

The Illuminator

Batten Disease Support and Research Association

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“A Light in a World of Darkness”

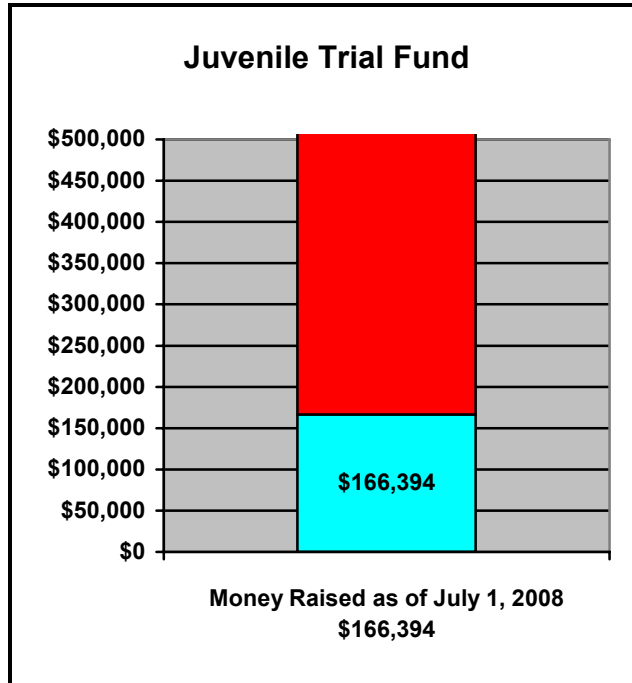
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Update on research

There is nothing new to report on the juvenile drug trial as of this issue of The Illuminator. The Clinical Trial Center at the University of Rochester is still waiting for IND (Investigation New Drug) authority from the FDA (Food and Drug Administration). While they are awaiting approval they are continuing their development of the actual trial. Unfortunately, we do not yet know what the parameters for inclusion into the trial will be or how many children will be able to participate in this initial trial. BDSRA currently has a bit more than \$150,000.00 toward the trial of an estimated \$500,000.00 requirement to launch the trial.

The group from the University of Rochester will once again be at the conference to take children through the Unified Batten Disease Rating Scale. This year they will be taking children with Infantile and Late Infantile in addition to children with Juvenile as they have in the past. Other research efforts are continuing. BDSRA received ten research proposals this year in response to our annual Request for Proposals (RFP) that is issued March 1 of each year. The proposals were sent out for peer review by other scientists. Awards will be announced at the conference in Denver on Saturday, July 19.



Research Money Awarded in April

April 18, 2008 — Beverly Davidson, PhD, University of Iowa, was awarded \$52,000 from BDSRA for the first year of her proposal titled, **“Dissecting the Molecular Basis of JNCL”**. This award was given to Dr. Davidson along with an award of \$61,000 from NCL-Siftung, a German Batten Disease family foundation.

April 18, 2008 — David Pearce, PhD, University of Rochester was awarded \$10,000 for his proposal titled, **“Correction of Stop-Codon Mutations in Neuronal Ceroid Lipofuscinosis”**. This award was given with funds from Taylor’s Tale.

Our Special Children

Special Child, USA: Shiv Rana (CLN6), Vienna, VA

I don't even know where to start my story. Our family was on top of the world. We just moved into our newly constructed house in the year 2000. I had a 4-year old daughter, and now I had a son. Our family was complete, and we were in our dream home. Then, when he was 5 months old, our son, Shiv, got RSV and almost died. It was so bad that he actually had to be helicoptered to the Children's National Medical Center. He made it through that, but the doctors were scratching their heads at why a full-term, healthy 5-month old reacted so severely to RSV. We were just happy to have him back.

Shiv continued breast-feeding, started eating solids and making some of his milestones, but when he was 1 year old he started getting recurrent bouts of pneumonia. They admitted him to our local hospital and found out that he was silently refluxing. He also had swallowing problems that caused him to aspirate, so they inserted a feeding tube and did surgery on him to tighten his esophagus so he would no longer get the aspiration pneumonias. They said that the feeding tube was reversible. They were perplexed and since he was a little behind on his milestones, they wanted to do some genetic and neurological testing. I wasn't really concerned, since my daughter was also a bit delayed with her milestones, and she was fine. All of his tests came back negative.

Shiv finally learned to crawl backwards, pull to standing, and say a few words. Then, on day when he was 1 ½ years old he stopped breathing. Luckily, my husband and I knew CPR. Again he was helicoptered, this time to Johns Hopkins. They said his trachea was still a bit cartilaginous and hadn't turned into bony structure yet, so he needed a trach tube inserted in his throat to help him breath. Again, they said not to worry since it was a reversible procedure. Here, too, they performed more tests on him to see what the underlying problem was. Again, he passed with flying colors. He was just delayed.

It was frustrating not knowing what was wrong with our child, and it was very scary. We spent a lot of time in hospitals. When Shiv was 2, we realized he could no longer do the things he used to do. When he was 3, he started having uncontrollable movements and started taking a drug that is used for Parkinson's patients -- still no answers. At age 4, he was hooked up to a ventilator because he stopped breathing, and this time they said it was brain-related. When he turned 5 he pretty much became bed-ridden, hooked up to the vent, and started having seizures. Finally, his test results started to show brain atrophy, etc, but not attributed to any underlying diagnosis.

At this point, we took him to Disney World, courtesy of Make-a-Wish Foundation, and he got very sick and had to be flown back home on a Cessna air-ambulance to our local hospital. There we met his neurologist's new partner. He looked at my son and asked if he had ever been tested for Batten's disease. I skeptically said no, and said he probably doesn't have it since he has never tested positive for anything. Then, I humored him and asked him what the diagnostic test would be. He said it would be a skin biopsy. I told him that we were not interested, considering my poor son had gone through muscle biopsies, spinal taps, and tons of needle pricks. We left the hospital.

