The Illuminator

Batten Disease Support and Research Association

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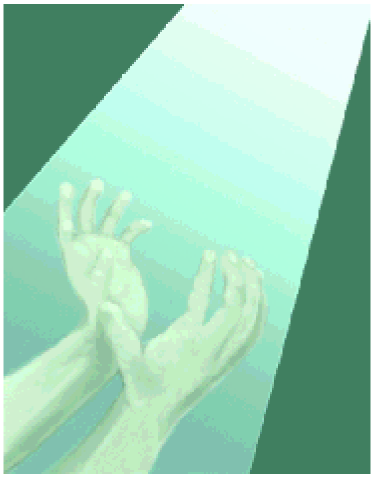


"A Light in a World of Darkness"

Research unveils new hope for deadly childhood disease

December 13, 2007 - Investigators at the University of Rochester Medical Center have uncovered a promising drug therapy that offers a ray of hope for children with Batten disease - a rare neurodegenerative disease that strikes seemingly healthy kids, progressively robs them of their abilities to see, reason and move, and ultimately kills them in their young twenties.

The study, highlighted in the January edition of Experimental Neurology, explains how investigators improved the motor skills of feeble mice that model the disease, helping them to better their scores on successive coordination tests.

"No treatment currently exists for these kids - nothing to halt the disease, or even to slow it down," said one of the study's authors, David Pearce, Ph.D., a nationally renowned Batten disease expert and biochemist at the University of Rochester. His team has published more than 50 studies on the disease's basic mechanisms.

"Since deterioration of motor skills is the rule - in fact, it's one of the primary symptoms in children with the disease - the idea that these functions might be able to be partially restored or improved is groundbreaking," Pearce said.

Last year, University of Rochester researchers discovered that, in mice with the disease, a set of the brain's receptor cells - known as the AMPA receptors - were unusually sensitive to glutamate, a neurotransmitter vital for learning and memory. These 'super-ticklish' receptors were located in the cerebellum, a brain region that plays a hefty role in sensory perception and motor control.

"For us, their abnormal activity made them key suspects in the brain dysfunction and neurological decline associated with the disease," Pearce said.

To test that, researchers administered a drug that partially blocks these receptors and dims their activity.

Impressively, when diseased mice that received the drug, they - for the first time - became able to better their scores on successive coordination tests.

And, though they never reached the same level of nimbleness as healthy mice did, they were fierce candidates for the title of "most improved players." Over the course of the testing, they achieved nearly the same degree of improvement in their before and after coordination scores as healthy mice did. In fact, almost second for second.

"It seems we may have corrected some sort of motor learning deficit in the diseased mice," Pearce said.

While optimistic about these findings, Pearce stressed the importance of reminding affected families that this work is preliminary.

"Much research is yet needed," Pearce said. "The prospect of offering this sort of investigational medicine to affected children is still years out."

Still, he is further encouraged that a drug called Talampanel - very similar to the blocking compound used by his team in Rochester - is currently in phase II clinical trials for treating epileptic seizures.

Unlike most anticonvulsants, which typically target cells known as NMDA receptors, Talampanel works by partially blocking AMPA receptors.

"This orally active new drug would be an obvious choice for clinical trials with juvenile Batten disease patients," Pearce said. "Especially since they routinely suffer seizures, as well."

Though only 150 children in the United States suffer Batten disease, Pearce is hopeful that this research will also likely also inform research efforts for a dozen or so of its cousins - other uncommon genetic diseases, each characterized by a glitch with the cell's toxin-ridding mechanisms, the lysosomes.

Some of these lysosomal-storage diseases, as they're called, include Krabbe disease (to which Buffalo Bills quarterback Jim Kelly lost his son, Hunter, in 2005), Tay-Sachs and metchromatic leukodystrophy.

"Our research might indeed open doors for learning how other neurological disorders might benefit from drugs that regulate AMPA receptors," Pearce said.

NEWS FROM BIOPHARMACEUTIQUES ****

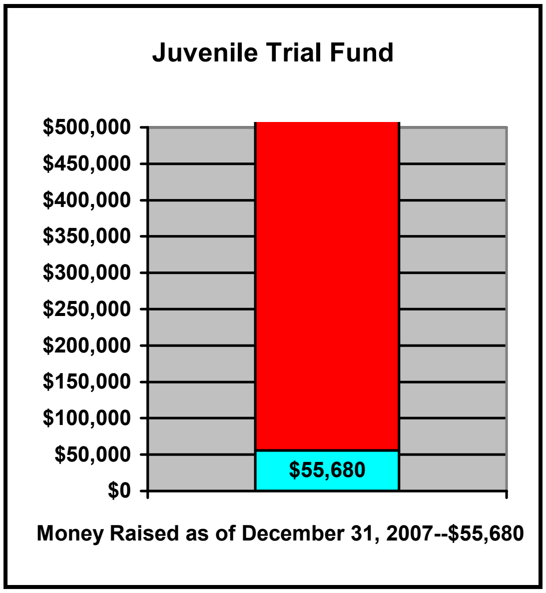
SIMPLIFIED ADMINISTRATIVE PROCEDURES FOR ORPHAN DRUG DESIGNATION

The news should cheer up a fair number of biotech companies on both sides of the Atlantic! The EMEA and the FDA have committed to simplifying the administrative procedures for obtaining orphan drug designation in the EU and the United States. This constitutes significant progress because the two agencies have just agreed to use a common application format - enabling sponsors to apply to both jurisdictions with one application at the same time. However, despite the common application format, the regulatory frameworks in the EU and the United States are different; the procedures are still separate and there is no harmonization of the data requited by each agency.

In practice, the 10-page form is composed of three sections: one reserved for the information required by both the EMEA and the FDA and the two others for each agency's specific requirements. Whereas the two zones differ in terms of the very definition of what constitutes a rare disease and the number of patients required (in the US, a disease is said to be rare if it affects fewer that one American in 200,000, whereas the EU sets a threshold at less than five in 10,000), Europe clearly requires more information than does the United States. The EU-specific information accounts for 3 pages of the form, versus just one page for the FDA! In particular, the EMEA asks a series of questions on the existence of other methods of diagnosis, prevention and/or treatment for the disease in question.

Above all, this initiative constitutes an unprecedented first for the two agencies and, in the long term, could herald the possibility of parallel regulatory developments. The industry has welcomed the initiative. Emmanuel Chantelot, Executive Director of European Biopharmaceutical Enterprises (EBE, a branch of EFPIA, the European Federation of Pharmaceutical Industries and Associations) emphasized that "this decision marks the first concrete example of transatlantic cooperation with a view to administrative simplification of drug development and registration in the European Union and the United States". Furthermore, the matter was on the agenda of the joint European Commission/EMEA/FDA working group, which met on November 28th in Brussels to launch further work. A list of 28 subjects concerning administrative simplification in four main fields (quality & inspections, pharmacovigilance, scientific collaboration and harmonisation of guideline & electronic submission formats) was presented by industry representatives. Following the joint form announced in the introduction to this first meeting, additional output from the discussions is expected by next June.

For more information on BioPharmaceutiques, go to:
http://www.biopharmaceutiques.com/en/



Special Child-USA: Macayla Smoak, Anderson, SC

Circle the Wagons or Stay on the Trail?

Macayla was born on May 22, 2001. She showed all normal development until around the age of two when her speech was not as developed as it should be. It was so minimal that we had to talk the pediatrician into referring us to a therapist. Macayla is a quiet and intelligent child with a quirky sense of humor. She has incredible memory even to this day. When she was two she could navigate her way around Greenville, SC where we lived. While riding in the car she could tell us where to turn to get to church, the doughnut shop (her personal favorite), home, school, or Grandma's house. She figured out how to use the TV and VCR before she was two. She even memorized the labels on VCR tapes even though she could not read. She knew what the movie was simply by the label's design.

