THE

ILLUMINATOR

Batten Disease Support and Research Association

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"A Light in a World of Darkness"

BDSRA, 166 Humphries Dr., Reynoldsburg, OH 43068

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UPDATE ON RESEARCH

Insights on Batten Disease from a Handful of Patients

We all know how devastating Batten disease can be. For a few families however, knowing whether their child really has Batten disease has remained an unanswered question. While genetic testing using DNA samples from patients has been routine for diagnosis for forms of Batten disease involving mutations in CLN1, CLN2 and CLN3 for a while now, some patients are negative for this test. As recently as 2 years ago few in the USA were diagnosed with defects or mutations in CLN5 and CLN6, but now this diagnosis is available.

A few researchers have dedicated their efforts to identifying the cause of Batten disease in patients where the more common mutations have been eliminated. In the last year two new genes or proteins have been added to the Batten disease family.

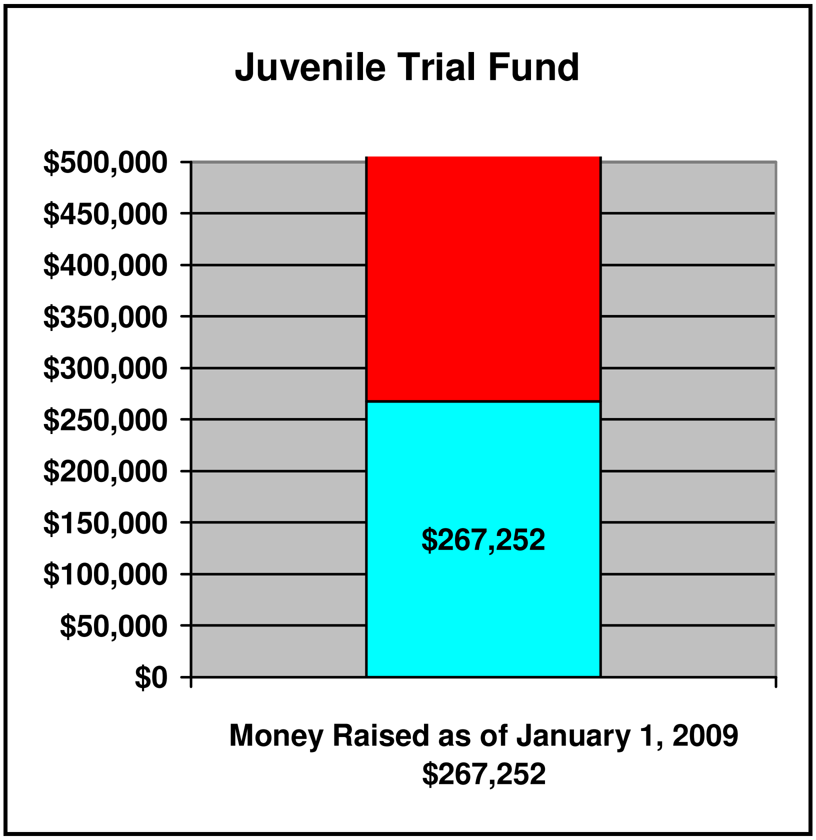
CTSD which is the gene that makes a protein called Cathepsin D was found to be defective in congenital NCL, an extremely rare early onset form of Batten disease. Further studies of defects on this protein are revealing information that may help to better understand all types of Batten disease. Why you may ask, would a disease so rare help others with Batten disease? The simplest answer is for two reasons. Firstly, Cathepsin D is a type of protein called an enzyme that is well known, being a particular enzyme called a protease which is involved in degrading other proteins in the cell. Secondly, for several years, Sheep and Dogs have been studied with a defect in the equivalent to the Cathepsin D protein in these animals, thus providing insight into how these animals deteriorate with this enzyme defect. An additional aspect of Cathepsin D studies that may benefit Batten disease research is that researchers in the Alzheimers field have become interested in this enzyme for a number of reasons. Although it is early days and there is no association between Batten and Alzheimers disease this interest may help studies on this enzyme and improve our understanding as it relates to Batten disease.

MFSD8 which is a gene that makes a protein designated for now, MFSD8, as we do not know what it does. However, these mutations have been associated to a rare form of Batten disease called CLN7. While we do not know what MFSD8 does, it provides another protein to study that will hopefully enable us to gain a better understanding of the basis of these awful diseases.

So, these rare forms add to the Batten disease researcher's toolbox in piecing together the puzzle that is these diseases. There is still a long way to go, however, in terms of diagnosis. Two more genes can now be tested so that families may in fact know for sure if their child does indeed have a form of Batten disease.

--Submitted by David Pearce, PhD

Juvenile Trial Fund—Where are we?



BDSRA 2009 Conference—St. Louis, MO

It's 2009 and that means it's time to start planning for our 21st Annual BDSRA Family Conference. This year we will be in St. Louis, Missouri. As always, the entire official Conference Pack will be included in the April Illuminator, but here are the basic details on the Conference.

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

Place: Marriott St. Louis Airport Hotel
10700 Pear Tree Lane
St. Louis, MO 63134
Phone: (314) 423-9700
Toll-free: (877) 264-8771
Fax: (314) 423-0213

Website: http://www.marriott.com/hotels/travel/stlap-st-louis-airport-marriott/

Location: The hotel is within sight of the Lambert-St. Louis Airport. There is also Metro Line access near the hotel that provides transportation to downtown St. Louis.

Reservation line: 1-800-228-9290

Conference name: Batten Disease Conference

Handicap Accessible Rooms: There are 16 rooms available. Reservations for these rooms must be made through BDSRA. Please call the BDSRA office at 1-800-448-4570 to reserve your handicap accessible room.

Room Price: $89 a night plus tax

Meals:

- Breakfast: $10.50/person
- Lunch: $12.95/person
- Dinner: $21.95/person
- Children 3 and under: FREE
- Children 4-12: We are still negotiating the price of these meals
- There is a 22% service charge added to each meal per person

Shuttle Service: Complimentary 24-hour shuttle service is available to/from Lambert-St. Louis International Airport with handicap accessible service also being available.

