



The Illuminator

"A light in a world of darkness"

April 2010
Volume 21, Number 2

Inside this Issue

- 1 Important News
- 2 Research Update
- 3 Special Child
- 7 From the Nurse's Corner
- 10 3rd Quarter Honor Roll
- 14 In Memory

Special Child



JUSTIN PECK -- LINCL

Emma's Hugs \$25,000
Challenge Grant for
INCL Research
Page 4

Batten Disease Centers
of Excellence
Page 6

Batten Disease Support &
Research Association
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**BDSRA 2010 CONFERENCE
CHICAGO, IL**
HOSTED BY MIDWEST CHAPTER AND NATIONAL OFFICE
JULY 29-AUGUST 1, 2010
CHICAGO MARRIOTT OAK BROOK HOTEL
OAK BROOK, IL

Dear BDSRA Members and Families,

Included with this copy of the Illuminator is our annual Conference Pack. This packet contains all the information you need for the 2010 BDSRA Conference in Chicago, IL. Please consult the packet for information on hotel, proposed agenda items, and the registration form. As always, Conference registration is free but attendees are responsible for the cost of rooms and meals.

There will be a limited number of stipends available. We encourage you to first ask your chapter (if you have one) for any money available to help with the cost of Conference. National stipend request forms are available by contacting BDSRA at 1-800-448-4570 or by email at bdsra1@bdsra.org. Priority is given to first-time families.

We hope to see many of you at Conference this year!

**BDSRA
CHICAGO 2010**



Field of Hope and Dreams

Research Update

BDSRA 2010 RFP is Now Available

The 2010 RFP for research grant money is now available on the BDSRA website:

<http://www.bdsra.org/media/content/244/2010%20RFP.pdf> Proposals must be postmarked by 11:59 pm, May 15, 2010. Proposals will not be accepted via email. Inquiries may be directed to Lance W. Johnston, Executive Director, BDSRA, at 1-800-448-4570 or 740-927-4298. Email address: bdsra1@bdsra.org.

BDSRA Funds Remaining Half of Research Proposals and One New Proposal

In July 2009, BDSRA had committed funding to the following six proposals. However, with that commitment, we agreed to fund half of their proposed budget with the remaining half of the money given to them after a 6-month progress report. We are happy to announce that we received 6-month reports from all six researchers and were able to fund the remaining half of each proposal:

- Shannon L MacAuley (Mark Sands, PhD) -- Washington University in St. Louis
"Activated Astrocytes Therapeutic Targets in INCL" -- \$40,000
- Su Xu (Peter Lobel, PhD)--Center for Advanced Medicine and Biotechnology/Rutgers University
"Intrathecal Enzyme Replacement Therapy for LINCL" -- \$31,500
- Sandra Hofmann, MD, PhD -- University of Texas Southwestern
"Enzyme Replacement Therapy for Palmitoyl Protein Thioesterase Deficiency (INCL)" -- \$60,000
- Anil B. Mukherjee, MD, PhD -- NIH/NICHHD
"The development of a treatment strategy for patients with INCL, caused by PPT1 nonsense mutations" -- \$65,000
- Martin L. Katz, PhD -- University of Missouri
"A Possible Canine Model for Infantile NCL Therapy Development" -- \$37,326
- Sunita Biswas, PhD -- Massachusetts General Hospital, Boston
"Generation of Human NCL iPS cells for study of NCL disease biology" -- \$40,000

BDSRA also received a request for funding from Dr. Mark Sands at Washington University in St. Louis. After a careful peer-review of his proposal, BDSRA was able to fund Dr. Sands and his research.

- Mark Sands, PhD -- Washington University in St. Louis
"Determine the efficacy of AAV5-mediated gene therapy and Cystagon for INCL" -- \$9,792

Fundraising News **7th Annual Trivia Night** *Columbia, MO*

A big thank you to the Hein family for hosting their 7th Annual Trivia Night on February 19, 2010. This event has always been a big success and we're sure this year was no different. Great job!

Pittsburgh Rocks for Grady's

This event was held on February 27th at the The Rhythm House Café in Bridgeville, PA and featured an all-star line-up of local bands. A silent auction was also held featuring a signed copy of "Born in the USA" by Bruce Springsteen. Great job Grady family on a successful event!

Emma's Bayou Bash

The 2nd Annual Emma's Bayou Bash took place on March 20th and helped raise **\$52,000** for the Emma's Hugs Foundation as well as BDSRA. The event, held in Baytown, TX included a motorcycle ride, silent and live auction, and the best BBQ in Texas. Great job Dunnam family and all of the Emma's Hugs Foundation volunteers. For a full recap, please visit www.emmashugs.com.

Bake Sale--Dallas, TX

Leilani Anderson is hosting a Bake Sale on April 10, 2010 to help raise funds for BDSRA and Juvenile research. Leilani continues to be inspired by her daughter, Kari, who lost her battle to Juvenile Batten Disease in 2008. We wish Leilani the best of luck on her upcoming event!