She never talked much, but it came across as shy more than delayed. Her preschool teacher always bragged on how much Macayla could do when many of the other children were still struggling in the same areas. She could write her name and knew her alphabet and colors. But we started speech therapy around two and it helped some. Macayla's younger brother, Jacob, benefited the most from her speech therapy as he listened to us work with Macayla. Unfortunately, Macayla's speech never got better. In fact it got worse. She also seemed to have difficulty following directions from time to time. But none of these things were outstanding enough to make us believe we were dealing with more than just personality traits or a different learning style. We had other struggles with Macayla's health, but nothing stood out on its own and nothing seemed to connect any dots for us or doctors. She had viral croup two summers in a row, kidney reflux, unexplained vomiting spells (once every 1-2 months), constipation, and speech delay. That was her symptom list but it never coalesced for us.

Near the end of 2004 we started researching seminaries to finish work on a Masters I had started. That led us to make a decision in February 2005 to go to New Orleans that coming fall. Our house in Greenville sold in March but at the beginning of April 2005, Macayla began having some strange episodes. She seemed to be falling for no apparent reason and we never actually saw what was causing the problem until one day when she was working a puzzle on the floor. She was fitting two pieces together, she paused and had a tremor in her torso that caused her to rock forward and almost fall face first onto the floor. But it was over so quick that she stopped herself from falling and went right back to working on the puzzle. If she had been standing, she would have fallen. This episode earned us an appointment with the radiologist for a CT. The CT was on a Monday. On Tuesday evening she started running a fever and on Wednesday, she collapsed multiple times in front of us. It looked as if all the bones were instantly removed from her body and she would just crumble. She bloodied her face and was very scared. We spent the next three days in the hospital doing a lumbar puncture, MRI, EEG, blood work, and X-rays. All of the test were negative and gave us no explanation as to why Macayla was falling. The radiologist and neurologist both said her CT and MRI were normal. Our stay in the hospital also coincided with a follow up on her kidney reflux that required a live x-ray and renal ultrasound. During the ultrasound of the kidneys, the tech spotted stones in Macayla's gall bladder. This earned us a surgery a few weeks later to remove her gall bladder. This did offer us an explanation as to Macayla's previously unexplained vomiting spells. In the meantime, she kept having episodes that we could only think were seizures, but we were not sure. It seemed to never happen in front of the doctor or nurses.

In spite of this, we were reporting enough frequency in the episodes that our neurologist set up a 72-hour video EEG. It ended after 24 hours because they had already recorded over 100 petit mal seizures. They would last a few seconds each. Some seizures had minor jerking with them that was notable, but most of the seizures were unnoticeable from the outside. Unfortunately, the neurologist was a bit cavalier about treatment and basically said, "Take two Lamictal and call me in the morning. Macayla will outgrow this." But in spite of the increasing Lamictal schedule, Macayla's episodes worsened. We were told that she was not getting worse, but that we were just better at spotting the seizures. It is true that we got better as spotting them, but as the medication levels increased her seizures increased as well. The one thing that did improve was the falling occurred less frequently for a while. After a while, we became frustrated and wanted to get more answers as to what was causing the seizures. It was apparent to us that this was not simply benign, absence seizures. We went for a second opinion and another neurologist immediately saw a problem when he reviewed Macayla's MRI from April. In our experience, always get a second opinion on an MRI. He saw an underdeveloped area in her cerebellum and he also considered Macayla's seizures to be absence with myoclonic and atonic components. He called it myoclonic astatic epilepsy. According to him, this type of epilepsy is more difficult to deal with and control. We ran every test thinkable to try and find an underlying cause of her seizures, speech disorder and developmental delays. As our genetics doctor said, "We had the million dollar work up." Every test was negative and we had no diagnosis, just symptoms.

This helped us decide to stick to our plan to go on to New Orleans and start school. There was a great children's hospital there with an epilepsy center and we had met so many people on the seminary campus who worked in child development and special needs therapy. It was hopefully going to be a great opportunity to get some fresh eyes on Macayla. But after two weeks in New Orleans, hurricane Katrina sent us back to South Carolina. While we were evacuated, Macayla's speech and motor skills declined more significantly. She stopped running and spoke in two or three word sentences. She began falling again. We got a second MRI done in December 2005 and it confirmed that the "under developed" area in her cerebellum had spread and now the cerebrum (main section of the brain) was being affected. This narrowed down the search for a cause and our neurologist who is talented beyond words, guessed that Battens or a mitochondrial disorder would be the most likely causes. Macayla was diagnosed with INCL and we were told two days after Christmas 2005. We were blessed to discover a diagnosis as fast as we did (April 05-December 05). Many families go much longer before they know and not knowing is very difficult. Being told that your daughter is going to die is not easy either, but knowing helps us now.

After we got the news, my wife, Jennifer, and I walked out into the parking lot and broke down. Immediately I wanted to circle the wagons and close out the world. I wanted to protect our daughter and our family. But after much sobbing and some praying and talking, we realized that this was Macayla's life. This was our life. It is not the one we asked for or ever wanted, but it is the one we have. We determined then that Macayla would not be a hermit and that we would let her experience as much as possible for as long as possible. We need to keep to the trail even though it was not the trail we wanted to be on. As Macayla digressed more, I stayed at home with her and my wife worked. She is a nurse and the hospital benefits are much better than any I could get. The irony is that she's the nurse and I am as un-medical as you can get. But it was what worked for us.

We have settled down in Anderson, SC near Greenville and we will remain here until Macayla goes to the ultimate home with Jesus. In the meantime, a sweet family member has set up a website (www.smoaksignal.com) to keep family and friends up to date but even it has become a bit more than that. We have discovered a strength in Macayla that surpasses our own. We have discovered an unexpected vessel of grace in our son Jacob as he keeps us laughing and honest through out this journey. We are thankful that he is only a carrier. We have amazing family that supports us and help out all the time. Macayla's grandparents are a great blessing. We have a great nurse that comes when she can and we have met some other nurses that help out. We have been provided for in spite of our own financial limitations and Macayla has much needed equipment. We have met some incredible people along the way on this journey that we would have never met otherwise. In short, we have found abundance in this life we never expected. The website has been a way to communicate some of that for others. We found that it has helped us to hear from others and to learn from their experiences and struggles so we share ours in hopes that it will help others. We hope to comfort others with the comfort we have received. Macayla will be turning 7 in May and she is now almost completely immobile, completely tube fed, no longer talks and is on four seizure meds, three GI meds, and sleep medication. She has had her feeding tube relocated this past November and that was due to constant struggles with her previous tube site and granulation that kept releasing blood in her stomach. We are blessed that Macayla still has some vision and can respond to us. Her memory is still in tact and this has augmented her loss of vision. She still has movies memorized and all she needs to do is listen to enjoy them. She can still see the images in her head.

Knowing our daughter will die in the next few years is the most difficult knowledge we have ever possessed. However, knowing why and the prognosis has helped us plan and think through what is to come. We have already been able to make end-of-life decisions so that we can prepare our hearts and minds (if that is possible) for when Macayla's body stops working. We were fortunate to be able to meet with three of our doctors who openly and frankly discussed the options and ethics of interventions. Being in denial of the inevitable will not help our daughter. We know that one way or the other Macayla will be healed completely. Either on earth with us or in Heaven with Jesus. I would love to see her restored with us, but while we wait to see if that happens we will plan to make Macayla as comfortable and loved as possible. Macayla is a victim of a fallen world. We already grieve over all that we will not get to experience with her; her first game or recital, her first prom, her wedding, her own children, etc. But we also revel in the smiles and surprises that she brings to our family. We thank God for everyday we have with her. We thank God for all that has been provided, especially the peace that we have in the midst of all this. It is a peace beyond understanding. Every now and then we want to stop and circle the wagons, but then we remember that this is her life as much as ours. We must stay on this unexpected trail and live this unexpected life.