A few days later I got a call from his neurologist saying that she spoke to the geneticist and that there was a new blood test available for Batten testing. I was doubtful of the whole thing, but reluctantly went along. Soon after, we got a phone call from his neurologist. She said that the Mass. General report showed that he was a carrier for the CLN6 mutation (Variant Late Infantile Neuronal Ceroid Lipofuscinosis). Even though carriers are not supposed to have the symptoms, as it is autosomal recessive, he does have the symptoms.

Although I knew how terrible the disease was, I was relieved and at peace that we now had a name for his suffering. I always knew whatever my son was going through was terrible, so labeling it wouldn't make it any worse. I felt I now had a cause, a support group. He had an Electro-Retinogram a couple of years ago at Johns Hopkins which showed mild retinopathy.

He will be 8 in July of 2008. It has been a roller coaster of emotions, but we take things day by day and we are blessed with so many good things in our life. Shiv is a wonderful and loving child.

Written by by Suneeta Rana, mother

**Special Children, International:
Carlos, Javier, and Cristian Paoletti (JNCL), Argentina**

Translator's note: This is the story of Maria Teresa Paoletti of Argentina, a mother of five with three sons affected by Juvenile Batten disease. The original text was in Spanish and has been translated.

Hello. My name is Maria Teresa Paoletti, and I am 59 years old. I have been separated 26 years and am the mother of five children. My girls are Maria Gabriela (36) and Marcia Elizabeth (27). These are my two healthy children. I have three sons with Batten Disease: Carlos Alberto died on June 17, 1997, at the age of 27; Gerardo Javier (32) is still living; and Cristian Gustavo died on June 17, 2007, at the age of 27. Carlos Alberto and Cristian passed away on the same day and at the same age just 10 years apart.

Now I will tell a little about them and this nightmare. The three boys began having seizures at the age of 9 and began to find it difficult to walk and keep their balance. We had many tests done, but nobody could tell me what was wrong with them. The doctors prescribed anticonvulsants and by age 12 the boys were already in wheelchairs. The wheelchairs left blisters underneath their testicles, and they were very painful until they burst. With every seizure came the loss of their ability to walk. They began to lose their vision and began stumbling on their words. We had to let them go to school, and they stayed in school up until the fourth grade. By the time the boys were 18 they could only speak a little and had to sit very close to the television in order to watch it. By age 20 they could no longer feed themselves or speak.

Cristian's progression of the disease was always complicated. He would have several seizures a day. He would have so many seizures that they had to inject him with Valium to make them stop. They changed his medication several times but nothing seemed to help. Cristian was the one that had the biggest problems: attacks of pneumonia that lasted several weeks, terrible nose bleeds, and he would grind his teeth day and night. He had a trach and would also receive oxygen through tubes in his nose. He was on oxygen for over 2 years and spent his final days in his bedroom.

Alberto was always calm. They never changed his medication but instead would increase the amounts of his Logical 200 and Luminal 0, 1, 2 times to the day. We never had to place him on Valium because his seizures were not as severe. Alberto did have many bronchial problems, like pneumonia, and we had to put him on a breathing machine for two months. However, just four years later Alberto came down with a strong case of pneumonia which caused him to have seizures every five minutes. This case of pneumonia and seizing only lasted 20 days before Alberto passed away.

Gerardo has the least problems of my three sons. Since the beginning of the disease he has always taken the same medication, 200 Logical and Luminal 0, 1, 2 per day. I have never had to put him on Valium. He has not had real lung or breathing problems, but if he has a lot of phlegm, I have to suction him. He also had problems with his teeth. All of his teeth became rotted and fell out. Because of this, he would often have infections in his gums.

Gerardo is very calm. He eats well and loves to eat yogurt, flan, and Jell-O and can still eat by mouth. He cannot move anymore, and when you lay him down you must turn him from side to side. He does not see, but he hears and understands things that are said to him. Gerardo likes to listen to music and soccer games on television. It is hard to tell when he is in pain. He will make a face at me, but I have to guess what is hurting him. He also takes laxatives or an enema to keep him regular. I do nebulize him, and I also suction him if necessary. I raise his hand and check his pulse. I give him his medications and anything else I can do to help him.

Once a doctor told me, almost 30 years ago, "Be patient and learn to live in their world, and remember that they do not live in your world." At that time I did not understand what he meant. I had not yet been through 30 years of raising five small children. I took care of them alone and had to work at the same time. Over time I realized exactly what that doctor meant. I regret not being able to remember that doctor's name.

Today I thank God for a beautiful granddaughter named Luana, who is the light that shines my way. During my life there were times that were sad and difficult, but there are moments of joy when one sits accompanied and supported by many people who love her with their whole heart. I thank God that I never lost the will to live with hope, a lot of faith, and the comfort of knowing that there will always be a better tomorrow.

Written by Maria Teresa Paoletti, mother

Board Election Results

The BDSRA Board of Directors' election took place during April. Members who had paid their 2008 dues were sent a ballot by mail. Four slots needed to be filled and the results of the election are back. The following people have been elected to the Board:

- Chris Hawkins, North Carolina
- Chris Lowden, North Carolina
- Sara Thompson, Michigan
- Kim Zellmer, Kansas

Each of these new Board members will serve a three-year term. Board officers will be elected at the July Board meeting. These new officers will be announced during the Conference general session. We want to thank the following outgoing Board members for their time served helping BDSRA and its families:

- George Maxim, President, Saskatchewan
- Eric Faret, 2nd VP, New York
- Gregg Froio, New Jersey
- Carl Schwartze, Missouri

Good luck to all of the new Board members and the entire Board. We look forward to your leadership and guidance as we head into an exciting time.

Revised Medication Book

BDSRA Nurse, Nancy Carney, has been working hard to update her *Medication* book to include all of the latest and most up-to-date drugs used for children with Batten Disease. Since the debut of her book in 2001, many changes have happened in regards to medications and those typically prescribed to our children. She hopes that this newly revised version will help parents be better prepared when talking about medications with their pediatricians and neurologists. Her book is now available! To receive a copy of the book, please contact Nancy at 1-877-642-5512 or nancycarney@bdsra.org

From The Nurses Corner

These past several issues I have talked about Hospice & Palliative Care Issues leading up to the Conference Sessions on the same topic. In this article, I am going to mention the titles of the Sessions that will be discussed at the Conference and a little bit about each Session.