2009 DUES ARE DUE!

Please remember that your 2009 DUES can be paid to BDSRA immediately. The cost is $20 per family or per member who would like voting privileges. Paying your DUES allows you to vote in the yearly Board elections. Each $20 DUES payment entitles you to 1 vote in the election. Paying your DUES helps sustain the BDSRA operating fund and the existence of our main office. It also helps pay for the quarterly Illuminator and Lighthouse newsletters as well as our annual Conference expenses and many other things. If you have an active chapter, your dues are to be paid to your chapter. If you do not have an active chapter, please send your dues to BDSRA, 166 Humphries Drive, Reynoldsburg, OH 43068. Please do your part to keep BDSRA in existence. PLEASE PAY YOUR 2009 DUES NOW! Thank you very much.

BDSRA Staff Update

Just a quick update from the BDSRA office. Amy, our Coordinator of Family Services, was married on November 7, 2008. She and her husband, Jeff, had a beautiful ceremony and reception with approximately 200 guests in Toledo, Ohio. Now that she is married, she will be going by Amy Lombardi. Her email address will remain kirka@bdsra.org. Congratulations to Amy!

Guardian Light Guild

BDSRA wants to recognize and thank those people who have included BDSRA in their estate plans and wills. To do this, BDSRA has create the Guardian Light Guild. The following people are now members of the Guardian Light Guild. Upon acceptance into the Guild, members will receive a certificate of appreciation and recognition in the quarterly Illuminator. We sincerely thank these people for making one of the largest gifts a person can make. It is because of them that the mission of BDSRA will continue on for many years to come.

Dolores Toomey (deceased)--New Bedford, Massachusetts

Cecelia Martin (deceased)--Fayetteville, New York

Gladsia Bland (deceased)--Dexter, Missouri
Barbara Tegen (deceased)--Auburn, California
Diane Plasko--Brielle, New Jersey
Lance & Elaine Johnston—Reynoldsburg, Ohio
Lars & Leilani Anderson—Carrollton, Texas

*If you have included BDSRA in your estate planning, or have questions on how to do so, please contact the National Office: 1-800-448-4570.

Jacob Scores Winning Goal

Jacob Geer (age 6—unknown NCL) did something that most soccer players only dream of: he scored the winning goal to break a 5-5 tie during his final soccer game of the season. Jacob's team played the Division 1 boy's champion high school soccer team, East Kentwood, on November 8, 2008. They beat the high school boy's team 6-5. Jacob, who's been playing soccer on the VIP team set up by the local American Youth Soccer Organization, was very proud of his shining moment. His name was announced on the loud speaker and he was "high-five"ing everyone around him. His mom, Chris Geer says, "It was a very special moment for him!" The VIP team has players of all ages with diagnoses like Down's Syndrome and Autism. Jacob is the only one with Batten Disease, but that doesn't stop him from having fun. The team plays each Saturday during the regular Fall season and then one Saturday a month throughout the Winter. Every player has a "buddy" who helps them on the field and every game ends in "circle time" where each buddy will remark on something great their player did that day. The VIP soccer team has been a great thing for both Jacob and his family. To read the article about Jacob's winning goal, please visit:
http://www.mlive.com/highschool/grpress/index.ssf?/base/sports-0/1226512508307030.xml&coll=6

Taylor Participates in 5K Jingle Jog

Ten year old Taylor King (INCL) from Charlotte, NC participated in her first Jingle Jog totaling 3.1 miles on Saturday, December 13th. Along with the help of another sighted jogger from Taylor's school, the pair finished the race in just over 55 minutes. Taylor has been a part of the group, "Girls on the Run" since August. "Girls on the Run" is a program dedicated to emphasizing self-respect and healthy living through running. Taylor is like so many other children with Batten Disease, always proving that this horrible disease will not stop them from living their dreams. Great job, Taylor! To read the news article in the Charlotte Observer, please visit:
http://www.charlotteobserver.com/104/story/414415.html

OUR SPECIAL CHILDREN

Hailey & Carter Goranflo—LINCL Shepardsville, KY

This is the story of our two precious angels, Hailey and Carter. Our names are Neil and Miranda Goranflo. Our children were diagnosed with Late Infantile Batten disease in January 2008, the worst day of our our lives. Out of everything it could have been, it had to be one of the most brutal childhood diseases known. They are so brave through it all and are real troopers, with all the doctors, medicines and therapies. We could have never imagined something like this could ever happen to our family. It seemed like we had it all. A happy marriage, a beautiful new home, a wonderful daughter and the sweetest little boy anyone could ever ask for. We were completely devastated to know that our lives would never be the same again. All we ever wanted was a normal life, nothing special, just normal. We thought that we would never smile again and didn't even know how we could go on. But through the strength of God and our beautiful children, we somehow manage to deal. Some days are much harder than others, but for the most part we try not to think about it too much. Even looking into the future is too hard. We have learned to live in the moment and cherish each and every day that we have with them.

Hailey is 6 and she started showing symptoms at age 2 1/2. She began having seizures, which got much worse over time. She began to regress very quickly. Originally, we were told that it was childhood epilepsy and that she would grow out of it. Even though she continued to deteriorate, we always had ourselves convinced that she would grow out of it, just the the doctors had promised us. Most parents say that they knew it was something more. We however were very naive and that's just how we dealt with it. Through Hailey's sickness, we tried everything in an effort to help her. Every seizure medicine, vitamin supplements, diets, even herbs from an Amish doctor... to no avail. In a matter of one year, she lost everything and is now completely dependent on myself and my husband. She is bed-ridden, on a feeding tube, unable to communicate in any way and the doctors believe she is nearly blind.

It was in January of this year that Carter had his first seizure. We couldn't believe it. We had somehow learned to deal with Hailey's illness and we knew that we would always have Carter to keep us going. He sure knows how to put a smile on someone's face. It absolutely crushed us to know that he would suffer the same fate as his sissy. He is still walking and talking some, though he is very delayed. It is so hard for us, picturing him like Hailey.

As soon as we got the diagnoses and got over the shock of it all, we immediately began researching our options. Unfortunately as many of you know, there isn't much out there for our babies. We knew that it was too late for Hailey to be a part of any trial here in the U.S., as she was too far progressed. So after speaking to other parents, we learned of stem cells in China with a price tag of $50,000. At first we thought it would be impossible, but we quickly got motivated and began fund raising. We raised the money very quickly and Hailey and I made our first trip to Beijing, China last summer.