Written by: Jeff Smoak (father)

Special Child-South Africa: Tristan Quarmby, Cape Town

Tristan – Our Angel

Tristan is a beautiful eight-year-old boy.

He was born on the 21 January 1999. He was a big baby and never crawled, but started walking at the age of 10 months. Tristan was incredibly active and ran everywhere. He was a tough little boy who hardly ever cried and was always happy. He often used to laugh in his sleep.

He would always wake up early, normally at around 05h00, and come running through to our bedroom. We'll never forget the sound of those tiny feet running down the passage. He loved his breakfast and would drag one of us out of bed to the kitchen where we would make his favourite porridge, Jungle Oats. He loved everybody and was extremely affectionate. Without any persuasion he would smother us with kisses and hugs.

He did everything at a hectic pace and was fearless.

Looking back now, it seems that he was trying to squeeze his whole life into a couple of years – almost as if he instinctively knew what was going to happen.

Tristan has always been extremely strong willed, has always had huge amounts of energy, and was determined to succeed in anything he attempted. He never, ever gave up, and we believe that his determination to succeed continues. Only this time, he is fighting for his life.

Tristan was a healthy child up until the age of three. He began having seizures just after his third birthday. Initially he was diagnosed with epilepsy and placed on anti-convulsant medication. These medications affected him adversely and we tried medication after medication without much success. He went through a period where he was having seizures of up to 10 minutes and we often found ourselves rushing to the hospital at all hours of the day and night. During this time, often as a result of the medication, he experienced all types of different seizures.

We searched the world for answers and eventually came across the Ketogenic Diet. We bought the movie "First Do No Harm', a movie based on a true story that resulted in the discovery of the Ketogenic Diet, and we were convinced that it was the answer to Tristan's 'epilepsy'.
The Ketogenic Diet was new to South Africa and there was not much local experience. We spoke to The John Hopkins Clinic in The USA, and eventually managed to find a local dietician who had some experience in the Ketogenic Diet. Tristan was her second patient. We eventually managed to persuade Tristan's neurologist to assist us with introducing the Ketogenic Diet to Tristan and spent four unsuccessful months trying to control Tristan's seizures through this Diet.
At around this time we started looking for alternative therapies and 'natural drugs', as we saw the negative effects that chemical drugs were having on Tristan and began losing faith in Western medical cures. We discovered a natural anti-convulsant from China and introduced this to Tristan. We lowered his dosages of chemical drugs and eventually discovered a balance between using the Chinese medication and chemical drugs. He is still on this Chinese medication today with a very small dose of chemical anti-convulsant and it has definitely assisted with the control of his seizures.

Approximately a year after the onset of the seizures, Tristan began losing his balance.
It was during this period that we really started to panic. We took Tristan from specialist doctor to specialist doctor, as well as to a few alternative medical practitioners. We were given all sorts of misdiagnosis ranging from life threatening diseases to harmless illnesses. We spent hours (days) on the Internet searching for answers and in the process coming across all sorts of terrible diseases that caused even greater anxiety.

At this time, Tristan was really suffering and he went through a number of months where he would scream uncontrollably for hours at a time. Looking back, we believe that this was the time when he began to feel the unexplainable changes occurring and began to understand that he was losing his functionality.

We could see the changes occurring and it was heartbreaking to see the pain Tristan was going through. He was at the stage where he was battling to walk and would crawl around.

There is one particular morning that we will never forget.
On this particular morning, Tristan had woken up early and had obviously decided to let has have some extra sleep. When we awoke, the house was abnormally quiet. Tristan was not in his bed and we searched the house for him. The first place we searched was the lounge as he loved watching Shrek and Toy Story, so we presumed he was watching a DVD. It was clear that he had been in the lounge as the DVD draw was open and Shrek and Toy Story were lying open. He had obviously tried to play them but, as he was losing his motor co-ordination, he could not put them in the DVD player.

The next place we searched was the garage as we have two small dogs that sleep in our garage at night. Tristan would always be the first to let them out in the morning. There is a step down into the garage and it was here that we found Tristan. He had fallen down the step and was wedged between the bottom of the step and the wall, unable to move. In typical Tristan fashion he was not crying but was quietly complaining to himself, and struggling to move. It was clear that whatever functionality he had awoken with, he had lost. We picked him up and carried him back to our bed where we held him tightly, promising him that everything was going to be alright. We had no idea that it would never be alright!

We could not find any answers.
We tried everything that was recommended, including Quantum Therapy, Ozone Therapy, Neuro-Therapy, Homeopathy, Cranial Sachral, Chinese Therapy – laser and massage, Hyper Allergenic Diet, Physiotherapy, amongst others, and, of course, we prayed.

It took about 18 months to diagnose Battens Disease.
South Africa does not have the facilities to diagnose these rare syndromes so it involved sending blood to laboratories in Europe for testing.
We had a number of misdiagnosis and eventually in August 2005 we received the dreadful news that Tristan had Batten Disease. Tristan has been diagnosed with NCL2.

Today, Tristan is blind, bedridden, cannot communicate in any way, is incapable of even moving his head, and is fed through a tube in his stomach. He also has hundreds of uncontrollable seizures and painful muscle spasm's a day. As he cannot swallow he requires constant suctioning to avoid suffocation and/or chest infections.

Even though he is in the advanced stages of Battens, Tristan is still very strong and we will never give up hope that a cure will be found in time to save his life.

He still has physiotherapy, Cranial Sachral therapy, and for the last year we have been performing the Linda Scotson Technique of Therapy, on Tristan. Since introducing the Linda Scotson therapy a year ago, Tristan has not had any lung infections and his respiratory system has strengthened. We have also started changing his diet from a formula based diet to a natural food diet.

We try our best to keep Tristan as healthy as possible while we wait for that miracle cure.
We also keep abreast of all developments worldwide with regards to Battens clinical trials, etc. We have attempted to get Tristan onto a clinical trial, however he has been rejected as he was deemed to be too sick for the one trial and, the other trial only included US residents.

Through Tristan's life challenge, his unspoken word has imparted so many different lessons to us and everybody that comes into contact with him.
Tristan requires so little to make him happy – a loving touch and a happy voice bring a smile to his face.

We love him dearly – he is our angel.

Written by: Shaun Quarmby (father)

3rd Annual Mid-Year Retreat

The 3rd annual Mid-Year Retreat for the "Life Goes On" Families is scheduled for February 8th, 9th, and 10th in Orlando, Florida. The event will be held at the Renaissance Orlando Hotel Airport located at 5445 Forbes Place, Orlando, FL 32812. The hotel does have an airport shuttle. Families need to contact the hotel to reserve their own room and can do so by calling 1-800-228-9290. By mentioning that you are staying for the BDSRA Mid-Year Retreat, families can reserve single and double rooms for only $99.00 a night. This rate is available for three days before, and three days after the conference. There are a limited number of rooms available.

This retreat is a time set aside for those families who have lost a child to Batten Disease. This event gives families a chance to receive the support of other families going through the "Life Goes On" stage of the disease. Events scheduled include a Friday night social event with the National Board, Saturday sessions about bereavement and the grief process, and a Sunday morning memorial service and good-bye coffee time. To register for the retreat, please contact National Office at bdsra1@bdsra.org or 1-800-448-4570.