The titles are:

Palliative Care vs Hospice Care

Pharmacology

End Of Life Planning

Nutrition/Hydration During A Terminal Illness

How To Help The Sibling(s) Of A Terminally Ill Child

Palliative Care vs. Hospice Care will talk about the differences between the two entities. How did Palliative Care develop? When one starts and the other one can take over. How insurance programs view the two differently, and eligibility into the two programs. Hospice/Palliative Care settings, whether it be in the home, hospital, or a nursing home/long term care facility. Ethical and legal issues in Palliative and Hospice Care. Principles of medications and pain management. Grief and bereavement, death education and family support as death approaches in the care of a patient in the Palliative/Hospice Care setting.

Pharmacology will cover medications in general that children with Batten Disease take and/or try over the years of the disease, including side effects, routes of administration, etc. of the many anticonvulsant, antipsychotic, anti-anxiety, and all of the different medications that children with Batten Disease need to take during their lifetime. It will also cover the narcotics/opiates (pain management) that are used for comfort measures at any point during the course of the illness and especially at the end of life.

End of Life Planning will discuss feelings, emotions, and marital issues during and at the end of the life of a child. How to make decisions and express your feelings to your loved ones. It will help you plan a funeral either prior to the actual death or at the time of the death and throughout the entire process.

Nutrition/Hydration During a Terminal Illness. This session will help you make those tough decisions how to handle issues when your child begins to deteriorate and the need for a GTube comes up. Do you insert a GTube or don't you? If you do, you know the life of your child will be prolonged, but now you can give your child the medications he/she needs, can supplement them with feedings if he/she has a bad day with oral feedings, but also the suffering will be prolonged as well. If you don't, you know your child will aspirate and develop pneumonia and probably die from no nutrition, and are you ready to handle all of this?

How To Help the Sibling(s) of a Terminally Ill Child. This session will help the parents talk with their other children about their child who is affected with Batten Disease. How do you tell them the diagnosis and at what age do you tell them? These children are smart; they see their sibling deteriorating and not able to do the things they used to do. How do you tell them that their brother or sister will eventually become a vegetable and die way too young, and what age do you try to explain all of this to them? How do these siblings deal with their school friends who see their sibling affected with a disease? Are they made fun of? All affected children and siblings are different, and we will answer a wide variety of questions.

These are just some of the issues that will be discussed at the Conference. If you are unable to attend the Conference and would like the handouts that are given at the Conference, please notify me and I can send you one or all along with the book "Death & Dying: A Helpful Guide In Dealing With The Many 'End Of Life' Issues" that I have written and is available on CD or in paper form.

Nancy Carney RN, BDSRA Family Medical Liaison/Educator
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From Family Services

Title V Programs for Children with Special Health Care Needs

Did you know that each state has funding from the Federal Government to help families who have children with special health care needs like Batten Disease? Title V funding was created in 1935 as a part of the Federal Social Security Act. While the program was originally referred to as the Crippled Children's Services Program, it helped to identify children with disabilities and provide healthcare services to them. Congress voted to provide each state with funding for Title V services in the 1970's and since the expansion, the number of eligible children has grown as well. Today the program serves children with chronic illnesses, developmental disabilities, sensory impairments, and other special health needs.

Title V Programs have a variety of names. While Congress mandated that states provide funding for Title V Programs they did not mandate that each state had to call the program by the same name. This makes finding the program very difficult, especially if your family has moved from one state to another. While many of the programs can be found by inquiring about Children with Special Health Care Needs (CSHCN), the exact name of the program could include "Children's Medical Services", "Bureau for Children with Medical Handicaps", or "Division of Specialized Care for Children".

The names aren't the only thing that can be different from state to state. Congress allowed each state to manage their own Title V funds and decide how the funds would be used, the population the funds would serve, and the services that would be provided. This means that a family with a certain income level may be eligible in one state but in the next state they may not be eligible. Some state's programs serve families with income levels up to 300% of the Federal Poverty Level while other states may only serve families with 185% of the Federal Poverty Level. Also, while a child with a certain medical condition may receive services in one state, that same child may not meet the eligibility requirements in another state. (However, if this is the case, a family should do what they can to fight the state's decision).

There are a number of services that Title V funding may provide in your state. In most states, Title V Programs provide case management or care coordination services. They work with you and your providers (doctors, nurses, specialists, therapists) to assure that you are getting a consistent level of care and that everyone is involved and engaged in a child's overall healthcare plan. Some state's Title V Programs help pay for medical equipment. They may also help pay for doctor's visits, therapies or surgeries. Unfortunately each state is very different so becoming knowledgeable about your state is what is most important. Besides providing direct healthcare services, Title V Programs work hard to change legislation and the state's overall healthcare system as it pertains to children with special health care needs. They focus a significant level of effort on defining, describing, and making family-centered, community-based care available to all CSHCN and their families. Parents have become an integral part of Title V Program advocacy work in an effort to make the system better for everyone. These Programs also fund family-to-family support organizations and support families in their efforts to play an active role in the development of program and policies that are of benefit to all children with special needs and their families.

The Child and Maternal Health Bureau, at the Federal Level, has supported the development of the "Directory of State Title V CSHCN Programs: Eligibility Criteria and Scope of Services" through a grant to the Institute for Child Health Policy at the University of Florida. This directory can provide you with information relating to your state's Title V Programs. Please take a look at the directory and the website for your state to see if you are eligible for services.

<http://cshenleaders.ichp.edu/TitleVDirectory/directory.htm>

For more information, please do not hesitate to contact me at the office. I'm happy to talk more with you about your state's CSHCN programs.