MN Chapter 5K Run/Walk

Lake Phalen, MN

The BDSRA Minnesota Chapter will host their annual 5K Run/Walk on May 1, 2010. The event is happening at its usual location of Lake Phalen. Over the past several years, this event has raised over \$20,000 each time! We're sure this year will be no different. For more info please visit www.mnbdsra.org.

Kick-A-Thon--Norwalk, OH

The Nikolajevs family is hosting their annual Kick-A-Thon on May 1st. This all-day event features kickers of all ages! There are several kicking competitions that take place as well including "Most Kicks in 1 Minute". The money raised goes to BDSRA and the Asher Nikolajevs Trust. We wish the Nikolajevs family the best of luck! For more information, please visit www.actionforasher.org.

4th Annual OurBoys 5K

The 4th annual OurBoys 5k will be held on Saturday May 8th, 2010 at Harris Road Middle School, please save the date. 8am 5k and 9am One mile fun run. Please be aware that this year the processing fee is included in your pricing. Please tell your friends and pass this around. We are still seeking sponsors, so don't pass up the opportunity to advertise your business and support a great cause! Visit www.ourboysjourney.com for more information.

Wine Around the World for Taylor--Charlotte, NC

Taylor's Tale is hosting the Wine Around World for Taylor fundraiser on May 13, 2010. The event will include wine tastings from wines around the world. This will be a unique experience for all attendees. For more information, please visit www.taylorstale.com.

Hope for Batten Cure 5K Dallas, TX

The 2010 Hope for Batten Cure 5K/2 Mile Walk will take place on May 15th at Bachman Lake in Dallas, TX. There will also be a 1 Mile Fun Run. Nancy Lowden is heading the event with support from area Dallas families. For more information and registration procedures, please visit www.bdsra.leapserve.com.

**Special Child – Justin Peck
Late Infantile Batten Disease – Colorado Springs, CO**

Arriving September 28, 2006, as scheduled (c-section), Justin was beautiful, healthy and tiny! Just over 5 lbs., he charmed our doctors, nurses, friends and family who came to see our "Little Peanut" – a nickname he acquired in the delivery room. He had the biggest, most gorgeous gray/green/blue eyes that seemed to focus in on you from day one. We were thrilled! Justin was an incredibly easy baby! He ate well, slept through the night (6 hours) by 4 months, and rarely fussed. Over the next two years, Justin reached all milestones at or before the "average" timeframe. He was walking by 10 months -- running by 11 months! We taught Justin sign language as an infant which he used for basics (milk, more, food, parents, ball, etc) by 5 months. His first words were "dada", "bobo" or "mama" – depending on who you ask... dad, brother or mom! He had a sweet, almost musical voice. People were always commenting that it sounded almost like he was singing his words. No matter what he said, his voice brought a smile to you. Justin loved his family – every night we told stories about his family, incorporating all 5 of his cousins, 8 aunts/uncles, brother, 4 grandparents, mom, dad and dog. Justin filled in the blanks with the appropriate names and would correct me or change the direction of the story if I told it wrong! When he was 16 months old, he started picking out two Children Encyclopedia volumes for his bedtime story, rather than your typical children's book. We would go through every page with him asking "What's that?" until he knew the words. Over time, we reversed roles, and I would ask him "What's that". That became our bedtime routine – along with 1-2 stories about his day and family. Justin was a sponge and wanted to know everything.

Justin had an unbelievable love for cars, trucks, trains, buses, tractors, motorcycles – all things vehicular! He carried 1-4 cars/trucks around with him at all times. He had amazing balance – sometimes having 2 items in each hand and one in the crook of his elbow as he climbed the stairs. It was next to impossible to get him to put all down at the same time. He slept with his cars too – choosing 1-3 cars each night. Once he'd fallen to sleep, I'd slip in and remove so that he couldn't hurt himself only to be woken up (sometimes in the middle of the night) with a holler of "Where's my (whatever color/name) car"?! By the time he was 18 months old – he shocked all of us with his ability to distinguish make/model of cars on the road. We would be driving down the road, and he would yell out "Zane's car white" (or whatever color the car he saw was) whenever he saw a Jeep Grand Cherokee – mind you, not just a Jeep, but a Jeep Grand Cherokee. Justin would identify all of our close friends/family cars in that fashion – it was amazing!