International Batten Disease Awareness Days

The first ever International Batten Disease Awareness weekend is scheduled for June 7 & 8, 2008. Developed by the BDSRA Board of Directors, this weekend is meant to bring attention to Batten Disease, our exciting research, and the worthy cause the BDSRA represents. It is a time when everyone can join in a united front to raise money and awareness for Batten Disease.

This will be a "grassroots" effort for everyone as it will take the support of all of our families to spread the word. There are many things you can do to help raise awareness for Batten Disease. BDSRA has an informational booklet about easy fundraising ideas. The website will also have information available about ways you can raise awareness and funds with things like a "No-Show Potluck."

If you have questions, ideas, or would like to help out with the International Batten Disease Awareness weekend, please email Warren Shuros: wshuros@msn.com. As more information becomes available, please continue to check the NewsFlash and the BDSRA website to stay up-to-date.

2008 BDSRA Conference

The 2008 Conference will be held Thursday July 17 through Sunday July 20 at the Renaissance Hotel, 3801 Quebec Street, Denver, Colorado 80207. Please note that airfare into Denver will be expensive. Start looking for plane tickets to Denver now. The earlier you book your tickets, the better rate you will get.

The full conference information package will be mailed out with the April issue of the Illuminator. The following information is available now:

Room rate—$94 per night plus applicable taxes. There are 26 handicap accessible rooms available. The entire hotel is NON-SMOKING.

Reservations—Conference Name: Batten Disease Conference
Call for reservations: 1-888-238-6762
NOTE: The hotel *does* have a shuttle between the Denver airport and the hotel. Hertz car rental is also available in the hotel lobby. The hotel also provides free shuttle service to nearby shopping.

Complimentary USA Today newspaper delivered Monday thru Friday, cable television, coffee maker, hair dryer in all guest rooms.

The hotel has the Copper Canyon Grill & Bar restaurant that offers a full menu of contemporary, yet casual Colorado cuisine in an open-air atmosphere. Three meals served daily; casual attire. The hotel also has a lounge/bar available. Within the hotel you will find a heated indoor/outdoor swimming pool, sauna, and fitness center. You can find shopping available within the hotel gift shop, or at the nearby Shops at Northfield or Stapleton Town Center. During the conference, you can expect temperatures to be at a high of 87° and a low of 48°.

Within a 5-10 minute walk from the hotel are the following restaurants:
-Arby's
-Papa John's Pizza
-Panera Bread
-Country Buffet
-McDonald's
-Subway
-Chipotle
-Casey's Pub
-Coral Room
-IHOP
-Starbucks

Things to do in Denver and other parts of Colorado:

Downtown Aquarium-Denver, CO

Mixes family fun, upscale casual dining and spectacular marine life in Denver. Explore Aquarium Adventure Exhibit with more than one million gallons of extraordinary exhibits. Dine in the Aquarium Restaurant seated around a 150,000-gallon aquarium while you feast on a variety of delicious selections. Open Daily. Sun - Thurs 10am-10pm; Fri - Sat 10am-11pm.
http://www.aquariumrestaurants.com/downtownaquariumdenver/flash_content/index.html

The United States Mint-Denver, CO

The United States Mints have operated for over 215 years. The U.S. Mint in Denver has been in operation since 1904 and produces 65 million to 80 million coins every day! Public tours of the U.S. Mint are only given at the Philadelphia and Denver locations. This is a great opportunity to learn about a long-standing tradition in U.S. history. Guided tours are available Monday thru Friday from 8:00 am to 2:00 pm. Reservations are required.
http://www.usmint.gov/mint_tours/index.cfm?action=StartReservation

Buckskin Joe Frontier Town and Railway-Canon City, CO

Gunfights, 30 minute scenic train ride for best view of Royal Gorge, entertainment, authentic 1800s buildings, trolley ride, restaurant, saloon and more family fun. Pets welcome! http://www.buckskinjoe.com

Rocky Mountain Dinosaur Resource Center-Woodland Park, CO

Enjoy everything prehistoric at the Rocky Mountain Dinosaur Resource Center. The Center has many different dinosaur skeletons on display and offers hands-on learning opportunities. The Dinosaur Resource Center is open 7 days a week: Monday thru Saturday 9am-6pm and Sunday 10am-5pm. http://www.rmdrc.com/index.htm

Ghost Town Museum-Colorado Springs, CO

Ghost Town Museum serves as a permanent example of what the wild west towns of 100 years ago might have been like. It has been done in a way that is enjoyable for young and old alike. There are many hands-on activities for the kids. Crank a butter churn, operate an old time arcade or nickelodeon. See a short film on the gold mining era or pan for real gold in the extensive panning areas, (seasonal). Shop for Colorado gifts, have a picnic, or sip an old time sarsaparilla. http://www.ghosttownmuseum.com/

Visit http://www.denver.org or http://www.colorado.gov/colorado-visiting-activities/ for more information on things to do while in Colorado!

Australia Chapter Conference

For the first time this year (2007) we attended the Australian Batten Disease conference. Bryce, our 6 year old son, is affected with the late-infantile form of the condition. It was obviously very devastating news and no news any parent wants to ever hear. At first, knowing how rare it was, we thought that there would be little support for us and Bryce. Then we found the BDSRA.

Bryce was diagnosed in 2005- we could have gone to the last conference. But, as a new family, we felt that it was too hard for us. We weren't yet prepared for the influx of information. To be honest, we didn't want to see the kids affected- we were too afraid, knowing that Bryce would eventually end up in a wheelchair.

Two years on and we have learnt to accept the condition and in a small and strange way, embrace it, as we work in a proactive frame of mind. We endeavour to understand what Batten Disease is and what we can do to help not only Bryce, but other families too. It is true that information is the key.

The 2007 conference was a blessing for our family. As a new family we felt just like that; a family. Like we were all related to all the other attending families. I can say the strangest and most satisfying thing for me was being in the same room with others who knew exactly how you felt- who were going through the same problems, emotions and who had the same questions.

It was wonderful to hear the speakers, to share the stories, to give and receive advice and to also enjoy and have a good and relaxing time. As a new family we were very happy with the running of the conference, the location and the company (the food was good too!) It gave us the chance to have a family holiday and enjoy each others' company and the company of other families. At the conference you can make contacts and feel as though you 'belong'. We thank all who organised the conference and the guest speakers very much- especially Vanessa who obviously always works very hard for the cause.

And finally...we have decided to enjoy life with our special Bryce. We are determined that it will not rule or control our lives. We will smile and laugh. We will cry. There are days of sunshine and there are days of rain. And then come thunderstorms- but the clouds will always part for the sun at some stage. The BDSRA are the rays of sunshine from that sun. We have decided that we will always somehow be a part of the charity and will most certainly be attending future conferences and hope that one day...hopefully sooner than later... a cure or treatment will prove successful and we know that we will not be the only ones cheering at the tops of our lungs with tears in our eyes....

By Lorraine Colbert
(mother of Bryce Colbert-Daley; South Australia)

From the Nurse’s Corner
Reasons For Palliative Care

In the last issue of the Illuminator in October, my article was directed at the difference between Palliative Care and Hospice Care. That difference is that Hospice Care treats a child and or family member with a life expectancy of 6 months or less while Palliative Care treats a child or family member from diagnosis of a terminal illness to the point where Hospice takes over.