Referenced Documents: Reiss PhD, John. "An Introduction to State Title V Programs for Children with Special Health Care Needs". <http://cshcnleaders.ichp.edu/PDFFiles/AnIntroductiontoTitleV.pdf>

--Amy Kirk, MSW, LSW--Coordinator of Family Services

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Tax Deduction for Medical Conferences

The Internal Revenue Service has ruled (Ruling 2000-24) that "Amounts paid by an individual for expenses of admission and transportation to a medical conference relating to a chronic disease of the individuals dependent are deductible as medical expenses under Code section 213." This can be found in IRS Topic 502: Medical and Dental Expenses.

Here are some other important details to know about the Medical Expenses/Conferences Deduction:

- Medical expenses are deductible only to the extent that they exceed 7.5 percent of an individual's adjusted gross income, and that limitation applies to this deduction as well;
- Costs for admission and transportation to a medical conference relating to your dependent's chronic health condition are now deductible, if the costs are primarily for and essential to the care of the dependent.
- Costs of meals and lodging related to a conference, however, are **not** deductible. (Note, however, lodging, up to \$50 per night, is deductible if you must travel and stay at a hotel while your dependent is receiving medical treatment from a licensed physician in a hospital or a related or equivalent setting.)
- Costs are "primarily for and essential to the care of the dependent" (and therefore deductible) if:
 - The parent attends the conference upon the recommendation of a medical provider treating the child;
 - The conference disseminates medical information concerning the child's condition that may be useful in making decisions about the treatment of or caring for the child;
 - The primary purpose of the visit is to attend the conference. While at the conference, the parent's social and recreational activities in the city he or she is visiting are secondary to attendance at the conference;
 - The conference deals with specific issues related to a medical condition and does not just relate to general health and well-being.

Website: www.wrightslaw.com/info/tax.2006.benefits.oconnor.htm

You may also want to have your child's doctor or neurologist recommend, in writing, that you attend this conference. Many medical expenses eligible for a deduction must be recommended by the child's physician.

Please note: This information is relevant for year 2007 tax filing. You should check with a certified tax expert regarding this information for the 2008 tax year. Visit this website for more information: <http://www.irs.gov/taxtopics/tc502.html>.

United Way (UW) and Combined Federal Campaign (CFC)

Every fall the *United Way* runs their drive to get people to make a pledge. The money raised by the *United Way* is given to charities after they have deducted their expenses. BDSRA is NOT a *United Way* agency, agency meaning charity. However, BDSRA IS a **WRITE-IN** agency. This means that you can write Batten Disease Support and Research Association in on your pledge card. If you have questions about where to do this on the pledge card, talk to the person responsible for the UW drive or call your local UW. Millions of people pledge donations to charities served by the *United Way*. This turns into millions of dollars. You can help BDSRA get a portion of this by pledging your *United Way* donation to BDSRA. Ask your co-workers, family and friends to consider BDSRA this fall.

The Combined Federal Campaign (CFC) is the Federal government's *United Way*. Federal employees, i.e. postal service, military, etc. are urged to pledge to the CFC in much the same way as *United Way*. Money collected by the CFC is given to charities same as *United Way*. BDSRA IS an authorized agency of the CFC. Each year BDSRA submits an application and supporting documentation that proves that we are a nonprofit and do what we say we do. BDSRA has been accepted for this year's CFC campaign. Each agency/charity is assigned a number and BDSRA is **11781**. Like the UW, the CFC raises millions of dollars each year. Again, you can help BDSRA get a portion of this by urging your family, relatives, friends and co-workers to designate **11781** on their pledge card.

Ironman for Batten Disease

Adam Weaver is a triathlete. He is also the older brother to two young men who have both succumbed to Juvenile Batten Disease. When Tyson died in 2004 Adam had been competing in various types of triathlons for several years, but had never gone beyond an Olympic Distance Triathlon. Grieving for his younger brother he decided that he wanted to do something to memorialize and honor him. Running an Ironman (a 2.4 mile ocean swim, a 112 mile bike ride, and a 26.2 mile run) seemed like the perfect way. He set his sights on Ironman Florida, November 2006. Adam's training was interrupted 2 months before the event by the death of his other brother with Batten's, Timothy. Overwhelmed by grief, at first he was not sure he could compete in Ironman Florida. Being the tenacious and driven person that he is, that feeling soon gave way to an iron clad conviction that doing so would be the very best way to honor his brothers who never had a chance to become athletes or do any of the other things we all take for granted every day. Adam ran that race in 10 hr. 10 min. 6 sec.!

Inigorated by his success, he set his sights on the ultimate of Triathlons, Ironman Kona, Hawaii. Being the World Championship, this race is extremely hard to qualify for. Each year tens of thousands of athletes compete in qualifying events all over the world, vying for one of the 1700 coveted spots at Kona. On May 30, Adam MADE IT! He will be running that race October 11, 2008. His wish is that he can use this event to not only memorialize and honor Tyson and Timothy, but to raise funds and bring awareness to Batten Disease.

Your contributions and support for this event would be greatly appreciated. For more information, please contact Nori Weaver (Adam's mother) at grandmanori@comcast.net. For more information about Ironman Kona, Hawaii, visit the Ironman website at <http://ironman.com/>.

--Written by Nori Weaver

Family & Friends Fundraising

Salon Benefit for Batten Disease — Caledonia, MI

Heidi Christine's Salon is the family salon for David and Joan Ditmar (son, Mitchell--JNCL) in their town of Caledonia. Their stylist, Dana, and salon manager, Chris, came up with the idea of this benefit for Batten disease. The salon offered discounted services on haircuts, manicures and pedicures with all of the proceeds, tips and donations benefiting ongoing Batten disease research. The benefit was March 22, 2008, and raised **\$1,730** for BDSRA!

Kick-a-thon — Berlin Heights, OH

Victor and Leisa Nikolajevs (son, Asher -- INCL), along with the North America Martial Arts Institute, sponsored the 5th annual "Action For Asher" Kick-a-thon on April 12, 2008. Students from the martial arts school sought pledges for the number of kicks they completed or a straight pledge for the time they kicked. Participants kicked for 15 minutes straight without a break, trying to achieve as many kicks as possible! Over 50 kickers participated and raised over **\$6,000** for BDSRA. All ages participated in the event from preschoolers up to adults. Needless to say, a fun time was had by all!