As many of you may have seen on the news, our trip was a bit delayed. We had a layover in Canada and just by looking a Hailey's condition, they refused to let her fly. After several more days of trying different airlines, Hailey went into status and was rushed to the emergency room, where we spent several days. After days of begging and pleading with hospital officials, they still refused to let her make the trip tp China. They told me to take her home to die. We were sent home on a medical flight days later, more frustrated and disappointed than ever. After returning home, we knew we had to come up with a bigger and better plan. With the help of our local congressman, we worked one on one with an airline and explained our situation it great detail. This was truly a matter of life or death. Knowing that they would get a lot of good publicity out of this, as we had been on the national news several times by now, United airlines wanted to step in and save the day... which we are extremely grateful for.

After finally arriving in China, we were greeted with the most friendly faces and they were so good to both Hailey and I. Over the 7 weeks, Hailey received 4 stem cell injections (each injection containing 10,000,000 stem cells) via lumbar puncture. She also received intense physical and occupational, as well as massage therapy. Since Hailey's treatment, she has made remarkable improvements. Before we left for China, Hailey was in the hospital ICU every week for 5 weeks and the doctors here were preparing us for the worst. They only gave her months to live. We are extremely grateful for what the Chinese doctors have done for Hailey and we truly feel like they saved her life. They have reversed more than 8 months worth of damage and have stopped the progression of the disease. She no longer needs home oxygen, she is much stronger and healthier and the biggest improvement, her seizures have been reduced from 500+ seizures a day to 5 or less.

Hailey and I are planning our second trip to China February 12th. We are really looking forward to this trip and cannot wait to see even more improvements. Unfortunately, all of the doctors have left the hospital we were at before and we will be going to a new, better hospital. The doctors in China have been working on gene therapy for some time now and it will be ready for Hailey's next trip. We are a little nervous about it, because we know very little about it, but we feel like we don't have any other options. We just really think we need to try this for her and are very eager to see how she does. The treatment at the new hospital is also much cheaper, half the price of the old one.

As for Carter, we have been patiently waiting for the Cornell trial to start, but are getting increasingly frustrated with the dates getting pushed back further and further. My husband and I have made the decision that if we do not hear anything by this summer, than Carter too will go to China for Hailey's third trip. This has been a very difficult decision for us and we hate just waiting and seeing. As you all know, time is of the essence.

Our family had a wonderful Christmas and I hope everyone else did too. We live in such an amazing community that has supported us the entire way. We had so many people donate tons of new toys and clothes for the kids, so they really racked it in this year.... and they deserved every bit of it!

The best advice I can give to families struggling with this terrible disease is just to make to most of every day. We try to do more special things with our kids and make great memories with them... and take lots of pictures. They are all so brave and I don't know how they do it. But as long as they are willing to fight and keep going, we will do everything in our power to help them. I think that's what really keeps us going now, just knowing that we're giving it everything we have. We know that no matter what happens, our babies will be in good hands.

God is good and He has kept us strong through all of this and we know that he will continue to lead us in the right direction. I am very eager to share Hailey's progress with everyone, especially with her next trip and if you'd like to follow our story, you can visit our website at www.haileyandcartersdream.com. I wish everyone the best and God bless you all.

Written by: Neil and Miranda Goranflo

International Special Child: Tatyanna Zazalak—LINCL Brandon, Manitoba Canada

It's kind of crazy how quickly your life can change in a year's time. Last year we entered the new year feeling positive and optimistic. Our 4 year old had received a tentative diagnosis of PDD-NOS and her seizures were finally under control. The rest of the kids were healthy and we felt certain that the worst was finally behind us. We had no idea of the events that were to unfold.

Tatyanna was born at home on February 28, 2003. Other than weighing a very surprising 9 1/2 lbs there was nothing about that day that would prepare us for what was to come. Tatyanna was an extremely active little girl and justly earned the nickname of "Stitch" in reference to the loveable but destructive alien from Lilo & Stitch. Except for having a speech delay, she met all of her childhood milestones early. By the age of 2 she could scale cupboards and was always the first kid at the top of the climbing structures at the local parks. She could run for hours and I used to find myself wishing that I could bottle that energy so that I could use it after a long day of chasing her around!

It wasn't until April 2007 that we became concerned that something was wrong. Tatyanna had started to become increasingly clumsy and frequently trip and fall. After having an EEG, it was determined she was actually having seizures. Although we weren't thrilled with this diagnosis, we weren't too concerned either. After all, we knew people with epilepsy and they were able to manage their symptoms quite successfully.

During that summer, Tatyanna’s seizure activity increased in both severity and type and we struggled to find the right medications and a proper diagnosis. We noticed that she was starting to have difficulty finding the right words and then getting those words out. She also developed problems with her balance and co-ordination and our once active child was barely able to stand up without falling over. While many of these symptoms could be associated with the medications that she was taking, my husband and I knew deep down that something was very wrong. We began to push for more testing and a referral to a pediatric neurologist. In December, the MRI results came in as normal, baffling everyone involved. We breathed a sigh of relief and began to enjoy the Christmas season. Tatyanna was on a new medication and the seizures seemed to be under control.

In mid January, our “vacation” came to an abrupt end. The seizures were back with a vengeance and our daughter was once again “stuck” to her kid-sized recliner in the living room. It wasn’t until this point that we were able to meet with a pediatric neurologist at the Children’s Hospital in Winnipeg. Assessments were done, blood was drawn and previous tests were reviewed. We were then informed that the MRI was not normal and that it was possible that Tatyanna suffered from some sort of progressive myoclonic epilepsy. It was a very long 3 weeks while we waited for those lab tests! When we got the call to come back to Children’s Hospital for a conference—without kids, we knew it was bad. Despite that premonition, nothing can prepare you to hear that your child will not get to grow up. On February 19 2008, we were told that Tatyanna had LINCL. We were devastated. Here we had this beautiful 4-year-old daughter who loved to snuggle while watching classic Disney movies and was crazy about horses and we were told to take her home, contact Westman Dreams for Kids and wait for her to die. This was not acceptable to me and I immediately went home and “prepared for battle”.

After doing hours of research and sending enough emails that my fingers would cramp up, we decided to take a chance and bring her to a neurological centre in Beijing for treatment. We knew it wasn't a cure but were hopeful that it would at the very least slow down the ravages of a disease that was quickly taking our daughter away. Going to China for something that could really be described as experimental at best was not a decision that we made lightly, but for us, it was the right decision and we have no regrets.