In this article I would like to explore with you more on the Palliative Care portion and what we can do for our children with Batten Disease from the time they are diagnosed until the time when Hospice or some other organization may take over our child’s care for us in the last days of their lives. **The major goal, for our children amidst the turmoil, is the need to remember that at the end of the day for both Hospice and Palliative Care, is to continue to improve end of life care for our children and their families.**

You, as parents, need to be asking your medical insurance companies or Medicaid if they are paying for any type of palliative services at the time of diagnosis, not waiting until hospices services are needed to see if your insurance company or Medicaid will pay. Palliative care should be available to all of our children at time of diagnosis, to have their lives, what ever time they have left, the best that it can be. If not, then believe it or not, parents can help more than you can ever realize. One of our Moms talked to her Senator a little more than a year ago. Our Social worker, Amy Kirk, went to a NORD (National Organization for Rare Diseases) meeting in September of which Batten Disease is a member. From there, Batten Disease was selected as one of the diseases; Amy was invited to go to Washington DC, to speak before the Social Security Administration Hearing about the process of getting social security benefits for individuals with rare diseases. More specifically, Amy addressed the unique needs of families that have children with terminal rare diseases, like Batten Disease, and the challenges facing those families when applying for benefits. I have attended two conferences on Palliative/Hospice Care this past October and November of which Amy also attended one of them as well. We are continually working very hard in all areas to help children with Batten Disease. So, from one Mom, along with others’ input, I am sure, it has gone this far in basically one year. If more Mom's or a group of Mom's, talked to our law makers, where could we go for our children with Batten Disease?

The definition of Palliative is - to palliate means to make comfortable by treating a person's symptoms from an illness. Hospice and palliative care both focus on helping a person be comfortable by addressing issues causing physical or emotional pain, or suffering.

Here are some questions about the differences between Palliative and Hospice Care and then the answers I found in an article on the internet, followed by more detailed information by a publication that I bought at the Palliative/Hospice Care Conference this fall.

Question	**Palliative Care**	**Hospice Care**
Who can receive this care?	Anyone with a serious illness, regardless of life expectancy, can receive palliative care	Someone with an illness with a life expectancy measured in months, not years.
Can I continue to receive treatments to cure my illness?	You may receive palliative care and curative care at the same time	Treatments and medicines aimed at relieving symptoms are provided by hospice
Does Medicare pay?	Some treatments and medications may be covered	Medicare pays all charges related to hospice
Does Medicaid pay?	Some treatments and medications may be covered	In 47 states, Medicaid pays all charges related to hospice.
Does private insurance pay?	No, there is no 'palliative care' package, the services are flexible and based on the patient's needs	Most insurance plans have a hospice benefit
Is this a package deal?	No, there is no 'palliative care' package, the services are flexible and based on the patient's needs	Medicare and Medicaid hospice benefits are package deals
How long can I receive care?	This will depend upon your care needs, and the coverage you have through Medicare, Medicaid or private insurance	As long as you meet the hospice's criteria of an illness with a life expectancy of months not years
What organization provides these services?	Hospitals spices Nursing Facilities Health Care Clinics	Hospice organizations Hospice programs based out of a hospital Other health care organizations

Where are services provided?	Home Assisted living facility Nursing facility Hospital	Usually, wherever the patient resides, in their home, assisted living facility, nursing facility, or hospital Some hospices have facilities where people can live, like a hospice residence, or receive care for short-term reasons, such as acute pain or symptom management
Who provides these services?	It varies. However usually there is a team including doctors, nurses, social workers and chaplains, similar to the hospice team.	A team - doctor, nurse, social worker, chaplain, volunteer, home health aide and others
Do they offer expert end-of-life care?	This varies, be sure to ask	Yes, staff experts in end-of-life care

The following information is from a book entitled *Hospice And Palliative Care: Concepts and Practice, published in 2003.* The eligibility for palliative care differs from hospice care in that there are no federal guidelines. Rather, palliative care programs have many slightly differing interpretations. Some programs may use the Medicaid definitions of hospice as a guideline; others may not. The following is a commonly accepted definition of palliation care as it differs from hospice care developed by the Last Acts Task Force: Palliative Care refers to the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. It is especially suited to the care of people with incurable, progressive illnesses.

Thus, with palliative care, there is usually a diagnosis of a life-limiting illness with no specific diagnosis. In most palliative care programs there is a holistic perspective of the patient. However, the palliative care team can be consulted while curative options are pursued to assist with pain and symptom management and offer support. As a patient becomes more debilitated, the palliative care team can then provide care more focused on the end stage treatment of the disease, including the terminal phase.

Palliative Care Reimbursement

Medicare

Palliative care, like hospice services, can be delivered in a multiplicity of sites, including in a hospital, an outpatient clinic, a home, a rehabilitation setting, or a nursing home. Because it may be administered directly by inpatient health care providers or in a home setting, Medicare Parts A and B may both be utilized.

Under home health benefits, Part A is utilized. However, care must be skilled and usually encompasses pain and symptom management or monitoring of current, active treatments. Specifically, a patient must be homebound, need intermittent skilled nursing, physical therapy, speech language, pathology, be under the care of a Physician, and receive services from a Medicare certified home health agency. Home health agencies were paid in the past either by actual costs, median costs, or a complete equation based on the agency's individual Medicare population. However, the 2000 guidelines have heralded a new program.

New home health agencies are paid by prospective payment, a diagnosis related group (DRG) for home care.

Likewise, Medicare skilled nursing facilities (SNF) also began a prospective payment based on facility rates. This is to assure that the Medicare SNF benefit is only for the brief post-acute care to shorten hospital length of stay.

In the hospital, Physicians and advanced practice nurses utilize Part B for billing.

Medicaid

Medicaid does not specifically recognize palliative care. However, the care for the management of the disease would be included in hospital care and home health care. The issue usually is medications, because some state Medicaid benefits may not cover the wide variety of medications and technology for pain and symptom control. In addition, psychological support may need to be provided under state mental health benefits.

Commercial Benefits

Commercial Insurance may not cover "palliative services" per se. However, creativity may be used to get reimbursement under other benefits such as home care, hospice, and site-specific benefits. Usually, it is most beneficial to request a designated care manager to discuss the overall picture of care, so that goals can be specified and care delivered appropriately to the patient's needs.

Physician Services Reimbursement

Medicare

Generally, Physicians use the same technique for care whether the patient is in hospice or palliative care. However, there are specifics in how the billing must be done.

Medicaid

Coding for Medicaid patients is similar to the federal guidelines. However, each state may vary in specifics. It is important for the practitioner to understand and become familiar with the guidelines within his or her specific state. Again, hospice may be better recognized in billing than palliative care.

Palliative Care

Palliative care reimbursement is based on both the International Classification of Diseases, 9th Edition (ICD-9) diagnosis codes and (CPT) codes. Established by the American Medical Association. In palliative care, the most frequently utilized procedure/service code is the evaluation and management (EM) codes. They are therefore billing under a procedure or service code and a diagnosis code. HCFA, now known as CMS, promotes extensive documentation to support EM codes. Particularly in palliative care, the provision if time is important in billing, because the care demands extensive communication. Therefore, when a visit is composed of more than 50% counseling, time may be the factor that determines which evaluation and management code to use.

Commercial Insurance

Although some commercial insurance products recognize terminal care, many do not. They may have some hospice coverage, often modeled after the Medicare Benefit. However, Physician's services are separate and billed according to the previously established system. Palliative care, however, is not commonly recognized. Some companies are looking into the broader umbrella of end of life care to explore expanded hospice and palliative care coverage.

So you see many Palliative care units and Physicians across the United States will accept children with terminal illnesses. Curative type treatments can still be done and insurance coverage continues. I strongly

encourage you to look into your own insurance coverage for your family and make sure you are familiar with your coverage's and if no Palliative Care benefits are available, I would be asking further questions, because our children with Batten Disease are eligible for it, and deserve the best care available.
Who is on the Palliative Care Team? The Palliative Care Team is a variety of health professionals may participate as part of a team to give palliative care.