Basket Party & Spaghetti Dinner — Charlotte, NC

The Hawkins Family (Brandon and Jeremy—JNCL) along with the W.R. Odell Elementary School Academically and Intellectually Gifted Class hosted a Basket Party on Friday, April 18th. Attendees bid on over 60 themed baskets. They also gave away door prizes and grand prizes. Overall, the event raised **\$1,750** for BDSRA. The Hawkins also took part in an all-you-can-eat spaghetti dinner event held for them by Forest Hill United Methodist Men's Group on May 7, 2008. For only \$5.00, attendees received spaghetti, salad, drink and dessert. The proceeds raised from this event are being used to benefit BDSRA.

3rd Annual Jackson's Hope Golf Tournament — Sarasota, FL

The Smithers family hosted their 3rd Annual Golf Tournament in memory of son and grandson, Jackson (INCL), on Sunday, April 20th, 2008. The tournament was held at the Oak Ford Golf Club in Sarasota. This tournament has helped raised almost **\$10,000** annually for INCL research and local scholarships for students. Great job, Smithers' family.

No-Show Potluck Event — Caledonia, WI

Sue and Joseph Sivulka are remembering their daughter, Linda's (JNCL) day when she went with the angels by having a No-Show Potluck event. Sue and Joseph simply invited friends and family to "not show up" to a potluck event! The event has raised almost **\$2,000** for BDSRA and Juvenile research. They had some fantastic results with this event. Great job, Sivulkas!

Art of Imagination Show — Reno, NV

Derek and Christy Allbee (son, Connor—JNCL) hosted an evening of magic, illusions and comedy that was fit for the whole family on April 16, 2008. The evening's events were led by world-renowned magician and entertainer Garry Carson. The Art of Imagination Show was a first for the Allbee family, and they raised **\$6,300**. Great job!

The Relay: 199 Mile Relay Race — Vacaville, CA

The Allio family (daughters, Catie and Annie—JNCL) participated for the 8th time in a 199 mile relay race from Calistoga, CA, to Santa Cruz, CA, on April 19th and 20th. Three teams ran in the event. Each team consisted of 12 runners who ran between 13-19 miles in a relay-style race! Joe Allio participated on one of the teams while wife Kathy, son Tony, and daughters Catie and Annie helped feed the runners before the race and helped throw a party in Santa Cruz for the runners after the race. Joe ran with his colleagues in the police.

Filipino Dinner Fundraiser — Eagan, MN

Warren and Lois Shuros, along with daughter, Kesley (INCL), were thrown a Filipino Dinner fundraiser by friends on Friday, April 25. The dinner raised over **\$3,300** for BDSRA! Besides the magnificent cooking and food by chef Joey Martinez, the night also featured a silent auction with items up for grabs like Twins baseball tickets, wine and beer baskets and other goods. A great time was had by all!

Walk with Nick Against Juvenile Batten Disease--Baltimore, MD

On April 26, 2008, John and Tina Heuchan along with their son, Nick (JNCL) and daughter, Addie, hosted the “Walk with Nick Against Juvenile Batten Disease” at Norwood Elementary in Baltimore. The event included a walk for the elementary school students, a ½ mile community pledge walk and a car show. Entertainment was provided by DeeJay Jimmy. Overall, the “Walk with Nick” event raised **\$1,600** for BDSRA and Juvenile research! For more information, please visit the “Nick’s Battle” website at www.nicksbattle.org.

Hope for Batten Cure Run/Walk Event — Dallas, TX

Nancy Lowden, grandmother of Chris and Danielle Lowden’s children (son Eric, daughter McKenna—JNCL) hosted her first ever Run/Walk/Fun Run to help benefit Batten disease research and BDSRA. The race was on May 10th at Flagpole Hill in Dallas. Participants started the race bright and early at 9 am. Prizes were awarded to the top runners. For more information, visit the Hope for Batten Cure website at www.bdsra.leapsolve.com. Great job, Nancy, Lowden family, and all of our Dallas/Ft. Worth families!

Minnesota Chapter Annual 5K Run/Walk — St Paul, MN

The Minnesota Chapter of BDSRA held their annual 5K Run/Walk for Batten Disease on May 10, 2008. The event was held at Lake Phalen, just as it has in years past. Once again this year, the Ramsey County Sheriff’s Department co-sponsored the event. The event also included a silent auction and prize raffle. Overall, the MN Chapter raised over **\$38,000!** They will be presenting the proceeds at the Denver Conference. Great job to all of the families, friends, and community members who participated.

Bands, Dancing and More! — McCoy, TX

Roger and Sheri Mitzel (daughter Jamie—JNCL) hosted an all-night music event in their hometown of McCoy, TX, on May 17, 2008. The Wildcat Grille and Saloon featured a handful of local bands throughout the evening. Those who attended enjoyed a variety of music, dancing, a bake sale, silent auction, and more. They were even able to auction off a prize-winning bull which earned \$950 by itself. The Mitzels raised over **\$3,500** for the Juvenile Trial and BDSRA! Great job, Mitzel family.

Hayden’s Hope Benefit — Two Rivers, WI

The Thelen Family (daughter Hayden—INCL) held their first ever Hayden’s Hope Benefit on May 23, 2008. The event was held at the Two Rivers Community House from 6-11 pm. The night’s events included a silent and live auction, raffles, kids’ carnival, food, drinks, bracelets, t-shirts, and much more. For more information, please visit the Hayden’s Hope website at www.help Hayden.com.

BDSRA National Headquarters Trivia Night--Reynoldsburg, OH

The BDSRA National Office held its First Annual Trivia Night on May 31, 2008. The event included a 10-round tournament with 10 questions in each round. The Trivia Night also had a silent auction, raffle, door prizes, food, and entertainment. The National Office staff and volunteers were able to raise **\$867** for BDSRA programs and services.