At about 2.5 years, we saw subtle changes in J's personality. He became cautious of new things and painfully shy. He was fine at home and with friends, but withdrawn in big groups or around new people. It concerned us enough that we brought it to the attention of our pediatrician, who told us not to worry. In the doctor's defense, J wasn't shy at all around him as he loved Dr. C's office. We were hoping it was just a stage. J continued to develop forward physically, mentally and emotionally, but seemed to struggle socially. Just before his 3rd birthday, he took a big fall. It surprised all of us as J was typically so agile. Justin fell/tripped 4-5 times that weekend and took a big tumble at preschool on Monday. We actually made a joke of it, teasing Justin that his shoes were the cause – that he needed to get new shoes so he wouldn't trip. As we were finishing up dinner I grabbed the camera to get a picture of his scrapes and bruises. Still teasing, Justin covered his eyes and the scrape on his cheek. I asked J to remove his hands. He ignored me and seemed to freeze. I thought he was playing, but as the flash went off, J went into a grand mal seizure.

Upon arriving at hospital via ambulance, they checked him out thoroughly, and Justin seemed okay. We went for a little walk down the hall to the little boy's room and were awaiting the doctor's return when he had a second grand mal in the emergency room. Needless to say, we were terrified! After several tests and a few days in the hospital, J was sent home on anti-convulsive drugs, and we were told that, based on J's medical history, we were dealing with an isolated event or possibly epilepsy. We began sleeping with one eye open.

Justin's Story (continued from page 3)

After five months of no seizure activity, we began to hope that the anti-seizure meds were a precaution, not a necessity. We began to breathe again.

Then, on March 9, 2008, three weeks before we hit the 6 month mark seizure free, Justin had a seizure. With that seizure, it was like a dam broke within our little boy. Seizures began to torment Justin - every type, no rhyme or reason as to their cause. We began our quest for answers. Within a few weeks, the seizures were accompanied by ataxia, and our doctor's realized they were dealing with something more than epilepsy. We were sent to Denver Children's Hospital for diagnosis. By June 12, 2008, we had genetic confirmation of LINCL.

There's no need to tell any of you how heartbreaking it is to watch your child be taken little by little or explain to you the effects of this horrific disease. We decided at the very beginning of this nightmare that we would have plenty of time for self-pity, anger, hurt and tears later. Easier said than lived! We are encouraged by the research being done on LINCL, frustrated at the timeframe in which it is happening, and determined to do anything we can to help in the quest for a cure for our son.

Justin's smile will melt your heart and his laughter is so infectious he can have the room roaring with laughter in short time. He loves his movies, books, horseback riding, swimming, walks, school, friends and family. Justin never ceases to amaze us and so many people have been inspired by his strength, his determination and his love of life. As his parents we have been blessed and have learned so much from our special little guy, and we are determined to fill Justin's world with as much love, laughter, and joy that we can cram into each and every day.

By parents, Cheri Whobrey & Corey Peck

Board of Directors Nominations

We have 5 board positions available for a 3 year commitment to serve the organization beginning at the July conference in Chicago. Ballots will be mailed out to all current paid members on May 1st and ballots must be received by 11:59pm on May 15. If you have not sent in your membership dues you must be paid for 2010 in order to vote. The Board of Directors would like to thank Fred Weaver and Warren Shuros for their service to the BDSRA. They are not running for re-election this year and we certainly appreciate their years of service. Please thank them the next time you see them! Results of the election will be announced the third week in May.

Emma's Hugs \$25,000 Challenge Grant

Kelvin and Christy Dunnam are the parents of Emma, who one month shy of 4 years old, recently passed away with Infantile Batten Disease.

Emma's Hugs (www.emmashugs.com) has generously offered a \$25,000 challenge grant for Infantile Batten disease research. Emma's Hugs will contribute dollar for dollar any contributions made toward this effort before July 1, 2010. This challenge grant provides us the opportunity to increase research for infantile Batten disease. Please reference "Emma's Hugs Challenge Grant" on your contribution to qualify.

BDSRA Medical Equipment Exchange

BDSRA maintains a Medical Equipment Exchange for its families. We have many pieces of equipment available including wheelchairs, suction machines, bath aides, feeding supplies, etc. These items are available to BDSRA families at NO COST! If you need a piece of equipment or have equipment to donate, please contact Amy Lombardi (kirka@bdsra.org).

Battin' for Batten Disease First Annual Softball Tournament

The Joyce family of Blue Springs, MO will be hosting their softball tournament fundraiser on May 22, 2010. It will be held at the Blue Springs South High School. For more information, please contact Clarissa Joyce at cjoyce1207@sbcglobal.net.

Barkin' For Batten

The 1st Annual Barkin' For Batten Charity Dog Walk will take place May 22, 2010 at Hannah Park in Gahanna, Ohio. Events include a one mile dogwalk, contests with prizes, demonstrations, raffle prizes, rescue and adoption groups and much more! Visit the website at www.barkinforbatten.com to register and get more information.