Next month will be the one year anniversary of our life-changing journey as parents to a child with Batten Disease. In that span we have learned to become advocates and researchers. We have travelled to places we never anticipated and gotten involved with amazing organizations like Children's Wish Foundation. We have learned to appreciate the small things and to live in the moment. Family has taken on a new level of importance and we strive to make each day as meaningful as possible. Some days are good, some not-so-much. But for the moment, Tatyanna is still smiling and still laughing and some days that's really all that matters.

Written by: Trenton and Janelle Zazalak

FROM THE NURSE'S CORNER

Behavioral Issues

If you recall, in the last issue of the Illuminator, I mentioned writing on different areas of Palliative/Hospice Care that will affect our children at some point along the disease process of their illness and how you as parents can possibly help them better work through some of these issues. So, in this issue, I am going to write about behavioral issues.

As many of you know, Batten Disease can show a wide variety of behaviors during the course of the disease process. Some children can be very calm during the entire disease and never have any issues with assertive or aggressive behavior while many others have a very difficult time for 2, 3, 4, years and sometimes longer. But, at sometime, it will pass, and the child will become more passive again.

This issue we will look at more of the behavioral issues of children with Batten Disease, and what we can do to help these children. First of all, the definition of behavior is: the manner in which one acts; the actions or reactions of individuals under specific circumstances.
As we have learned from studying Batten Disease, as the disease progresses, more brain cells continually die. Therefore, we see a slow deterioration of the body, and especially of the cognitive area in the learning and reasoning areas of the brain.

As a result, many behavioral issues become evident. I will list some of them.

1. Depression – This is a child who at one time was able to see and now is blind or almost blind. In other words, he cannot do what he was capable of once doing – watching TV, riding a bike, not doing as well in school, etc.
2. Frustration – losing friends, eating is different due to blindness, increased or decreased appetite, etc. also part of depression
3. Anger – associated with above 1 and 2, can have outbursts and temper tantrums

4. Loneliness – due to loss of friends, blindness, can also be associated with above 1,2,and 3
5. Anxiety – new situations daily, may be partially due to blindness
6. Sadness – due to any of the above
7. Tearful and Fearful – usually due to fear of falling due to blindness and items above
8. Attention-seeking from parents – all of above
9. Bodily Complaints – headaches, stomach aches, general aches
10. Sleep disturbances – reluctant to go to bed, nightmares
11. Increased incidence of colds and possible flu episodes – (may get run down due to depression)
12. Possibly more urinary and respiratory infections –(may get run down due to depression).

If you see any of these symptoms in the above group or in the list below, a visit to your doctor may be in order. Depression can be the key factor causing these behavioral issues above and you may decide to call your Doctor and discuss your options to treat your child with medications possibly an antidepressant. You can refer to the Medication 2008 guide for a detailed listing of drugs and side effects, etc. that is available through the BDSRA office by giving us a call at 800-448-4570 or email – nancycarney@bdsra.org.

Also, some of the children with Batten Disease can express many symptoms of aggressive behavior that is very difficult to manage and require different medications to control them, like an antipsychotic. A list of some of those symptoms follow:

1. Attempt to run away
2. Biting
3. Excessive possessiveness
4. Fixations
5. Hallucinations
6. Hateful
7. Hitting
8. Hysterical laughter
9. Kicking
10. Mean
11. Obsessiveness
12. Physically abusive to others
13. Refusal to eat or drink
14. Refusal to use the bathroom
15. Repetitive speech
16. Scratching
17. Screaming
18. Self-abuse
19. Stubbornness
20. Swearing
21. Uncontrollable sobbing
22. Unusual belligerence
23. Verbally abusive to others

Even though very difficult to manage yourself, your doctor is your first place to call. If you have a Palliative Care Team/Unit in your area, please get in contact with them. At the time your child is diagnosed with Batten Disease, he/she is eligible for Palliative Care Services which can follow you through the entire course of the disease process until it is time for Hospice Care to take over. They offer a wide range of services to help you and are a very compassionate team to guide you along your journey. It may take several tries between different medications to find the right combination/s of medications for your child, but please stay on it. If you start on a drug and after a week, 10 days, you do not see any changes, call the doctor and again discuss options of possibly increasing the dosage or changing to another medication. There is also a wide range of side effects with these medications, so please be aware of them.

When your child with Batten Disease has an unusual behavior that is too difficult for you to manage: there are several things to keep in mind:

1. Always make sure your child is in a **safe** environment – remove any stressors in the area.
2. Always consider that he/she may be having a side effect from a medication he is taking, example, if he is having hallucinations.
3. Always protect yourself and other children if a child is having a temper tantrum for example. Call for help if necessary.

4. Always record episodes/outbursts, how often they occur, how long they last, and any specific characteristics about each incident to report to your Doctor.

I hope this is helpful information. If you would like or need more information you can call or email me at the office. Also, if you would need help in getting services for Palliative Care in your area, Amy, our Coordinator for Family Services is very helpful and you can call or email her as well and as always, Lance is a good source of information with having experienced Batten Disease himself with his daughter, Lorena. So, please, do not hesitate to contact us.

Thank you!

Sincerely,
Nancy Carney RN
Family Medical Liaison/Educator
Batten Disease Support & Research Association
877-642-5512
nancycarney@bdsra.org

Amy (Kirk) Lombardi MSW, LSW
Coordinator of Family Services
Batten Disease Support & Research Association
888-379-2546
kirka@bdsra.org

FROM FAMILY SERVICES

Getting the Help You Really Need

"Everybody wants to help. I know it sounds crazy but sometimes it's overwhelming and I don't feel comfortable asking for what I really do need."

Most of us aren't very good at asking for help when we need it. We're used to being able to take care of our families on our own. And though our friends and family may want to help, they probably don't know how to offer it or even what would be helpful to you right now.

This is a time when you need to learn to accept the help you need. In doing so, you give others the chance to do something good for you and that makes them feel better at the same time. Being on the receiving end is a difficult thing for many. It is one of the gifts you do receive in this time of trials and worries and a gift you give to others.

There are probably specific things you need to keep your family afloat during this strenuous time. You may be dealing with dietary restrictions, changes you need to make at your home and new routines you need to follow. You might want to consider giving a list of the things that would be helpful to you to a friend or someone at school who is good at organizing and can be the contact person for connecting your needs with people who want to help.

