehlers
Mr. & Mrs. Brandon
Schlesinger
Mr. & Mrs. John Schlesinger
Mr. Randy Schlesinger
THE SIKORRA FAMILY
Mr. Andrew Azzarello
JOHN SIKORRA
Mr. & Mrs. Jeff Klein
MASON SMERDEL
Anonymous
Ms. Bernadette Demoura
KRISTIN SMITH
Mr. & Mrs. Robert Ficken
Mr. & Mrs. Richard Steinbeck
MATTHEW STEWART
Mr. & Mrs. Kevin Stewart
KACPER SZNAJDER
Piotr Sznajder
NATALIE TARAIO
Mr. & Mrs. D.W. Ramming
NOAH, LAINE & THE VANHOUTAN FAMILY
Mr. Michael Beebe
Mr. & Mrs. Nick
Costanzi
Mr. & Mrs. Eric Kallback
Ms. Eileen Kenah
Mr. Bert Kisselburg
Ms. Vivian Levy
Mamo
Mr. & Mrs. Steven Sager
ALAN VISCONTI
Mr. & Mrs. Don Visconti
RACHEL von TUNGELN
Mr. & Mrs. Donald Beadle
Ms. Sue Bradley
Mr. & Mrs. Christopher Calos
Ms. Dru Glenn
Aunt Julie

Mr. Joseph Killen
JULIE ANN KLEE
Dad & Mom
JULIE LEFFLER'S BIRTHDAY
Dad & Mom
Ms. Gail Waters
ZANE MAXIMUS LEWIS
Ms. Sharon Grabill
MATTHEW & RICK LOWTHER
BDSRA – Southeast
Chapter/Debbie Lowther
KEVIN LUMM
Mom
ETHAN McCORD
Ms. Laurie Wolfe
LEAH KATHERINE McFARLANE
Grandma Phillips
BILLY MILANI
Mr. & Mrs. Victor Karl
Mr. & Mrs. John Milani
BILLY MILANI'S 21st BIRTHDAY
Mr. & Mrs. Christopher Moore
NICOLE MILECKI
Dad & Mom
CHERYL NELSON
Mom
KAREN ELISE NEWTON
Dad & Mom
HALEY NICHOLS
Dad & Mom
**ZACHARY NOORDHOEK ON HIS 14th
BIRTHDAY**
Dad & Mom
**ROBERT NOORDHOEK &
GRANDSON ZACHARY**
Mr. & Mrs. Douglas Noordhoek
NATHAN OLIE
Ms. Marla Nelson
MEGHAN O'NEILL
Mr. & Mrs. Patrick Haynes
SARA PFALLER
Mr. & Mrs. Terry Bohn
Mr. & Mrs. Ty Kurth
Ms. Jean Walsh
DAVID PFOHL
Mr. Bruce Bell
Belmark Inc.
Ms. Norma Griswold
MICHAEL PINDER



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

Ms. Hanna Kurtz
Ms. Melissa McCarthy
Christopher & Ryan Muir
Ms. Catherine Smith
Ms. Jennifer Whelan
Ms. Gayann Wilkinson

NICHOLAS WELLNER

West High School

Canadian Chapter:

Averee's Purpose

Programs & Services:

Anonymous
Anonymous (Conference stipend)
Mr. & Mrs. Alan Alexander
Ms. Andrea Allio
American Endowment Foundation
Mr. & Mrs. William Batalden
Batten Disease Research/Maurice St. Gelais
Mr. & Mrs. Brock Benroth
Beyond Batten Disease Foundation
Mr. Roger Bowers
Mr. & Mrs. Charles Burkeen
Cal-Neva 7-Eleven FOA
Arturo Cerda
Ms. Alysa Chadow
Ms. Laina Cohn
Ms. Becky Cox
Mr. & Mrs. Dominick De Angelis
Mr. & Mrs. Del Duca
Ms. Joan Ditmar
Fight For Nicholas, Inc.
Mr. Jeff Freilich
Mr. & Mrs. Douglas Fuller
Ms. Maureen Gavin
Mr. & Mrs. Franklin Gould
Mr. & Mrs. Robert Hahner
Dr. & Mrs. Lee Harker/Omaha Community Foundation
Mr. Christopher Hawkins
Mr. Curtis Hudak
Ms. Heidi Hylback
Mr. Jess Johnston

RRI Energy Mid-Atlantic Power Holdings, LLC

SHIV RANA

Mr. Raymond Kelso

JAMES & MARK RICKMAN

Centa Corporation

Mr. & Mrs. Samuel Robinson

AMBER, SANDY & SARAH ROYALTY

Dad & Mom

Mr. Caleb Gilham

Mr. Cole Gilham

Ms. Barb Rowland

CHARLIE SCANLON

Dad & Mom

FRED SCHNEEMANN

Ms. Donna Fitzgerald

JOHN & ETHEL SCOTT

Mr. & Mrs. Norb Farnaus

MICHELE SHERIDAN

The Robke Family

Mr. & Mrs. Richard Zaski, Jr.