2nd Annual Hayden's Hope Harley Ride

The Harley Ride will take place Saturday, May 22, 2010. The ride starts at Stocks Harley Davidson in Manitowoc and ends at the Iron Buffalo Salon in Menchalville. For more information please visit the Hayden's Batten Disease Foundation website at: <http://www.help Hayden.com>

3rd Annual Hayden's Hope Benefit

The benefit will be held Saturday, May 29, 2010 at the Two Rivers Community House. Activities will include a Kid's Carnival, auction, food & beverages. For more information, please visit the Hayden's Batten Disease Foundation website at: <http://www.help Hayden.com>

Four New Members Appointed to National Neurological Disorders and Stroke Advisory Council

The National Institute of Neurological Disorders and Stroke (NINDS) announced that four new members have joined its National Advisory Neurological Disorders and Stroke Council. The council serves as the principal advisory body to NINDS regarding the Institute's research program planning and priorities.

Part of the National Institutes of Health, NINDS is the nation's primary supporter of basic, translational and clinical research on the brain and nervous system. The 18 member council, composed of physicians, scientists and representatives of the public, meets three times each year to review applications from investigators seeking financial support for biomedical research and research training.

Kim Zellmer is one of the newly appointment members. Kim has been a member of the BDSRA Board of Directors for 4 years, all of those years as Vice President. Most importantly, Kim is a mom. Sadly, her daughter, Madeline, passed away in January from Late Infantile Batten Disease. Below is the bio that was written about Kim for the Advisory Council's press release:

"Kimberly S. Zellmer, J.D., is an attorney and an advocate for research on Batten disease, a rare childhood neurodegenerative disorder that has affected her family. In 2002, she was appointed to serve on the Health and Human Services Secretary's Advisory Committee on Genetics, Health and Society. Currently, Ms. Zellmer is a member of the board of directors and vice president of the Batten Disease Support and Research Association headquartered in Columbus, Ohio. Ms. Zellmer's law firm in Kansas City, Mo., works with private charitable foundations and estate planning. She also assists families in creating trusts, guardianships and life plans for children with Down syndrome and other medical conditions, and for adults with amyotrophic lateral sclerosis (ALS), Alzheimer's disease, cancer and other serious illnesses. Ms. Zellmer received her law degree from the University of Missouri. She is a member of the American Bar Association, the Missouri Bar Association, the Kansas Bar Association, and several civic organizations."

We are very proud of Kim and all her accomplishments! She will be a great advocate for Batten Disease and every family dealing with the reality of taking care of a child with a rare disease.

Mayo Clinic in Rochester, MN, Now Testing for CLN1 and CLN2

The Mayo Clinic is now performing diagnostic testing for Infantile (CLN1) and Late Infantile (CLN2) Batten Disease. Presently, they are performing enzyme assay using whole blood samples only. Results are still given within 7 to 10 days. Both tests are performed at the same time and the cost of this test is \$282.20. You can get more information about the testing by visiting their website: <http://www.mayomedicallaboratories.com/test-catalog/Overview/89494>

If you have questions about diagnostic or carrier testing, please contact BDSRA.

Hayden's Hope Brat Fry

A brat fry will be held June 12, 2010 at Festival Foods at Manitowac, WI. Proceeds raised will benefit Hayden's Hope and INCL research. For more information, visit www.helphayden.com.

2nd Annual Kicking Battens For Carl Youth Soccer Camp--Arlington, WA

Lisa Boyle, friend of the Bergam family and former PE teacher for Carl Bergam, is organizing her 2nd Annual Kicking Battens For Carl Youth Soccer Camp on June 12, 2010. Carl Bergam loved to play soccer, even after his vision starting failing from his Late Infantile Batten Disease. Unfortunately, Carl passed away in February 2009. The Youth Soccer Camp is a way to preserve his memory and love for soccer. Last year the event raised over \$2,000. For more information, please visit www.kickingbattensforcarl.com.

12th Annual Melissa Froio Foundation Golf Tournament

The Froio family and the Melissa Froio Foundation are pleased to announce the 12th Annual Golf Tournament scheduled for June 18, 2010 at the Ramblewood Country Club in Sicklerville, NJ. The golf tournament has a long standing history within the community and is now a preservation of the legacy Melissa has left. Proceeds raised benefit BDSRA and the St. John of God Community School that Melissa attended. For more information, please visit www.melissafroio.org.

Batting Away Batten Disease Softball Tournament

Oxbow, Saskatchewan

The Amosah family is having their first Batting Away Batten Disease softball tournament fundraiser on June 18, 2010. The event is held in memory of their son Terrell and in honor of their son Dion who has Late Infantile Batten Disease. We wish the Amosah family the best of luck!

Continued on page 6

7th Annual Kevin's Fund Golf Tournament

Hagerstown, MD

The 7th Annual Kevin's Fund Golf Tournament will be held June 25, 2010 and is being hosted by Martin and Vicki Lumm. The money raised from the tournament benefits the Kevin Lumm Memorial Fund which in turn provides assistance to families with Batten Disease in the area and the BDSRA. The day typically includes donuts, coffee and juice in the morning, a luncheon buffet after the tournament, and a lot of fun! For more information, please contact Martin or Vicki at (240) 313-2234.