In the hopes of getting you really practical and useful help from those well intentioned and concerned friends, family, school community, faith community, etc. the list below is intended to make it easier to connect you with people that can help.

Letter for Friends on How They Can Help

Here's a letter you can hand to friends who want to help but don't know how. Please change and adapt this letter to meet your family's specific needs:

Dear Friends,
This is a very demanding and emotional time for all of us. We appreciate your interest and your desire to be here with us. We all know it is hard to ask for help and to know what to do to help. The truth is, we do in fact need your help in some areas. To make it easier for us both, we have some ideas that you can assist us with. This is just to be helpful and there is no pressure or obligation, we just wanted to make it easier for all of us.
Things that would be very helpful:

HOUSEHOLD IDEAS

- Mow the lawn when we're away for several days or circumstances prevent us from doing it ourselves.
- Arrange for transportation for our other children to get to/from school, sports and other activities. This can be shared among a few people; we can provide schedules, directions, etc.
- Sponsor a housecleaning session.
- Pick up meds at pharmacy or clinic/hospital.
- Shop for groceries with a list.
- Walk the dog regularly.
- Have our other children over to play or sleepover occasionally.
- Bring news from school, notes, cards, journal from the kids.
- Keep friends updated for us and express our appreciation

for their concern. This reduces the number of calls we need to make.

- Please call before visiting. We may be resting or having a rough day/night. We want to make sure we can honor your time too.
- Run errands we may need help with: will provide the list
- Come sit with my child so I can take a walk, go to church, have an occasional break with someone he/ she feels comfortable with
- Laundry! A few less loads would be heaven

FOOD

- The following food items are always welcome: bag lunches for when we are "on the go" at the clinic or hospital, etc., drinks and non perishable food and snacks
- gift cards for the grocery store or takeout food.
- Drop off take out dinners when we get home after treatments/long days at the clinic or appointments.
- Coordinate meals for a few days or weekly that can be frozen and reheated or simply prepped to eat. Fresh veggies/ fruit/ drinks are always welcome (we'll be sure to let you know of any special dietary needs).
- Drop off snacks and drinks for at home when we have many people in and out of the house.

We are deeply grateful for your care and concern for our family and anything you do will be a big help and a relief. Thank you for holding us all in your hearts and thoughts. It is good to know we are not alone.

Reprinted, with permission, Partnership for Parents:
http://www.partnershipforparents.org/
A Support Network for Parents of Children with Serious Illnesses funded and created by the Children's Hospice and Palliative Care Coalition: http://www.childrenshospice.org/

Monthly Chat

We will be having our Monthly Chat on Monday, January 26, 2009 at 9:00pm EST/6:00pm PCT. Instead of having a structured topic this month, this will be a free chat. Please feel free to join us to talk about whatever you like. We'll be there to answer your questions and give thoughtful advice. If you have a topic in mind that you'd like covered at the chat or for a future chat, please email Amy at kirka@bdsra.org. Instructions for accessing the chat and a reminder notice will be posted on the BDSRA Bulletin Board one week prior. As always, please contact me with any questions. Thanks and hope to see many of you on January 26th!

Calling All Sibs!

We know how much fun the Sibs have at Conference every year reuniting and catching up. For many of you, this is the only chance you get to see and talk with some of your friends. This is why we're hosting a **Sibs Chat** on Thursday, February 5, 2009. The chat will be at 9:00pm Eastern Time/6:00pm Pacific Time. The chat will be hosted by Brittany Caracciolo (Sibs leader) and Amy Lombardi (Coordinator of Family Services). Join us to catch up, ask questions, tell us about your special Batten sib, or anything else! Here are the instructions for accessing the chat room on the BDSRA website:

1. Go to www.bdsra.org
2. Click on "the Family Rooms" tab on the left
3. Click on "TeenScape" to go to the Teens/Sibs chat room
4. Click on the "Live Chat" button that has a coffee cup on it
5. Make sure your computer is Java enabled
6. Type in your name and a brief description
7. Click on the "Chat!" button
8. A new window will pop up with the chat room
9. Start chatting!

Make sure you have your pop-up blocker turned off or allowing pop-ups from this site. If your pop-up blocker is enabled, the chat will not work correctly

This is an all-ages chat. If you (or your parents) have any questions, please feel free to email Amy at kirka@bdsra.org or call 1-888-379-2546. We can't wait to see you on February 5th.

Batten Disease Featured on ABC News Website

On November 13, 2008, ABCNews.com published a news article about Batten Disease in its Health news section. The article talks about Tricia and Phil Milto and their two sons, Nathan and PJ, who are diagnosed with LINCL. Milto talks about his motivation for finding a cure and establishing the Nathan's Battle Foundation to raise money for the cause. The article also features remarks from Dr. David Pearce and Lance Johnston. Both men talk about the positive steps being made in research and the challenges we face being a rare disease and establishing FDA approval.

We are always looking for ways to promote Batten Disease and its devastating effect on families at a national and global level. BDSRA wants to thank everyone for their continued advocacy efforts in both research and awareness of the disease. This story is a big step in the right direction! To read the article, please visit:
http://abcnews.go.com/Health/Story?id=6237901&page=1

New Project Approved by BDSRA Board

The BDSRA Board has just approved the development of a new video. This video will be specifically for the education of children with Infantile or Late Infantile. We need your help with this project. We need video clips of children with Infantile and Late Infantile Batten Disease. Specifically, we need video clips from school settings. However, any video will be helpful to this project. Your submission of video clips is also your permission to use the video for this project. Please send to:

Wendy Bills
1141 W 13200 S
Riverton, UT 84065

You may also send electronic video to:
wbills@murrayschools.org

Another project we hope to develop is the making of a "Chicken Soup for the Soul" for Batten Disease families. Please send your hopeful, insightful stories to the above contact to help with this project. Thank you for all of your help!

Thoughts of a Mom --By Maureen K. Higgins

Submitted by Paula Mendes, mother to Joao (JNCL)--Portugal

Many of you I have never even met face to face, but I've searched you out every day. I've looked for you on the Internet, on playgrounds and in grocery stores. I've become an expert at identifying you. You are well worn. You are stronger than you ever wanted to be. Your words ring experience, experience you culled with your very heart and soul. You are compassionate beyond the expectations of this world. You are my "sisters."