Doctor: Usually acts as the care team leader; makes treatment plans and decides on medication and dosing; may consult with other doctors such as pain specialists. The doctor may be available to make home visits or may supervise the care plan without actually seeing the patient.

Nurse: Gives direct care to the patient; can also assist with managing pain and other side effects of an illness or its treatment; may act as a liaison with the rest of the team. When people are enrolled in home hospice programs, nurses visit them at home several times a week and sometimes more than once a day.

Social worker: Helps with financial issues; arranges family meetings; assists with the discharge from the hospital to home or hospice care.

Hospital chaplain or other spiritual advisor: Counsels the patient and family members on religious and spiritual matters.

Dietitian: Helps with nutritional concerns.

Physical therapist: Helps maintain movement and assists when mobility is impaired or there are concerns regarding safety in the home.

Grief and bereavement coordinator: Helps with planning memorial services and counseling for the patient as well as family members.

The Principles of Palliative Care are:

- Affirms life and regards dying as normal
- Neither hastens nor postpones death
- Perceives the patient and family as a unit
- Creates a caring, comforting environment
- Coordinates care
- Provides relief from distressing symptoms
- Maintains the independence of the patient for as long as possible
- Provides information
- Endeavours to reduce fear and anxiety
- Promotes an atmosphere where an open and honest exchange of views can take place
- Helps the patient to come to terms with impeding death
- Endeavours to alleviate isolation
- Offers a support system to family to help them cope with illness and bereavement

The role of communication:
Communication is a central element of palliative care as it helps to clarify needs and expectations. The following are some practical tips to help promote good communication with the health care team:

- Find Physicians who are willing to answer questions and listen to your symptoms and your concerns.
- Ask questions about the diagnosis and treatment. Listen to the answers and ask the Physician to explain things that are not clear.

- Tell the Physician and nurse about pain, discomfort, or other side effects, such as mouth sores, nausea, vomiting, and constipation.

If you have any further questions or comments, please contact me at 877-642-5512 (toll-free) or nancycarney@bdsra.org.

Pension Protection Act of 2006

The Pension Protection Act of 2006 (PPA 2006) which allows certain tax free deductions from IRAs will expire at the end of this year (2007).

Anyone (over age 59 1/2) can take money out of their IRA and then make a charitable donation of the same amount. They will recognize ordinary income for the amount they withdraw from the IRA account and often will get a full offsetting charitable deduction for the donation - which is the same effect as the charitable rollover.

The only people who may not get the same benefit are those people who do not itemize deductions or whose itemized deductions are limited because of their income. Also, if someone is making a charitable donation which is greater than 50% of their income for the year, then they would not receive a full charitable deduction that year (but the excess can be carried forward to the next year).

Although this provision is expiring, this does not necessarily rule out making charitable gifts from IRA account funds. You should talk with your accountant to see whether you would get a full offsetting deduction.

For information regarding this go to the website
below:
http://www.buzzle.com/articles/how-to-make-sizable-charitable-donation-from-ira-tax-free.html

You can also inquire with the IRS.

BDSRA Invited to Speak to Social Security Administration

Amy Kirk, MSW, BDSRA Coordinator of Family Services was invited by the Social Security Administration, Office of Disability Programs, to make a presentation at a Compassionate Allowances Outreach hearing on Rare Diseases at the International Trade Commission Building in Washington, D.C. on Wednesday, December 5, 2007. The purpose of the hearing, as stated in the Federal Register: "(The Social Security Administration) is considering ways to quickly identify diseases and other serious medical conditions that obviously meet the definition of disability under the Social Security Act and can be identified with minimal objective medical information. At present, we are calling this method 'Compassionate Allowances.' We plan to hold four public hearings over the next year. The purpose of this first hearing is to obtain your views about the advisability and possible methods of identifying and implementing compassionate allowances for children and adults with rare diseases."

Social Security pays benefits to individuals who meet their rules for entitlement and eligibility and have medically determinable physical or mental impairments that are severe enough to meet the definition of disability according to the Administration's laws. The rules for determining disability can be very complicated, but some individuals have such serious medical conditions that their conditions obviously meet our disability standards. To better address the needs of these individuals, the Social Security Administration is looking into ways to allow benefits as quickly as possible.

As one of only 10 rare disease organizations invited to speak, the Batten Disease Support and Research Association felt honored to represent its families, as well as other families throughout the United States who face the hardships of having a family member with a rare disease. If you have additional questions regarding the Compassionate Allowances hearing or the Social Security Administration, please contact Amy Kirk, Coordinator of Family Services, at the National Office or go to www.socialsecurity.gov/compassionateallowances/ for pictures, testimonies, and more.

Monthly Chats

As a way to get more communication between families, besides the one time a year at Conference, I have begun hosting Monthly Chats. These chats are about topics important to our families. Our first chat in November was about Fundraising, and in December we discussed "Emergency Preparedness for Families who have Children with Special Needs." On Monday, January 14, 2008, we will be having our next Monthly Chat at 9:00 pm EST/6:00 pm PST. Our topic will be "Navigating the System—the first steps on getting government-paid services." I will post a reminder on the Bulleting Board in early January along with instructions on how to access the Chat Room. Please mark your calendars as this should be an information-filled chat. Hope to see many of you there.
-Amy Kirk: Coordinator of Family Services

I could use a hand!

Let's face it, even the most loving and caring parents of a child with Batten Disease need a break every once in awhile. Whether it's time to spend with your other children, time to spend as a couple, or care needed when parents may not be able to be there for their child, respite becomes a familiar term to parents with special needs children. Not to be confused with private-duty nursing care, respite care is a short-term care option to give parents time away. Sometimes respite is provided while parents are out of the home, but it can also be provided when a parent is in the home. Respite can be as informal as having a relative come over to watch your child while you take some time for yourself, or can be as formal as hiring a respite care worker who is professionally trained to watch after your child while you are not at home.

Getting respite care can be a challenge. While most states' Medicaid programs will pay for respite, most private insurance companies will not, or at least not right away. And while most states' Medicaid programs agree to pay, they may not have money in their budgets to pay at that moment in time. I have known several parents to encounter the familiar phrase, "Yes, we'll grant you respite. Unfortunately, we don't have the funds in our budget to pay for respite right now." You may also be fortunate enough to be granted respite and have the funds to pay for a worker, but then have the daunting task of finding your own respite worker to care for your child.

The first thing to do is ask your insurance company, whether private or state-funded, if respite care is covered under your policy. It may be a service provided under the mental health section of your insurance coverage. This type of care may also be labeled as "skilled nursing care," "home health aides," or "attendant care." There are a few key differences to be aware of when looking at these labels. Some skilled nursing care requires a patient to have certain medical conditions in order to receive services. For example, your child may need to have a feeding tube, tracheostomy, or some other complex medical condition in order to receive this type of service. You may be able to get your doctor to write a note of medical necessity for this highly skilled level of care, if you and your doctor believe this is necessary. It is also important to know that the level of skill, education, and experience may be different for each of these labels. It may also differ just based on the agency you go through to find a worker. You have the right to ask a nursing provider agency what their requirements are for hiring these para-professionals. Important things to ask include: "Do they need CPR and first-aid certification?"; "What is the highest level of education they need to have completed?"; "Can they administer medications to my child?" Be sure to look into multiple agencies to find the agency that best suits your needs and your family's needs.