3rd Annual Hayden's Hope Volleyball Tournament

The 3rd annual tournament will take place the weekend of July 30 – August 1, 2010 at Sports Bar and Grill in Two Rivers, WI. For more information please visit www.helphayden.com.

Battle of the Bands

Jessica Montville will be hosting an all-day band fest on August 7, 2010 at the VFW Hall in East Templeton, MA. More information to come!

Nick's Golf Outing

Jill Wellner, along with the MN Chapter, will be hosting the 1st Annual Nick's Golf Outing on August 21, 2010 in Waterloo, IA. The event is still in the planning stages so please check back for more information!

2nd Annual Batten Disease Research Golf Tournament

The 2nd Annual Golf Tournament will take place August 23, 2010 at the Allendale Country Club in Dartmouth, MA. Last year the event raised over \$10,000 for BDSRA and Batten Disease research. You can check out www.battendiseaseresearch.com for new information about the event!

Batten Disease Centers of Excellence

BDSRA is proud to announce the development and implementation of two Batten Disease Centers of Excellence. Batten Disease Centers of Excellence are available to all families interested in receiving treatment from a team of professionals who have experience dealing with and treating all forms of Batten Disease. Children will be seen by a lead neurologist as well as other healthcare professionals like a nurse, social worker, genetic counselor, etc. A child may also have the chance to receive a consultation from other medical professionals like a cardiologist, pulmonologist, gastroenterologist, physical therapist, etc.

The first two Centers of Excellence are located at Massachusetts General Hospital in Boston, MA and Nationwide Children's Hospital in Columbus, OH. Each Center of Excellence has a designated "Clinic Day" where appointments are only available to individuals with Batten Disease. These Clinic Days are available each month.

- **Massachusetts General Hospital will have their Clinic Day on the SECOND MONDAY of each month.**
- **Nationwide Children's Hospital will have their Clinic Day on the THIRD THURSDAY of each month.**

BDSRA is also working with the University of Rochester Medical Center to finalize the plans for their Center of Excellence. Information will be announced when it becomes available. BDSRA has hopes to expand this program to other hospitals around the country.

For more information about the Centers of Excellence, please contact BDSRA.

Social Security Adds 38 New Compassionate Allowance Conditions

The Social Security Administration announced this month that it will be expanding its list of Compassionate Allowance conditions from fifty to eighty-eight. The initial list was issued in October 2008. Among the list of new conditions is Batten Disease!

The Compassionate Allowance program helps expedite the process of Social Security eligibility for the list of accepted conditions. The normal eligibility process can take months but with a disease listed with the Compassionate Allowance program, the eligibility process will be a matter of days. The Compassionate Allowance program does NOT eliminate the FINANCIAL ELIGIBILITY guidelines that families or individuals must meet to receive SSI benefits. If you have any questions, please contact Amy Lombardi at kirka@bdsra.org.

Do You Speak Another Language?

We are learning about new families around the world every day. Some of these families do not speak English. If you are bilingual and would like to act as a contact person for a new family, please let BDSRA know. We are looking for all languages and dialects. You can email Amy at kirka@bdsra.org to let her know of your language abilities.

From the Nurse's Corner

by Nancy Carney

nancycarney@bdsra.org

1-877-642-5512

(This is the conclusion of the article on "Delirium and Acute Confusion" from the January 2010 Illuminator.)

7. Emotional Disturbance - patients with delirium may exhibit emotional disturbances. Anxiety, fear, depression, irritability, anger, euphoria, and apathy are common, with anxiety being the prevailing emotion. The delirious patient may be emotional labile, rapidly and unpredictably shifting from one emotional state to another.

8. Prodromal and Subsyndromal Signs of Delirium – some patients have prodromal symptoms (pertaining to a symptom prior to the earliest stage of a disease) such as restlessness, anxiety, irritability, distractibility, or sleep disturbance that progress to overt delirium over 1-3 days. In the subsyndromal symptoms, the patient has the similar symptoms, but never develop or progress into the overt delirium. Patients with the subsyndromal symptoms have the same risk factors and similar outcomes as those with delirium. These findings suggest that delirium is a spectrum disorder in which increasing number of symptoms are associated with increasingly adverse consequences. Patients noted to be exhibiting one or more prodromal symptoms or who report feeling "mixed up", having difficulty judging the passing of time, and having difficulty thinking or concentrating should be assessed for potentially reversible causes of delirium, and appropriate interventions should be initiated.