2nd Annual Family Festival for Batten Disease — Charlotte, NC

Chris and Wendy Hawkins, along with sons Brandon (JNCL) and Jeremy (JNCL) hosted their 2nd Annual Family Festival for Batten Disease on June 7, 2008, in conjunction with the *International Awareness Day*. This year's event included a 5k run, 1 mile fun run, and silent auction. Some of the silent auction items included an electric scooter, Bosch Table Saw, and 4 one-day park hopper tickets to Disney World. There was also a raffle with many other great prizes! The event was held at the Harris Road Middle School in Charlotte. The Hawkins were able to raise approximately **\$10,000** during this year's event! Great job, Hawkins family!

3rd Annual 'Toast to Dionysus' Event — Kingsville, ON

On June 7, 2008, the Mastronardi Estate Winery held the 3rd Annual "Toast to Dionysus" event in memory of Brittany Matronardi, daughter of Tony and Eadie Mastronardi. Brittany succumbed to LINCL in 2002. Proceeds from this event will go to BDSRA. The "Toast to Dionysus" is being held in conjunction with the *International Awareness Day*. The event featured dinner, plenty of wine tasting, and a performance by Pavlo, Mediterranean guitarist extraordinaire! For more information about the Mastronardi Estate Winery and the "Toast to Dionysus" event, please visit their website: www.mastronardiwines.com.

Denim Day — Waterloo, IA

Jill Wellner (son Nicholas—INCL) invited her friends and co-workers to participate in a Denim Day on June 7, 2008. Employees could pay \$5 to wear jeans for the day. Jill also posted signs around the store about *International Awareness Day* and Batten Disease. Twenty employees participated in the event raising **\$140** for BDSRA and research. Jill hopes that next year the entire company will participate. Great job raising awareness and funds for BDSRA and Batten Disease!

Bake Sale and Random Acts of Kindness — Middlesex, NJ

Peggy DiCapua (in memory of son Christopher—LINCL) helped to spread awareness and raise funds on *International Awareness Day* (June 7) in her hometown of Middlesex, NJ. Peggy hosted a bake sale which helped raise over **\$200** despite the 90 degree heat. Her daughter's Girl Scout troop sent letters to friends and family educating them about Batten Disease and asking them to conduct a random act of kindness for someone and tell them about Batten Disease. Peggy and her daughter were able to provide four random acts of kindness by passing out \$10 grocery gift cards at their local supermarket. Great ingenuity and creativity, DiCapuas!

Jewelry Party — Spring Hill, TN

Katie Godfrey (in memory of son JR—INCL) held a jewelry making party on June 7, 2008, for the *International Awareness Day*. A few of Katie's family and friends gathered to have fun, make jewelry, and donate to BDSRA and Batten Disease. Katie's jewelry party raised **\$45.00** for BDSRA. Great job, Katie!

Letter Campaign — Madison, TN

Sherry Hatchett (son Stephen—JNCL) knew she could do something to help contribute to our *International Awareness Day* on June 7, 2008. She put together a short email to their friends and family with information on BDSRA and fundraising efforts. They thanked the recipients for their love and support over the years and encouraged them to visit the BDSRA website to learn more about Batten Disease and our organization. To read Sherry's email please email her at sherryhatchett@comcast.net.

Jumping For a Cure — Plainview, NY

What would you do to help a child with a fatal disease? If he was your grandchild, would you jump out of an airplane? Elna Faret, of Plainview, NY, is 73 years old and made her first sky dive on Saturday, June 7 (*International Awareness Day*), at the Blue Sky Ranch in Gardiner, NY. She jumped for her grandson, Ryan, to help raise awareness and research for Batten Disease. The Faret family are members of the Metro NY/NJ Chapter of BDSRA. Way to go, Elna – you are an inspiration! (See Elna in action at www.youtube.com/watch?v=gr0Jhs18HMc.)

Great Clips Against Batten Disease — Baltimore, MD

John and Tina Heuchan (son Nick—JNCL) in cooperation with Lynch Manor Great Clips in Dundalk, MD, hosted a Cut-A-Thon on June 8, 2008. The event was held from 5-7 pm. Nick started off the event by having his hair cut first. The Cut-A-Thon raised nearly **\$1,000** for BDSRA and Juvenile research! The Heuchans have already been asked to repeat the fundraiser again next year. For updates, please visit www.nicksbattle.org.

Walk for Elisabeth — Nevada City, CA

Keith and Alice Johnson (daughter Elisabeth—JNCL) hosted their 5th Annual “Walk for Elisabeth” event during the month of June. When the event started in 2004, the Johnsons actually hosted a live walking event. During the past three years, Keith and Alice have done a “virtual walk” by simply sending letters and pledge requests to friends and past participants asking them to donate instead of walking. Even though they didn’t hold a “live” event, the Johnsons were able to raise **\$6,215** for the Juvenile Trial and BDSRA Programs and Services. Thank you for all your hard work, Johnson family!

Melissa Froio Foundation Annual Golf Outing—Sicklerville, NJ

The Froio Family (daughter Melissa—LINCL) will be hosting their 9th Annual Golf Outing on June 20, 2008. This event has helped raise money for BDSRA and Late Infantile research. With over 150 golfers in attendance every year, the 2008 outing should be no different. The golf tournament features lunch and dinner, refreshments, a Chinese auction, and sports memorabilia. This year the Philadelphia Eagles Cheerleaders are expected to make an appearance and will be part of the foursome pictures. BDSRA families are welcome to attend. For more information, please go to the Melissa Froio Foundation website at <http://www.melissafroio.org>

5th Annual “Kevin’s Fund” Golf Tournament—Hagerstown, MD

Martin and Vicki Lumm (in memory of son, Kevin—JNCL) are hosting their 5th annual “Kevin’s Fund” Golf Tournament on Friday, June 27, 2008. The money raised from the tournament benefits the Kevin Lumm Memorial Fund, which in turn provides assistance to families with Batten disease in the area and BDSRA. The day includes donuts, coffee and juice in the morning, a luncheon buffet after the tournament, and guaranteed fun! For more information, please contact Martin and Vicki Lumm at (240) 313-2234.