LINDA SIVULKA

Ms. Beverly Jester

KARLIE SKAVLEM

Dad

ANNA SOCHA

Mr. & Mrs. Casimir Mikrut

THOMAS SOMERS

Uncle Lee & Aunt Ellouise &

Family

Crew & Friends at Fort Fairfield

Rite Aid

Jessica & Robin Dionne

Mr. Thomas Houghton, III

Mr. & Mrs. Allen Jandreau

Mr. & Mrs. Edward Jandreau

Ms. Linda Matteson

Presque Isle Memorial Works

Ms. Lorraine Shortslef

MARY KING STEWART

Mr. & Mrs. Scott Adams

EMILY THOMPSON

Mr. & Mrs. Wasyl Karpenko

TYSON & TIMOTHY WEAVER

Mr. & Mrs. Steven Hanson

MEMORY OF BEN WEMPNER

Buerkle Company



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

Mr. & Mrs. David Kennicott
Kroger Community Rewards
Mr. Mike Lin
Ms. Mindy Lipsey
Ms. Jeannie Lowe
Mr. & Mrs. James Magisano
Ms. Catherine Marshall
Ms. Robin McCarl
The McKinley Family
Ms. Renae Minikus
Network Logix/Andrew Moon
Mr. & Mrs. Mark Morris
Mr. & Mrs. Randall Munkres
Noah's Hope Fund of the
DuPage Community
Foundation
Mr. & Mrs. Steven Northrup
Pat Rooney
Ms. Robin Rose
Ms. Yvonne Rose
Mr. Rinaldo Sarazen
Mr. & Mrs. Carleton Schaller
Ms. Carol Schmitt
Mr. & Mrs. Tony Seidel
Ms. Christina Seilkop
Mr. Richard Simpson
Ms. Emily Strickler
Tyco Electronics
Mr. & Mrs. Lance Van Dusen
Veterans of Foreign
Wars/Ladies Auxiliary
4222
Ms. Janet Vincent
Ms. Linda Vonah
Ms. Lucille White
Mr. & Mrs. Ronald Willard
The Wong Family
Ms. Patsy Wooden
Ms. Barbara Young
Mr. & Mrs. Zacek
Mr. & Mrs. Michael Zart
Ms. Ruth Zellmer
Mr. & Mrs. David Zuchowski

MICHAEL WHEELER

Pride International, Inc.

PAULA WHITE

Ms. Dru Glenn, Daughter
Ms. Marshall Shamblin,
Daughter

CAROLYN WILHELM

Dad & Mom
Mr. & Mrs. Thomas Shanks

N. DAVID YAMAUCHI

Mom

DANIEL YANAK

Dad & Mom
Ms. Beverly Kurtz
Mr. Garrison Kurtz
Mr. Ben Roth
Mr. William Weismann

MADELINE ZELLMER

Dad & Mom
Grandpa & Grandma Shell
Mr. & Mrs. Brad Williams

Research:

Mr. Thomas Cornell
Drew's Hope Research
Foundation
Ms. Julija Losane
Mr. David Ortland
Ms. Aimee Shull
Ms. Jayna Todisco (*in Honor
of all individuals with
Batten*)



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

HOPE LOVE PATIENCE GRACE

Fundraisers/Special Events:

NOAH'S RUN:

Averee's Purpose Inc.
"Mom" (*in Honor of Kaitlin
Bowman*)
Ms. Carolyn Brookshire
Ms. Carolina Cid
Ms. Jennifer Cockerton
Ms. Lauren Coughlan (*in
Honor of Averee,
Celia, Catie & Annie, and
"530 Noah Page Likes"*)
Mr. Fred Daniels
Yonie Davis
Ms. Diana De Santiago
Ms. Holly Doherty
Ms. Sophie Edwards (*in
Honor of Noah Coughlan*)
Ms. Tammy Evans
Ms. Shahane Everett (*in
Honor of Batten disease
research*)
Ms. Diana Firpo (*in Honor of
Catie & Annie Allio*)
Cheryl Gleason
Ms. Christie Gruber (*in
Memory of James &
Shirley Donick*)
Ms. Maja Grygo
Mr. Alex Hall & Family
Ms. Whitney Haman
Ms. Caitlin Harmer (*in
Memory of Craig George*)
Ms. Ciera Jacks
Ms. Rae Jackson (*in Honor of
all the beautiful children
fighting this disease*)
Mr. Steve Jacobs/Vacaville
Christian
Mr. Lance Johnston
Ms. Marcy Jukiewicz
Mr. & Mrs. James Klippel
"Dad & Mom" (*in Honor of
Eric & McKenna Lowden*)
Ms. Jazmyn Martin
Ms. Merri Martirosya

Batul Merchant
"Mom" (*in Honor of Michael
Metcalf*)
Mill Valley Police
Department/Ian Maddison
(*in Honor of the Allio
Family*)
Ms. Terese Moore & Ms. Mary
Winsch
Ms. Sonia Mora
Ms. Fabiola Niswonger
Bailey Rodgers
Kendal Rogers
Ms. Regina Sandoval
Ms. Mabel Seiden
Isha Shrestha (*in Honor of
Noah Coughlan*)
Ms. Lena Stell(*in Honor of
Catie & Annie Allio*)
Ms. Sarah Strachn
Ms. Jill Thompson
Mr. & Mrs. Randy Thompson
Ms. Kelsey Vera
Ms. Kathy Vo
Ms. Seungyeun Yoo

RARE DISEASE DAY:

Lisa Weston



APRIL 2011
ISSUE 22, VOL. 2

166 Humphries Dr. Reynoldsburg, OH 43068 | BDSRA.org

STAFF

Lance W. Johnston, Executive Director
* 800/448-4570 * bdsra1@bdsra.org

Adina J. Ryan, Director of Development
* 866/287-7233 * aryan@bdsra.org

Lisa A. Weston, Program Director
* 866/379-2546 * lisaweston@bdsra.org

Nancy J. Carney, RN
* 877/642-5512 * nancycarney@bdsra.org

Donna Gunn, Office Manager
* 800/448-4570 * donna@bdsra.org

Eric S. Leslie, Marketing & Communications
* 800/448-4570 * eric@bdsra.org

Ann S. Salladin, Parent Volunteer
* 800/448-4570 * ann@bdsra.org