Yes, you and I, my friend, are sisters in a sorority. A very elite sorority. We are special. Just like any other sorority, we were chosen to be members. Some of us were invited to join immediately, some not for months or even years. Some of us even tried to refuse membership, but to no avail.

We were initiated in neurologist' s offices and NICU units, in obstetrician' s offices, in emergency rooms, and during ultrasounds. We were initiated with somber telephone calls, consultations, evaluations, blood tests, x-rays, MRI films, and heart surgeries.

All of us have one thing in common. One day things were fine. We were pregnant, or we had just given birth, or we were nursing our newborn, or we were playing with our toddler. Yes, one minute everything was fine. Then, whether it happened in an instant, as it often does, or over the course of a few weeks or months, our entire lives changed. Something wasn't quite right. Then we found ourselves mothers of children with special needs.

We are united, we sisters, regardless of the diversity of our children's special needs. Some of our children undergo chemotherapy. Some need respirators and ventilators. Some are unable to talk, some are unable to walk. Some eat through feeding tubes. Some live in a different world.

We do not discriminate against those mothers whose children's needs are not as "special" as our child's. We have mutual respect and empathy for all the women who walk in our shoes.

We are knowledgeable. We have educated ourselves with whatever materials we could find. We know "the" specialists in the field. We know "the" neurologists, "the" hospitals, "the" wonder drugs, "the" treatments. We know "the" tests that need to be done, we know "the" degenerative and progressive diseases and we hold our breath while our children are tested for them. Without formal education, we could become board certified in neurology, endocrinology, and psychiatry.

We have taken on our insurance companies and school boards to get what our children need to survive, and to flourish. We have prevailed upon the State to include augmentative communication devices in special education classes and mainstream schools for our children with cerebral palsy. We have labored to prove to insurance companies the medical necessity of gait trainers and other adaptive equipment for our children with spinal cord defects. We have sued municipalities to have our children properly classified so they could receive education and evaluation commensurate with their diagnosis.

We have learned to deal with the rest of the world, even if that means walking away from it.

We have tolerated scorn in supermarkets during "tantrums" and gritted our teeth while discipline was advocated by the person behind us on line.

We have tolerated inane suggestions and home remedies from well-meaning strangers.

We have tolerated mothers of children without special needs complaining about chicken pox and ear infections.

We have learned that many of our closest friends can't understand what it's like to be in our sorority, and don't even want to try.

We have our own personal copies of Emily Perl Kingsley's "A Trip To Holland" and Erma Bombeck's "The Special Mother." We keep them by our bedside and read and reread them during our toughest hours.

We have coped with holidays. We have found ways to get our physically handicapped children to the neighbors' front doors on Halloween, and we have found ways to help our deaf children form the words, "trick or treat." We have accepted that our children with sensory dysfunction will never wear velvet or lace on Christmas. We have painted a canvas of lights and a blazing Yule log with our words for our blind children. We have pureed turkey on Thanksgiving. We have bought white chocolate bunnies for Easter. And all the while, we have tried to create a festive atmosphere for the rest of our family.

We've gotten up every morning since our journey began wondering how we'd make it through another day, and gone to bed every evening not sure how we did it.

We've mourned the fact that we never got to relax and sip red wine in Italy. We've mourned the fact that our trip to Holland has required much more baggage than we ever imagined when we first visited the travel agent. And we've mourned because we left for the airport without most of the things we needed for the trip.

FAMILY & FRIENDS FUNDRAISING

"Miracles Can Happen" Benefit—Mandeville, LA

Joe and Nikki Vigil (daughter Mary Payton—LINCL) along with the Mary Payton's Miracle Foundation hosted their first ever 'Miracles Can Happen' Benefit on Friday, October 3, 2008. The event was held at the Benedict's Plantation in Mandeville. Over 430 attendees enjoyed dinner, a silent & live auction, and music provided by Mainstreet, Three's a Crowd, and Bag of Donuts. The guest emcee, Roop Raj from local WDSU Channel 6 hosted the evening's events. The evening's proceeds will be used to support families who have children with Late Infantile NCL and LINCL research. For more information about the event including photos or information about the Mary Payton's Miracle Foundation, please visit http://www.marypaytonsmiracle.com.

Running Hawaii Ironman Competition for Batten Disease—Ft. Collins, CO

On October 11, 2008 in Kona, Hawaii, Adam Weaver completed a 2.4 mile swim in the ocean, 112 mile bike ride, and 26.2 mile run better known as Ironman. Ironman is the ultimate triathlon competition in which only the best 1,700 athletes from around the world compete against one another and themselves in a swimming, biking, and running competition that is unlike any other. Adam competed to raise awareness for Batten Disease and his two brothers, Tyson and Timothy, who died from the disease. Adam finished the race in 9 hours, 56 minutes and 58 seconds, accomplishing his goal of finishing in less than 10 hours! Of the 1,736 competing athletes, Adam finished in the 280th spot. To see a video of Adam's finish, please visit the site below and type in "Weaver": http://ironman.com/events/ironman/worldchampionship/?show=tracker&rid=172&year=2008

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

Dawn and Jeremy Jaeger (son Blake-LINCL) along with the Blake's Purpose Foundation hosted their 2nd Annual Blake's Purpose Golf Classic on October 17, 2008. The Golf Classic was held at Catta Verdera Country Club. This year's event featured a full day of golf as well as dinner and entertainment afterwards. Attendees were amazed and awed by the work of David Garibaldi whose celebrity splatter paintings were auctioned off shortly after their completion. Congratulations on a successful event! For more information, please visit the Blake's Purpose Foundation website at http://www.blakespurpose.org.

Junior Dragsters Against Batten Disease—Hagerstown, MD

The Heuchan Family (son Nick—JNCL) along with the Nick's Battle Foundation hosted their 2nd Annual Junior Dragsters Against Batten Disease on October 19, 2008. The event will took place at the Mason Dixon Dragway in Hagerstown. The drag race was open to all racers under age eighteen. Instead of paying an entry fee, drivers collected pledges to qualify for the race. This year the event raised **$5,100**! This event holds special meaning for the Heuchan family—daughter Addie has been racing most of her life and Nick also has a special connection with the sport. For more information please visit http://www.nicksbattle.org.