Midwest Chapter Quilt Raffle

The Midwest Chapter is raffling off a hand-stitched quilt made by a daycare worker of one of the member families. Tickets are \$1.00 each or 7 for \$5.00. This raffle is running now through the Saturday of Conference (July 19th). The winner will be drawn that Saturday night at the banquet. For more information, pictures or to purchase tickets, please contact Darlene Royalty at royalty@adams.net.

Motorcycle Ride for Batten Disease--Denver, CO & Rochester, NY

On July 20, 2008, a group of motorcycle enthusiasts will jump on their bikes and ride for Batten Disease. Larry Killen (in memory of son Bret—LINCL) is organizing a motorcycle ride to help raise awareness and funds in Denver. Those families staying an extra day after conference may want to check out the bike ride. It is set to happen on Sunday afternoon. There is also another possible motorcycle ride in the works for the end of August in Rochester, NY. More information will be available during conference or you can contact Larry Killen at killen@bright.net. Good luck, Larry, and all of our riders!

Operation Faith, Hope, and Love--Clearwater, FL

Nancy Garrison (aunt of Courtney and Noah Johnson, Ohio--JNCL) is hosting her first dinner theater event on August 1, 2008, at the Countryside Country Club in Clearwater, FL. The event, inspired by her daughters, niece and nephew, will be a fun-filled evening of Italian dining followed by an ice cream sundae dessert bar, dance team showcases featuring a former captain of the Tampa Bay Buccaneer Cheerleading squad, and a fashion show of children's/tween's clothing by a local designer. The clothes will also be for sale at the event and a portion of the proceeds will benefit the Juvenile Trial. Operation Faith, Hope, and Love will also have t-shirts for sale. For more information on the event, please visit their website at www.ofhl.org or email Nancy at nancygarrison@gmail.com. Good luck, Nancy, and the entire Johnson family!

7th Annual Golf Tournament — Jemison, AL

Becky Lucas (son, Chris Gaines—LINCL) is hosting her 7th Annual Golf Tournament on September 20, 2008, at the Lakeview Retreats Golf Course. Approximately 25 teams form every year to compete in a 2-man scramble style tournament. The cost is \$50.00 per person. The golf tournament has had players from all over the Southeast including Florida and Tennessee. Last year the event raised about **\$2,000** for BDSRA and Batten Disease research. Everyone who plays has a great time. Good luck to Becky and Chris!

2nd Annual Blake’s Purpose Golf Classic — Sacramento, CA

Dawn and Jeremy Jaeger (son Blake—LINCL), along with the Blake’s Purpose Foundation, have announced that they will be hosting the 2nd Annual Blake’s Purpose Golf Classic on October 17, 2008. The Golf Classic is being held at Catta Verdera Country Club. Last year’s event raised a substantial amount of money for Late Infantile Research, and it is the Jaeger family’s hope that this year will be even bigger and better. For more information, please visit the Blake’s Purpose Foundation website at <http://www.blakespurpose.org>

Heart of America Dinner Auction — St Louis, MO

The Heart of America Chapter is having their next Dinner Auction on October 25 at the Sheraton Chalet in St Louis. The money made from this evening will go to help Juvenile Batten Research. If you would like any further information, please feel free to contact Diane and Mike Carbrey at dinamik@usexpress.net. Anyone who would like to attend is welcome!

A Night to Light up the Children's Lives — Australia

The Australian Chapter hosted "A Night to Light Up the Children's Lives" on May 9, 2008, at 6:30 pm. Tickets were \$80 per person, and the evening's events included food and fine wines, dancing, a fashion show, and an auction like no other. The benefit raised **\$1,050!** For updates and more information about the event, please visit the chapter's website at www.battens.org.au.

City2Surf Race — Sydney, Australia

Many of BDSRA's Australian families will participate in this year's City2Surf race on August 10, 2008, in Sydney, Australia. The race is 14km (8.6 miles) in length and attracts more than 60,000 participants each year. The Australian families have created the "Battling Battens" team and are set to raise money and awareness both before and during Race Day. For more information, visit the City2Surf website at <http://city2surf.sunherald.com.au/home.php>. Good luck to all of our Australian BDSRA participants.

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. Visit his page and purchase his coffee today at <http://www.daveshomeroast.com>. It is delicious and makes a great gift, too!

Cookie Lee Jewelry — Dallas, TX

Jessica Griffith, older sister of 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. If you have questions, please email Jessica at jessicagriffith@cookielee.biz.

Lulu's Cafe

Lulu Calderon passed away from Late Infantile Batten Disease on March 25, 2008. As a way to honor and memorialize Lulu, her elementary school created "Lulu's Café". The Café is decorated in leopard print (Lulu's favorite) with pictures of her on the walls. There is a reading corner (she loved books), and they are selling leopard ribbon brooches, leopard rubber 'Lulu' stamped bracelets and Lulu coffee mugs. All sales profits go to BDSRA! It is a beautiful memorial to a magical little girl. She touched so many hearts. Here's to the future and a cure! *(Submitted by mom, Katarina Calderon.)*

Comrades Marathon for Batten Disease Awareness--South Africa

On Monday, June 17, Pam Jooste of South Africa (in memory of daughter, Shanade—LINCL) participated in the Comrades Marathon for the second time. Don't let the name mislead you -- the Comrades Marathon is actually a 56-mile (44 km) race! Each year over 10,000 runners participate in the event. The race is run from Durban and Pietermaritzburg in South Africa. Pam completed the race in 11 hours and 24 minutes, which was under the 12 hour cut-off mark. Here are some of Pam's reflections from the race:

"I have survived my Comrades marathon! It was much hotter this year than last year, and I had to continuously pour water over my head. The first half of 44km went really well, and I thought that if I could continue with the second half feeling as good as I did I would do well. Unfortunately, about 30km from the finish I really felt bad. I was extremely nauseous, and every time I ran I wanted to be sick. I ended up walking the last 23km to the finish. My stomach was playing up, and I was really feeling quite delirious at times. I managed to hang in there and met up with another runner from our club who was in a lot of pain with a knee injury, so the two of us encouraged one another to the end. We finished in a time of 11h, 24min, and we had 12 hours to complete the race. I am very disappointed in my time as I really wanted to finish in 11 hrs. However, considering the amount of injuries I have had this year causing me to miss quite a number of runs, as well as not running for the whole of May, I did well to finish. There was no way I was going to quit no matter how bad I felt; it was pure stubbornness and determination that got me to the end. What really made me feel better is that I got another medal for running back to back Comrades. That is running two years in a row!"