Find out the specific steps that your insurance company requires in applying for and obtaining this service. A letter of necessity may be required from a health professional like a doctor or counselor or a professional in the field of Batten Disease like one of our staff members or Medical Advisory Board members. Be sure to think of all the times when you would have needed or liked to have had a respite care worker in your home. Think about how many hours a day, week, or month would be enough to give you a needed break. If there are more specific hours of the day that you need care, like after school, be sure to include those in your request. The application can vary depending on your insurance company, so be sure to read the application carefully and follow all guidelines as requested. As always, any decision made can always be appealed. If you are unhappy, look into your insurance company's appeal policy and take the necessary steps. Remember, they may have denied you to make you go away even if you have a very valid claim. While appealing may be a little extra work, it could be enough to get you the decision you want.

So now you've been granted respite care. If you were granted this service from the state, you must go through the department under which this service is being funded. The respite care may be from the Department of Developmental Disabilities or possibly through the Department of Mental Retardation, or maybe through the Department of Health. Contact them to see what respite care provider agencies they recommend and reimburse. The same can be said about a private insurance company. If your private insurance company has a list of recommended providers, start by contacting them to get a worker in your home. Parents may also have the option to find their own respite care worker. If a friend or family member has experience taking care of your child, they may be able to become certified through the state to become a respite care worker. Not too much is required to make this happen. In most cases a person will fill out paperwork, participate in required trainings like CPR, First-Aid, or Ethics trainings, and have a criminal background check performed. The department under which the respite is being funded should be able to give you more information.

As parents, you have the right to choose the best person to care for your child. If a worker is assigned to you without your say but you do not like the care your child is receiving, you have the right to request a new worker. Many families have requested worker after worker until finding one that was the best fit for them. These are all things to consider while going through the process.

There may also be respite funding available through your local Child Abuse Prevention program. Studies have shown that children with special needs are more likely to be victims of abuse. In 2006, Congress enacted the Lifespan Respite Care Act. This Act was created to "assist states in coordinator state and federal funding streams and approve access to respite for all families regardless of age or disability." Currently, there is not sufficient funding to really support or help run the Lifespan Respite Care Act. There are a few states that have found the funding to fully support the program. With funding from the Lifespan Respite Care Act and Child Abuse Prevention programs, respite will most likely become a readily available service to families who have children with disabilities. Talk to your local congressman or senator about advocating for funding for this Act in your state.

There are other places to consider when looking for respite care funding. Look to your state's Developmental Disabilities Council for funding. You can also look at local charitable organizations for programs and services funding. These private charitable organizations include Rotary and Lions' clubs, Moose and Elk Lodges, and other fraternal types of organizations. It may also be of your benefit to ask your church or religious organization if they would be able to help you pay for respite care. Be sure to look into summer camps for children with developmental and other disabilities. These can be found through your local Easter Seals, Epilepsy, or Blindness Foundations. Many times the only qualification is seizure activity, visual impairment, or other disabilities.

A few key things to remember about respite care:

1. Contact your insurance provider to ask about the service first. Remember, it may be a service provider under the mental health portion of your policy.

2. Consider how much time you would like in terms of hours a day, hours a month, days a week, days a month, etc. You also have the right to appeal any decision granted to you.
3. Research your provider agencies carefully. If you are unhappy with a respite care worker, you have the right to request a new one. Ask about a family member or friend being hired as your respite care worker if this applies to you.

Never feel guilty for using respite care. Every parent needs time for themselves to rebuild their strength and stamina. You are doing what you need to do to be a better parent for your child.

BDSRA Board Member Nominations

The Board Member Nomination Committee is now accepting nominations to fill four Positions on the BDSRA Board of Directors. These Board positions have a three-year term and they will be filled via a general membership election in May. The Nominating Committee will approve a slate of qualified candidates based upon the following criteria:

1. Demonstrated commitment to the BDSRA mission.
2. Ability to devote time and energy to Board meetings and committee assignments
3. Demonstrated leadership skills
4. Ability to work well with others
5. Ability to communicate effectively

In addition, in order to meet specific needs within our organization at this time, we are specifically seeking board candidates with special skills and background in the following areas:

1) Major individual and corporate gift giving campaigns
2) Multi-media national / international public relations campaigns
3) Non-profit organization administration
4) Grant writing
5) Parent advocacy

Board members will be required to attend two in-person meetings (mid-winter and at the Annual Conference) and participate in four to five telephone conference calls. Each member will be assigned an area of responsibility while also supporting various ad hoc committees on an as needed basis. Areas of responsibility include:

1) Medical Liaison
2) Legislative
3) Chapter Development
4) Education
5) Family Outreach
6) Finance
7) Fund Raising
8) Public Relations
9) Sibling Outreach

If you wish to apply for a Board position, or want to nominate someone else, please contact the Nomination committee members listed below. Nominations will be accepted in via e-mail or mail and the nomination process will close on March 15th.

Larry McDonough	barblarmcd@aol.com
Wendy Bills	cnbear@burgoyne.com
Warren Shuros	wshuros@msn.com

Please note: In accordance with the Bylaws of BDSRA, ballots will only be mailed to those members who have paid their 2008 membership dues

Fund raising

Golf & Dart Tournaments—Jemison, Alabama

The Lucas family hosted a golf tournament on September 29th to raise money for BDSRA. The event had 25 teams register and play. They even had golfers from as far as Florida, Georgia, and Tennessee. The event raised $2,929! They even had Coach Nick Saban of the University of Alabama Crimson Tide play in the tournament and autograph a football to be raffled off. The event was a huge success and Becky and her son Chris (Juvenile) look forward to hosting the event again next year. On October 8, 2007, the Lucas family hosted a dart tournament for Batten Disease. With over 30 throwers representing 4 different lodges, the event raised $506! Both events were fun for everyone involved.

Bake Sale-Middlesex, New Jersey

Peggy and Melissa DiCapua held a bake sale in the parking lot of the Bound Brook Presbyterian Church on October 20, 2007. The 5-hour sale made over $472 for Batten Disease and sold out of all baked goods but 2 muffins and a few chocolate-covered marshmallows! Peggy and Melissa are planning to continue the bake sales, on a smaller scale, on a quarterly basis.

Touchdown for Taylor—Charlotte, North Carolina

Sharon King and Laura King Edwards hosted the first annual Touchdown for Taylor on November 9, 2007. This event was football themed with Roger Goodell, NFL Commissioner, as the honorary chair. The evening included a silent auction, delicious food, fun music, and friends and family from near and far. Touchdown for Taylor raised almost $40,000! A video Public Service Announcement from NFL Commissioner Roger Goodell about Batten Disease and Taylor's Tale can be found on the BDSRA homepage.

Cookie Walk/Bake Sale—Charlotte, North Carolina

The Hawkins family hosted a Cookie Walk on November 10, 2007. The idea behind this fundraiser is for an individual to purchase a box and the front door and walk through putting whatever will fit into the box. You can select as much or as little delicious baked treats as you like. The fundraiser also had a 50/50 raffle, kid's arts and crafts, and a raffle to win a $1,000 Belk's shopping spree. The Hawkins family helped raise about $1,700 for Juvenile Batten Disease research.

Drag Racing for Batten Disease-Hagerstown, Maryland

The Heuchan family participated in a Junior Dragster Pledge Run on November 11, 2007 to help raise funds for Juvenile Batten Disease research. Hosted by a high school student who wanted to complete his High School Graduation Project by putting on the event, 34 drivers raised $4,445.00! Instead of paying an entry fee, drivers collected pledge money. Coincidently, Adeline Heuchan, oldest daughter and Nick's sister, won the race! Washington D.C. Fox Channel 5 came out and did 3 hours of coverage on the event. Thank you to the Mason-Dixon dragway in Hagerstown for hosting the event.