Heart of America Dinner Auction—Maryland Heights, MO

The Heart of America Chapter hosted their 2nd Dinner Auction on October 25, 2008 at the Sheraton Westport Hotel in Maryland Heights, Missouri. The event was themed "Heroes Among Us" and was held in honor of Danielle and Holly Carbrey (JNCL). The event was able to gross over **$68,000**! The money made from the evening is going to help Juvenile Batten Research. There was delicious food, a silent auction with over 200 items and lots of entertainment. There was also a live auction featuring vacations with air fair, priceless sports memorabilia and many other unique items. "Red" Schoendienst (Cardinal Hall of Famer) and Dan O'Neill (Columnist, St. Louis Post-Dispatch) were Co-Honorary Chairmen for the Dinner Auction and its Committee. Great job Heart of America chapter and the Carbrey's for all their hard work.

All Day Scrapbook Party—Fairfield, OH

Sharon & Dennis Depoi, grandparents of Courtney and Noah Johnson (JNCL) hosted an all-day scrapbooking party on October 25, 2008. The event was held at the Fairfield Nazarene Church. Scrapbook enthusiasts spent the day doing what they love—SCRAPBOOKING! Participants were fed breakfast, lunch, and a spaghetti dinner. Dinner was also opened up to church members for a donation. Participants enjoyed the all-day session and created beautiful memories. Approximately **$6,000** was raised to help benefit the Juvenile Trial! Great job Depoi family!

Metro NY/NJ Chapter Bowl-A-Thon—Staten Island, NY

Members of the Metro NY/NJ Chapter of BDSRA hosted their 7th annual Bowl-A-Thon on Saturday, October 25th. Each year these families come together with members of the community to raise money for Batten Disease research. With many people and families in attendance, including members of the New York State Society of CPAs, the chapter was able to raise over **$18,000**. Over the past 7 years, the New York State Society of CPAs has raised over **$147,000** for the chapter! There was also a gift basket raffle in which 35 gift baskets were given away. The event was covered by local news affiliate NY1.

A video of the news story is available here:
http://www.ny1.com/Default.aspx?ArID=87852
The Surrey family also held a garage sale two weekends in September and was able to raise about $2,000. Needless to say, the Metro NY/NJ Chapter has been very busy. Great job chapter families and keep up the good work!

3rd Annual Festival of Hope—Raleigh, NC

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

Run for Batten Disease—Pullman, WA

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

TGIFriday's Fundraiser—Reading, PA

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

Dave’s Home Roasts—Chatham, IL

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

Cookie Lee Jewelry—Dallas, TX

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

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.

Family Fundraising Contributions

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

BDSRA Earns Money Through GoodSearch

A big THANK YOU goes out to everyone who uses GoodSearch as the search engine on the internet and to everyone who uses GoodShop to shop for items online. BDSRA was able to earn **$616** from October 2007 to September 2008. Each time you search using GoodSearch, BDSRA earns 1 cent. This may not seem like very much, but if everyone used GoodSearch each time they searched the internet, BDSRA could be earning quite a bit more money. GoodShop allows people to shop their favorite online stores with a percentage of each sale going to their designated charity. While you're shopping for family and friends this holiday season, why not make a stop at GoodShop.com first and help BDSRA earn money while you shop. I know with our continued efforts we can double the money earned through GoodSearch and GoodShop for 2009!

"Eight to Hope" by Wendy Bills

BDSRA Education Specialist, Wendy Bills, PhD, has written a new short novel based on factual events and stories involving children with Batten Disease. This book is a quick and enjoyable read and great for anyone in your life. Wendy was selling the books at Conference and all of the proceeds raised from her book are being donated to BDSRA.

If you would like to purchase a copy of Wendy's book for only $15 please send your check or money order to:

Wendy Bills
1141 W 13200 S
Riverton, Utah 84065

Australian Teen Raising Awareness for Batten Disease through Beauty Pageant

Katie Kerrisk is a teen model in Australia. Recently, she entered the Miss Teen Universe beauty pageant and has made it to the Top 25 contestants. Each contestant must choose a charity to raise money for. Katie has chosen the BDSRA because of her relationship with the Australian chapter through providing entertainment at their 2007 Conference. Katie is selling raffle ticket booklets, for sale through the pageant, to help her earn a guaranteed spot to the final round and benefit BDSRA. Prizes for the raffle include a trip to Fiji, a trip to the Miss Teen Universe Finals and a Pampers gift package.

Here is a little bit about Katie: Katie is 17 years old and lives in Crestwood Heights. She is a very motivated and determined young woman who runs an 'at home' day care for babies and toddlers with her mother Adrian out of their home. She is very outgoing and loves to be outdoors. She is a keen wake-boarder and although I haven't seen her myself, I believe she is very good at it!! Katie came to me about six months ago and was very excited about getting involved in modeling. So far she has been a finalist in the Miss Gold Coast Show and now Miss Teen Universe pageant. I believe her personality and motivation will see her competing in Miss Universe pageant once she has turned 18 and traveling the world to support the causes she is passionate about!

Good luck, Katie! We hope you do well.

Pavlo is Newest BDSRA Spokesperson

International sensation, Pavlo, has graciously offered to be an official spokesperson for the Batten Disease Support and Research Association (BDSRA). Pavlo, a Mediterranean style guitarist, is in the midst of a nationwide tour. He recently recorded his first PBS special titled, “Mediterranean Nights” which is currently airing on PBS stations across the United States and Canada. Originally from Toronto, Canada, Pavlo is a talented guitarist who has been playing since age five. Pavlo has released seven albums over the last ten years. He has toured around the world every year consistently, playing over one hundred and fifty concerts per year. Some of his awards include the Best Instrumental Album of the Year nomination for the 2000 Juno Awards (Canada’s equivalent to the Grammy’s), two Gold albums, a Billboard Top 10 release, and the honor of performing for His Royal Highness Prince Charles in 2001.

In August 2008, Pavlo offered to be an official spokesperson for the BDSRA. He has invited all families who have children with Batten Disease to attend his concerts at no charge and have the opportunity to meet him. BDSRA is excited to begin a strong and long-lasting relationship with this Mediterranean guitarist extraordinaire. For more information on Pavlo, please visit his website at www.pavlo.net and check out his page dedicated to meeting the children at http://www.pavlo.net/children.php. While you’re visiting his website, be sure to sign up for his newsletter. In his December Newsletter, he offered fans a special opportunity to donate $2 to BDSRA and receive a free copy of his Christmas/Winter CD, “Frostbite”.