Lion Shop & Share and Albertson's

Food Lion stores around the country are giving shoppers a way to save money and donate to their favorite charity at the same time. Through the Lion Shop & Share program, you can link your Food Lion MVP card to BDSRA, and a portion of your total grocery purchase will be donated to the organization. It is very easy to join the Lion Shop & Share program. Simply register for a Food Lion MVP card, then visit www.foodlion.com or call (704) 633-8250 ext. 3810, and link your MVP card to BDSRA.

Albertson's grocery store chain has a very similar program. Found mostly in Florida and the Northeastern United States, Albertson's allows its customers to link their Preferred Savings Card with the non-profit organization or school of their choice. The Florida Chapter of BDSRA is listed as a Community Partner, and families and friends of BDSRA in Florida can earn money for our organization by shopping at Albertson's. For more information, please visit <http://www.albertsons.com/cp/>.

GoodSearch and SmartRaise

Please do not forget about the FREE and EASY ways to earn money for BDSRA. By using GoodSearch as your search engine, BDSRA will earn 1 cent every time you search. GoodSearch also has an on-line shopping outlet called GoodShop. A portion of every purchase you make through GoodShop is donated to BDSRA. So far this year, we have earned **\$256.88** through all of your shopping and searching! Visit www.goodsearch.com today!

SmartRaise works the same way. Every time you make a purchase through a vendor on the SmartRaise website, a portion of the sale will be donated to BDSRA. They have many popular retailers like BestBuy, Target, Barnes & Noble, and others. Simply go to www.smartraise.com to begin your on-line shopping while raising money for BDSRA.

Perfect Empowered Drinking Water

Les and Deb Ham (in memory of son Daniel—JNCL) of Vancouver, Washington have begun selling a revolutionary new product: Perfect Empowered Drinking Water. This is not your typical bottled water and with all of the bottled waters on the market today, consumers are always looking for something different. Perfect Water is purified through a 15-step Proprietary Purification Process. It's then remineralized and enhanced with electrolytes and essential minerals. It is also ionized for enhanced pH, microstructured, and oxygen rich. Through their company Momentum III, Les and Deb are able to donate the profits made from selling Perfect water to the Juvenile Trial.

You can help by purchasing the water directly from Les and Deb Ham. A portion of each sold case goes directly towards the Juvenile Trial. For more information, please contact Les or Deb Ham at 1-877-691-0437 or lesham@momentumiii.com. You can also visit their website at www.momentumiii.com.

In Loving Memory

Robert Stennett, son of Robert and Alice Stennett, Dallas, NC
Born: 12/5/99—Died: 12/18/07—LINCL

Sara Schwartz, daughter of Moses & Katie Schwartz, Seymour, MO Died: 02/16/08 –LINCL

Frank Patane, father of Tamie Sue Patane (deceased), Fripp Island, SC
Died: 02/29/08

Joe Falkman, father of Stephen & James Falkman (both deceased), East Islip, NY Died: 03/19/08

Noah Hardy, son of David & Debbie Hardy, Orient, OH Born: 01/16/93—Died 03/25/08 –JNCL

Lulu Calderon, daughter of Daniel and Katarina Calderon, Los Angeles, CA Born: 08/01/98—Died: 03/25/08—LINCL

Hunter Watkins, daughter of Jacob & Trichelle Watkins, Mason, MI
Born: 07/13/00—Died 03/28/08—LINCL

Craig Johnston, son of Alec & Mary Johnston, West Lothian, Scotland
Born: 09/14/85—Died: 03/29/08—JNCL

Bryce Butenhoff, son of Brian & Laura Butenhoff, Mora, MN
Born: 10/17/99—Died: 04/07/08—LINCL

Nikki Davis, daughter of Paul & Deanna Davis, Hammond, NY
Born: 06/18/91—Died: 04/21/08—JNCL

Travis Carter, son of Derek and Jenny Carter, Hamilton, Ontario
Born: 01/12/98—Died: 05/31/08—LINCL

Peyton Foy, daughter of Jeremiah and Amanda Foy, Valencia, PA
Died: 06/2/08—INCL

Lester Wells, father of Tressie Wells (deceased), Fortune Bay, NF Died 06/25/08

BDSRA has been remembered many times in the past three months by family and friends of children with Batten Disease. To all of you we express our deepest appreciation.

Honor of CATIE ALLIO'S

H.S. GRADUATION

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Mr. & Mrs. Lars Anderson

Memory of GWEN BROWNE

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Mr. & Mrs. Montavon & Family

Memory of LULU CALDERON

Santa M. Calderon

Robert Hill

Ms. Marilyn Robinson

Mr. & Mrs. Terry Wong

Jennifer Novak Tutoring

Ms. Betsy Blankfield

Mr. & Mrs. Kao

Talbert Family Foundation, Inc.

Frantic Fred Hot Rods - Lu Badberg

Ms. Jane Ehrhart

Mr. & Mrs. Chuck Montavon &

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Hammond Teachers Association

Honor of EMILY DUGGER'S 27TH BIRTHDAY
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Honor of MRS. JULIA GRANDLE
For "Mother's Day."
Mr. & Mrs. Arthur Grandle

Memory of COURTNEY GUNTHER
Mr. & Mrs. Melton Frederick

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The Paul Hardy Family

Memory of ROSEANN HARDY
The Paul Hardy Family

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 Mr. & Mrs. Joseph Clor
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 Mr. & Mrs. Kenneth Martinek
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