Roasted Coffee Beans for sale on website-Chatham, Illinois

David Dahl, father of son Clifford (JNCL) has been roasting coffee for awhile now and even has his own coffee roasting business in Chatham. Dave recently found a website where people can sell their hand-crafted goods to a large spectrum of consumers. Through etsy.com, buyers can purchase Daveshomeroast special blends for only $10/lb. David is donating all the proceeds, including shipping costs and overhead costs, to the Juvenile Trial. Visit his page and purchase his coffee today. http://www.daveshomeroast.com

Midwest Chapter

Kevin (16) and Brendan (13) Pfaller organized a fundraiser in honor of their sister, Sara (15-JNCL) in September at Prairie Ridge High School in Crystal Lake, Illinois. "Batting for Batten Disease" was a home-run hitting contest for ages from 7th grade on up to the "Seniors"! Over $1,000 was raised in 3 hours! The top three hitters in each category won prizes donated by local stores, such as dinner certificates, Jamba Juice certificates, and pizza. Both boys are huge baseball players, so it was a lot of fun for them and their friends, especially with the beautiful weather we had that day. Thank you to everyone who helped!

Upcoming Fundraisers—Hamilton, ON, Canada

The Carter family has 2 fundraisers planned for 2008. On February 16, they are planning a Valentine's Day Dance. On June 17, they have a Golf Tournament planned. We look forward to learning of the outcome of both fundraisers. Great work and good luck, Carter family!

Minnesota Chapter Annual 5K Run/Walk for Batten Disease

The Minnesota Chapter of BDSRA has planned their annual 5K Run/Walk for Batten Disease for May 10, 2008. The event is being held at Lake Phalen, just as it has in years past. Once again this year, the Ramsey County Sheriff's Department is co-sponsoring the event. The event will also include a silent auction and prize raffle. The Minnesota Chapter also hopes to have one of our Batten disease researchers speak at the event. If you are interested in helping out with the event, donating an item to the silent auction or prize raffle, or have general questions, please contact Joni Metcalf at joni_metcalf@hotmail.com.

BDSRA is now an approved charity through MissionFish

As of November 5, 2007, BDSRA is now an approved charity through MissionFish. MissionFish, an exclusive provider for Ebay's Giving Works program, helps people sell their favorite items on-line and donate a portion of those sales to their favorite charity. BDSRA now has the opportunity to join the nearly 12,000 other non-profit organizations who currently benefit from this program. MissionFish and Ebay's Giving Works program have helped raise over $88 million for charities around the United States. This is an exciting and new way for BDSRA to tap into the on-line donation frenzy.

Here's how it works:

1. Sign up for an Ebay seller's account at http://www.ebay.com
2. After registering with Ebay, go to http:///www.missionfish.org and register to become a MissionFish approved seller and search for, or designate, your favorite charity.
3. Simply follow the steps to post and sell an item on Ebay through MissionFish and designated a portion of your sale to BDSRA.
4. Every sale made on Ebay using MissionFish will generate at least $5.00 for BDSRA. You can always choose to donate more of the sale!
5. BDSRA receives a check once a month from the donations generated through MissionFish and Ebay's Giving Works.

This fundraising effort is free to BDSRA. There is a small cost to sell an item on Ebay and MissionFish does deduct a small percentage of the donation to sustain their operating costs. Even with these fees, the benefits to BDSRA from this endeavor are overwhelmingly positive.

Please join us in this effort as we continue to work together towards a cure. Happy Ebaying!

Questions about this can be directed to Amy Kirk, Coordinator of Family Services, at kirka@bdsra.org or toll free at 1-888-379-2546. For additional information, please visit http://www.missionfish.org.

2008 Dues

Dues are to be paid to BDSRA once a year per family. The fee for dues is $20.00, the same as 2007. Checks can be made out to BDSRA with "Dues" in the memo line. This money helps keep things like the Illuminator, programs for families, and the National Office in operation. Please start sending in your 2008 Dues today. Dues are payable to your local chapter. If you do not live in an area with an active chapter, please send your dues to BDSRA National Office.

IN LOVING MEMORY

Hissien Hamed, daughter of Alia Hamed, Hilliard, OH Born: 06/01/90 – Died: 05/09/06 Late Infantile

Derek Trimmer, son of Michael & Michelle Trimmer, Sharpsburg,MD Born: 04/28/95 – Died: 10/15/07 Infantile

James Ronald Brazell, father of Tammy Peters, Mobile, AL
Died: 10/18/07

Jacqueline Malabed, daughter of Robert & Kathran Malabed, Anchorage, AK, Born: 01/09/97 – Died: 10/19/07 Late Infantile

Nicole Daniels, daughter of Jennifer Richards, Vancouver, WA Born: 07/23/82 – Died: 10/20/07 Juvenile

Ethel Flanagan, mother of Darryl & Danny Flanagan (both deceased) Died: 10/25/07

Monique Guzman, daughter of Mack & Sheilla Guzman, Leesville, LA Born: 08/09/85 – Died 10/30/07 Juvenile

Philip Sadler, son of Roy & Colleen Sadler, Tilghman Island, MD Born: 11/16/80 – Died: 11/05/07 Juvenile

Rick Tiszai, father of Grant Tiszai, Lake Wylie, SC Died 11/12/07

Carolyn Beth Austin, mother of Laura Ann Brigman (deceased) Lynwood, WA. Born: 12/13/52 – Died: 11/13/07

Denver Ray Casto, son of Pansy Casto-Charleston, WV
Born: 02/11/69 – Died: 11/29-07 CLN5

Cristopher Andre Waters, Jr., son of Lesley Bolton & Christopher Waters, Sr. – Manassas, VA Born – 5/131/93 – Died 12/23/07 Late Infantile

Ali Mohammed, Columbus Ohio—Died 12/23/07 Late Infantile

Cassondra Mortell, daughter of Sandra & Darrel Thomas, Gardner, KS & Cheryl Mortell, KC, KS – Born 7/7/91 – Died 12/24/07 Juvenile

Garrett Campbell, son of Scott & Renee Campbell, Charlotte, NC – Born 7/19/05 – Died 12/30/07 Infantile

BDSRA Lifetime Honor Roll and Guardian Light Guild

BDSRA has created a way to recognize those individuals who are generously giving of themselves to the organization. Much like other organizations, hospitals, and universities, BDSRA has created different levels of giving recognition. If you have donated money to BDSRA in the amount of $1,000 or more, you are now a member of the *Lifetime Honor Roll*. The Lifetime Honor Roll levels are as follows:

$1,000 or more—Bronze Level Member
$5,000 or more—Silver Level Member
$10,000 or more—Gold Level Member
$25,000 or more—Platinum Level Member
$50,000 or more—Emerald Level Member
$100,000 or more—Diamond Level Member

These levels are meant for an individual's cumulative giving. As you continue to remember BDSRA in your yearly donations, you have the opportunity to move into a higher level. Those members of the Lifetime Honor Roll will receive a certificate of appreciation and membership for their contributions. As we begin to collect the information needed to recognize these individuals, please bear with us. The first list will be published in the April 2008 Illuminator. If you believe you have made a donation to qualify you for the Lifetime Honor Roll, and do not see your name listed at that time, please let us know.

For those individuals and friends of BDSRA who have made the decision to leave the organization in their will or estate, BDSRA has created the *Guardian Light Guild*. This is a special group for people who would like to see the efforts and services of BDSRA continue even after they are gone. Members of the Guardian Light Guild will also receive a certificate of appreciation for their donation. If you have already designated BDSRA in your will or estate or are interested in learning more about the process, please contact BDSRA at your earliest convenience.

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.

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