Some common **predisposing** factors for development of delirium in Palliative and End of Life Care:

- Frailty
- Impairment (vision, hearing)
- Poor nutritional status
- Insufficient sleep
- Depression
- Neurological disorder (dementia, Parkinson's Disease, Stroke)
- Organ system failure (renal, hepatic)

Some common precipitating factors for development of delirium in Palliative and End of Life Care:

- Physical restraint or immobility
- Unfamiliar surroundings
- Sensory overload or deprivation
- Admission to intensive care unit
- Metabolic abnormalities (hypercalcemia (high levels of calcium), hyponatremia (high levels of sodium), uremia (body's inability to rid the body of waste materials)
- Anemia (low blood count)
- Hypoxemia (decreased oxygen in the arterial blood)
- Infection or sepsis
- Liver failure
- Acute neurological disorder (hemorrhage, infection, edema - swelling)
- Constipation
- Urinary retention
- Dyspnea – shortness of breath or difficulty breathing
- Pain
- Sleep Disturbance
- Anxiety
- Guilt
- Spiritual distress
- Medications

Diagnosis of Delirium

1. There are numerous rating scales or screening instruments to identify the presence of cognitive

impairments, but are not diagnostic of delirium. They are very helpful for identifying those patients who require additional evaluation. These scales may also be useful for monitoring improvement or deterioration in cognitive status in patients with delirium.

2. A thorough history and physical examination assist the clinician to identify the presence of delirium, determine potential causes of the delirium, and monitor the severity of this syndrome. Review the recent history of the patient's mental status changes, including both patient and caregiver observations and report your findings to the clinician.

- Note reported changes in arousal, levels of consciousness, orientation, and cognition
- Note onset of changes and any fluctuation over the course of the day, asking specifically about changes at night
- Review the medical history
- Note the primary palliative or terminal diagnosis as well as coexisting medical conditions
- Note diseases that directly affect the central nervous system and those associated with organ system failure
- Review medications
- Note medications directly associated with delirium
- Note medications with a potential for toxicity if given in high doses or in the presence of renal (urinary) or hepatic (liver) dysfunction
- Note any recently discontinued or refused medications with a potential for a withdrawal response
- Assess for a history of psychiatric disorders, including depression
- Assess sleeping patterns and signs of sleep deprivation

Continued on page 8

3. A thorough physical examination needs to be done including:

- Mental status – consciousness and cognition
- General survey – vital signs, especially fever and hyperpnea (increased respiratory rate); skin color – especially pallor (lack of color), cyanosis (a blue, gray skin color) or jaundice; skin turgor (refers to the state of hydration – when the skin is pinched up, if it returns to its normal state quickly, hydration is usually good, if it returns to its normal state slowly, there may be a need for increased hydration); or pruritis (itching)
- Respiratory system – dyspnea (difficulty breathing) or hypoxia (decreased oxygen content); cough or congestion
- Gastrointestinal system – pain or discomfort; bowel patterns including signs of constipation or obstruction; or nausea or vomiting
- Genitourinary system – pain or discomfort; urinary output; signs of retention or obstruction
- Musculoskeletal system – pain or discomfort; weakness or agitation
- Environmental/Psychoemotional assessment – signs of anxiety, fear or guilt; potential of “unfinished business” – interpersonal, financial or spiritual; depression; signs of spiritual distress; or potential of sensory overload or sensory deprivation

4. Diagnostic/Lab values – may assist in identifying an underlying medical cause of delirium. The extent to which any diagnostic work-up is conducted is dependent on the treatment goals and wishes of the patient and family and as well as the status of the patient's disease trajectory. As patients approach end of life, blood tests are

appropriate only when they directly influence the treatment plan. So a discussion with the Clinician needs to happen and he needs to know your wishes. Once the diagnosis of delirium has been made, then the plan of treatment needs to be initiated and follow up needs to be watched closely.

How does all of this affect children with Batten Disease? Most of the time, there is probably a mixture of delirium and dementia throughout the course of the disease. When children have adverse effects to medications it very likely could be some form of delirium. When some forms of aggressive behavior are prevalent it is most likely some form of dementia. But hopefully over the next few issues, you will at least have more general information to be able to see some of the differences.

If you have any questions or would like more information, you certainly can call your Physicians or you can call or email BDSRA and we will try to help you as best we can.

Pavlo Nominated for a Juno Award

We'd like to wish a big **CONGRATULATIONS** to our spokesman Pavlo for his Juno Award nomination for "Best Instrumental Album of the Year". This award is for his album "Trifecta" which was recorded with fellow Canadian guitarists Rik Emmett and Oscar Lopez. The Annual Juno Awards will be presented on April 18, 2010. We wish Pavlo the best of luck!

The 3rd Annual International Batten Disease Awareness

Weekend is scheduled for June 5 & 6, 2010. Please plan to raise awareness and dollars for Batten disease in your community. Visit our website for ideas, or contact Adina Ryan, Director of Development at 866-287-7233.