If you are interested in getting tickets for an upcoming Pavlo show, please contact BDSRA at kirka@bdsra.org or 1-800-448-4570. If you are interested in obtaining a press release to submit to your local newspaper about our newest spokesperson, please email Amy at kirka@bdsra.org.

2008 4th Quarter Donations

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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CONFERENCE

ANONYMOUS

WE WOULD LIKE TO GIVE A GRACIOUS "THANK YOU" TO ALL THOSE BELOW WHO RESPONDED TO OUR CHRISTMAS APPEAL THIS HOLIDAY SEASON!!!!

CHRISTMAS APPEAL

Mr. John Benson
Mr. & Mrs. Robert Cooper
Mr. & Mrs. Homer Midtlyng
MEMORY OF JULIE BECKSFORT
Mr. & Mrs. Jim Becksfort
MEMORY OF KIMBERLY & COREY BINGHAM
Ms. Margaret Bingham
MEMORY OF LESLEY C. & LYNN M. BLAKE
Mr. & Mrs. Jim Blake

MEMORY OF
JEFFREY M. BOBBY
Mr. & Mrs. Ron Bobby
MEMORY OF
HANNAH
CAULFIELD
Mr. n& Mrs. Joseph
Montalbano
Cindy Schaller &
Brenda Desena
MEMORY OF ALLY
CHANCE
Mr. & Mrs. Charles
Chance
HONOR OF SIDNEY
COOLIDGE
Mr. Carmen R. Ceo
HONOR OF RYAN
FARET
Mr. & Mrs. Karl Zacek
HONOR OF
AMANDA & LEAH
FITZGERALD
Ms. Donna Fitzgerald
HONOR OF CHRIS
GAINES
Mr. & Mrs. Robert
Rutz
MEMORY OF
ROBERT R.
GEBHARDT
Ms. Mary Anne
Gebhardt
MEMORY OF
KERRICK &
CHRISMOND GOLL
Mr. & Mrs. Fred Goll
MEMORY OF
TRACEY LYNN
GUERTNER
Mr. & Mrs. Ronald
Ouellette
MEMORY OF TYLER
HAXTON &
HONOR OF RYAN
HAXTON
Marsha & Tim Bagby
HONOR OF NATHAN
HOOVER
Mr. & Mrs. Larry
Hoover
MEMORY OF JAY
JENSEN
Mary Jensen
IN MEMORY OF
ELAINE JOHNSTON
&
BARBARA JO
PATTERSON
Ms. Susan Converse
HONOR OF
EKATERINA
KURYSHEVA
Mr. & Mrs. Roy
Truelson
MEMORY OF
STEPHANIE LYNN
LEIS
Mr. & Mrs. William
Sanford
MEMORY OF
WALTER LESKO
Mr. & Mrs. Douglas
Klee
HONOR OF THE
LONG FAMILY
Ms. Ann Schreiner
HONOR OF RYAN
MAYNARD
Mr. & Mrs. Steven
Cutter
Mr. & Mrs. Fred
Cutter
Mr. & Mrs. J.R.
Maynard
Mr. & Mrs. Randall
Stejskal
MEMORY OF
ROBBIE &
STEPHANIE MAXIM
Ms. Madeline Stone
Mr. & Mrs. Ron Asher
MEMORY OF
CHARLOTTE LYNN
McGINTY
Mr. & Mrs. Robert
Huddle
Mr. & Mrs. John
McCarthy

HONOR OF MICHAEL METCALF

Mr. & Mrs. David Morris

MEMORY OF NICOLE MILECKI

Mr. & Mrs. David Milecki

MEMORY OF HOWARD PITTS

Ms. Faye Reynolds

HONOR OF STEFANI PUSKAR

Ms. Inge Puskar

The Piibe Family

MEMORY OF COLLIN SCHMIDT

Mr. & Mrs. Kent Schmidt

HONOR OF TOM SCHULTZ

Mr. & Mrs. Kenneth Dechant

HONOR OF THE SKOWRONSKI FAMILY &THE SHOLTYS FAMILY MERRY CHRISTMAS!

Ms. Ann Salladin

HONOR OF EMILY ANNE SMITH & MEMORY OF SHELLEY ANNE SMITH

Mr. & Mrs. Chuck Cronon

MEMORY OF EMILY ANN THOMPSON

Mr. & Mrs. Stephen Thompson

Ms. Bonnie Thompson

MEMORY OF MICHAEL WHEELER

Pride International, Inc.

MEMORY OF N. DAVID YAMAUCHI

Ms. Pauline Yamauchi

In Loving Memory

Lucie Bennett, daughter of Ricky Bennett, Flemington, NJ
Born: 03/27/93 – Died: 08/04/08 – JNCL

France Pichette, daughter of Gilles Pichette , Grand Falls,. NB & Jackie Violette, Edmunston, NB Canada Born: 03/28/78 - Died: 08/04/08 – INCL

Kari Anderson, daughter of Lars & Leilani Anderson, Carrollton, TX Born: 05/25/88 – Died: 08/06/08 – JNCL

Juandre Killian, son of Johnny & Carol Killian, Grahamstown, South Africa
Born: 01/09/98 – Died 08/23/08 – LINCL

Melissa Tarailo, daughter of Ron & Radmila Tarailo, Fresno, CA
Born: 11/22/84 – Died: 06/29/07 – JNCL

Wilbert Rosche, Died: 10/03/08 & **Margaret Rosche**, Died 07/05/08
Parents to Robert & Susan Rosche, (also deceased) of the Rochester, NY area

Ana Laura de Freitas, daughter of Mr. & Mrs. Micivam de Freitas, Brazil
Born: 02/07/01 - Died: 05/07/08 – Unknown NCL

Michelle Newell, daughter of Bob & Marge Newell, Maple Valley,WA
Born:11/30/88 – Died: 11/03/08 – JNCL

Lucas Nitzschke, son of Marta Nitzschke, Sunbright, TN
Born: 08/22/86 - DIED: 11/06/08 – JNCL

Louise Jefferson, daughter of Kristin Kohler, Farmingham, England
Born: 6/26/88 - Died: 10/18/08 – JNCL

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

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