Australia Chapter National Awareness Day

The BDSRA Australian Chapter held their National Awareness Day on Wednesday, March 31, 2010. This year the chapter focused on selling Batten teddy bears and pens throughout schools across Australia. They have done their National Awareness Day for several years now and have always had great success. Please check the Australian Chapter website for more information and any updates on the day's successes: <http://www.battens.org.au/>

Using Facebook to Raise Money for BDSRA

Did you know that your friends and family can donate to BDSRA through Facebook? There are 2 simple ways to do this:

1) Invite friends to the “Batten Disease” Cause. Through this Cause page, people can donate to BDSRA and share the Cause with their friends.

2) Make a birthday wish. By creating a birthday wish, you're asking your friends and family to donate to the “Batten Disease” Cause in your honor. **Heather Allman** and **Jennifer Van Houtan** have both done this and have each raised over \$700! Great job ladies! Contact BDSRA for more info.

GoodShop and GoodSearch

Don't forget to continue using GoodShop and GoodSearch for all of your online shopping and searches! Just designated BDSRA as your charity of choice and we will receive money for every purchase or search you make! This is a simple and free way to raise money for BDSRA. Thank you for your support!

Reminder:

Dear BDSRA members,

There is still time to complete and return the anonymous, "Survey of Information and Attitudes about Genetics, Genetic Testing, and Batten Disease". This survey was distributed last fall via the BDSRA newsletter. We will be collecting the surveys through May 31, 2010.

As a reminder, the survey takes about 10 minutes to fill out. It contains some questions about your knowledge and attitudes towards genetics and genetic testing. We would like you to complete the whole survey, but you may skip any questions you don't feel comfortable answering. Your answers will be anonymous and confidential (please do not put your name on the survey). Your participation in this study is completely voluntary. You are free to not participate or to withdraw at any time for any reason.

If you received the survey last fall, we invite you to fill it out and return it using the attached self-addressed stamped envelope. If you do not have that envelope anymore, you can address surveys to:

Nicole Newhouse, project coordinator
Division of Child Neurology Box 631
University of Rochester Medical Center
601 Elmwood Avenue
Rochester, NY 14642

If your household already completed one survey, there is no need to complete a second one.

For more information about this research, you should contact:

Heather Adams, PhD
Division of Child Neurology Box 631
University of Rochester Medical Center
601 Elmwood Avenue
Rochester, NY 14642

If you have any questions about your rights as a research subject, you may contact:

The Human Subjects Protection Specialist at the University of Rochester Research Subjects Review Board, Telephone: (585) 276-0005, for long distance you may call toll-free: (877) 449-4441.

First Quarter Honor Roll

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.

IN HONOR & MEMORY OF ALL BATTEN CHILDREN

Miss Caroline & Anna Medley
Caroline, Anna Medley & Henry
Jacqmein (Lemonade Stand)
MEMORY OF BARON
ABDULNOUR
Mr. Ibrahim Abdunour
MEMORY OF KARI ANDERSON
GT AERO
HONOR OF BENJAMIN
ANNANDALE
Mr. Gary Annandale
MEMORY OF CURTIS ANTHONY
G. Grandpa Paul & G. Grandma
Elsie Anthony
HONOR OF CELIA BETZ
Ms. Nicole Donovan
Ms. Julia Todd
Ms. Jennifer Baunker
Ms. Christen Coyle
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BOER
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HONOR OF KAITLIN BOWMAN
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Ms. Patricia Stubbs
MEMORY OF LULU CALDERON
Ms. Robin Fleck / Mr. Richard
Graves
Ms. Michelle Plochere
HONOR OF DANIELLE & HOLLY
CARBREY
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Ms. Susan Miltenberger
Sully Ebinger
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CAULFIELD
Mr. Michael Caulfield
MEMORY OF DOMINIC
CERAVONE
Dad & Mom
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Friends of the Chatham Library
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Ms. Rosanna Taraborrelli
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Ms. Kathleen Ron
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Mr. & Mrs. Wayne Kiefer
MEMORY OF LEVI KNOWLES
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Mr. & Mrs. David Robinson
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Ms. Renee Becker
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First Quarter Honor Roll cont.

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.

Mr. & Mrs. Marlin Fried
Mr. & Mrs. George Hilts
Mr. & Mrs. Stephen Hoetzer
Mr. & Mrs. James Melchior
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SMITHERS
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MEMORY OF JACKSON SMITHERS
BIRTHDAY
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HONOR OF ELIZABETH STOOPS
Mr. William Stoops
MEMORY OF TAMMIE
Anonymous

First Quarter Honor Roll cont.

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

HONOR OF NATALIE TARAILOS
Mr. & Mrs. David Ramming
MEMORY OF IVY TERRAMAGRA
Mr. John Camuccio
HONOR OF NOAH & LAINE
VANHOUTAN
Dad & Mom
MEMORY OF GRACE VIRGINIA
WHITE
Ms. Linda Cash
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Ms. Debbie Ham
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Ms. Michele Hill
Mr. Jim Mader
Ms. Julie Brown
Ms. Paula Hiatt
Ms. Eileen Bashford
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Miguel Uribe
Ms. Wendy Bills
Mr. & Mrs. John Howard
Wines For Humanity & Robert Lang
Debra Ham thru UW
Mr. & Mrs. Warren Shuros
Mr. Larry Hoover
Anonymous

First Quarter Honor Roll cont.

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.

Ms. Catherine Marshall
Mr. & Mrs. Webster Ireland
Ms. Patricia Hablutzel
Tu Anh Quach
Mr. & Mrs. Kevin Peck
Ms. Jeana Adams
Mr. Maurice St. Gelais
Ms. Krista Hill
Mr. & Mrs. William Limneos
Ms. Tarshua Moore
Mr. Andrew Spiller
Ms. Andrea Allio
Mr. Bob Bunting / Fairfield Police Dept.
Ms. Yvonne Rose
HONOR OF CHRISTINE RATZ
Mr. & Mrs. Gene Emanuel
ANNUAL APPEAL
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Mr. & Mrs. Joseph Petsche
Ms. Ann Schreiner
Mr. & Mrs. Ron Hayes
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Mr. Gregory Nelson
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Mr. Thomas Buckoski
Ms. Deborah Buckoski
MEMORY OF ALLY CHANCE
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HONOR OF KENNETH DOCKTER
Mr. & Mrs. Arthur Mezzano
MEMORY OF THOMAS ELLERBROCK
Mr. & Mrs. Dennis Rosengarten
MEMORY OF ERIK & JON EVENSON
Mr. & Mrs. Tom Swanson
MEMORY OF AMANDA FITZGERALD
Mr. & Mrs. Richard Grob
HONOR OF JENNA HILL
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Ms. Maureen Rodgers
MEMORY OF BILLY & HONOR OF JOEY MILANI
Ms. Mary Ann Murrough
MEMORY OF JESSIE DON MOODY
Mr. & Mrs. Don Moody & Dustin, Austin & Justin Bloodgood
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Ms. Constance Nelson
HONOR OF ASHER NIKOLAJEV
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MEMORY OF MINDY & MARCY PINDER &
HONOR OF MICHAEL PINDER
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Foundation Inc.
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Mr. & Mrs. James Betz
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Angel Tile & Marble
Ms. Marjorie Botellio
LOVING MEMORY OF ADAM PEDERSON
Mr. & Mrs. Jerry Pederson
RYAN FARRET CHRISTMAS APPEAL
Mr. & Mrs. J.M. Sorenson
Mr. & Mrs. James Mueller
Mr. & Mrs. Thomas Tresselt
CONFERENCE
OH Chapter BDSRA
CONFERENCE STIPENDS
Anonymous



In Loving Memory



Baron Abdulnour, son of Abraham and Lody Abdulnour, Burbank, CA
Born: 09/20/98 - Died: 12/27/09 - Late Infantile NCL

Adam Hawthorn, son of Will & Pam Smith, Black Falls, AB
Born: 01/26/89 - Died: 01/06/10 - Juvenile NCL

Timothy Nordquist, son of Don & Kathleen Nordquist, Bismarck, ND
Born: 02/02/83 - Died: 01/18/10 - Juvenile NCL

Hailey Goranflo, daughter of Neil & Miranda Goranflo, Shepherdsville, KY
Born: 10/30/02 - Died: 01/18/10 - Late Infantile NCL

Madeline Zellmer, daughter of Todd & Kim Zellmer, Shawnee Mission, KS
Born: 12/09/96 - Died: 01/18/10 - Late Infantile NCL

James Rickman, son of David & Carol Rickman, Biloxi, MS
Born: 08/19/96 - Died: 01/21/10 - CLN6

Emma Dunnam, daughter of Kelvin & Christy Dunnam, Baytown, TX
Born: 03/01/06 - Died: 02/01/10 - Infantile NCL

Joshua Smith, son of Randy & Mary Smith, Parkersburg, WV
Born: 02/24/86 - Died: 02/07/10 - Juvenile NCL

Michele Sheridan, daughter of Steve & Bonnie Sheridan, Plymouth, MI
Born: 04/06/82 - Died: 02/11/10 - Juvenile NCL

Jeffrey Scanlon, son of Janis Scanlon, Glendale, AZ
Born: 08/04/78 - Died: 02/18/10 - Juvenile NCL

Amanda (Mandy) Cordova, daughter of Brandi Cordova, Brownsville, OR
Born: 12/13/80 - Died: 03/20/10 - Infantile NCL

Batten Disease Support and Research Association
166 Humphries Drive
Reynoldsburg, OH 43068

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