A light in a world of darkness

THE ILLUMINATOR

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October 2010 Edition
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Batten Disease Support & Research Association
166 Humphries Rd
Reynoldsburg, OH 43068
1-800-448-4570
www.bdsra.org

FEATURED FAMILY

Families of Serbia

Even today it is not clear -one day you complete a perfect life, a perfect child, the perfect marriage the perfect job and the next day you're told "Lady, go home, wait for your child to die" …*Cont'd pg 2*

SERBIAN FAMILIES

By Eric Leslie, Awareness Director, BDSRA

As Lance Johnston, Executive Director for BDSRA and Dr. Katharine Sims travelled to Serbia, in order to meet with a series of families either diagnosed or looking for a diagnosis for Batten disease, the one word Lance mentioned to research and pay close attention to was, **"život", which means "life" in Serbian**.

The word *život* is also the name for the Batten disease foundation founded by the parents of Zoe and Aleksina. Their battle with this disease has helped spark awareness in their local community and bring to light the possibility of four other children in the area having Batten disease.

During their visit, Sims and Johnston held an awareness seminar and were able to take blood tests from the potentially affected children.

Here are a few words about these two families' journey, from their website, www.zivotorg.org:

"*…I remember at one point even asking "Do I have the right to so much happiness?" And then it happened-Zoe's first attack ... I was with my grandma as the snow just fell…Zoe soon ceased to speak, walk or recognize me... In London in August 2009 we found out of the diagnosis, Batten disease….It is good that parents here like me will not wander through the world's laboratories to do the blood tests for diagnosis, because Dr. Sims and Mr. Johnston from BDSRA came from America to do it for free.*"

"*Alex was born on April 7th 2004. By his third birthday he had developed quite normally. Only a slight delay in speech, but pediatricians say that boys are lazy and will speak when he wanted…The turning point occurred when Elana started to convince me that Alex does not see. One geneticist has agreed with our assumption that there may be intracranial pressure that*

causes all these problems, and deterioration of vision…Upon hearing of our case, Lance sent us a paper in which we take Aleksina's blood and then send it to him..."

We continue to struggle with the hope that no more children will have to live for years in a hospital without a diagnosis. Plans are underway to bring the leading neurological pediatrician from Serbia to the U.S. for training.

GOING GREEN

BDSRA is proud to announce we are going green! Our quarterly newsletter, The Illuminator is going electronic beginning with the spring 2011 edition. With escalating production and mailing costs and our commitment to eco-friendly efforts, the January 2011 edition is the last you'll receive on paper.

Future versions will be delivered as a PDF file to your email inbox we have on file. As always, the newsletter will also be available on our website: www.bdsra.org.

If you need to continue receiving a print version, verify your email address, or provide an updated address, please contact Adina Ryan, Director of Development at aryan@bdsra.org prior to December 31, 2010.

STAFF PROFILES

Meet the Staff of BDSRA

WELCOME OUR NEW PROGRAM DIRECTOR, Lisa Weston: Hello! My name is Lisa Weston and I am the new Program Director for BDSRA. In my role here, I am responsible for developing and managing the programs and services BDSRA provides to families affected by Batten disease. I will also help with the Annual Conference, project management and special administrative assignments.

I am absolutely thrilled to be here, working with such devoted and passionate people! Lance, Nancy, Donna, Adina, Eric and Ann have been incredibly patient as I learn about Batten disease, our families and the organization, and I look forward to learning from (and meeting) all of you. I will strive to make the various programs we offer the best for our families, continuing the high quality of care and support Amy Kirk Lombardi provided. In future issues of the *Illuminator*, I will include updates, changes and progress about our programs and other BDSRA projects.

My experience in the nonprofit sector includes working for the Columbus Museum of Art as a corporate fundraiser and managing the Museum's annual black tie gala, as well as working for the American Diabetes Association of Central Ohio, managing its community programs, providing administrative support and assisting with events. My passion for volunteering introduced me to all the good work taking place in my communities and I have been involved over the years with several organizations in both the Cleveland and Columbus areas.

It is a privilege to be a part of BDSRA and I welcome you to contact me with questions, concerns, ideas and to just say hello. I am excited about this challenging new role, the people I will meet and the contributions I can make.

Lance Johnston, Executive Director of BDSRA, first became a member in 1987, having a daughter with Juvenile Batten disease. Lance has served on the Board of Directors as a member and also as President until his appointment as Executive Director in 1995. Since Lance's appointment, he has built the organization from a one man household run effort to a 6 person staffed, internationally recognized, non-profit business. Lance's efforts to find a cure for Batten disease continue as he travels and teaches around the world.

Adina Ryan is the current Director of Development for BDSRA. She comes to the organization with over 10 years experience in various forms of fundraising. Her primary goal is to identify and encourage philanthropic support for the organization. Her role is to shape the strategic vision and to cultivate and develop support of fundraising projects. Her vision includes creating an annual fund to sustain the organization, increase grant opportunities, promote more awareness of the disease with media and public relations efforts, and assist families with fundraising and event support.

Nancy Carney, RN answers medical questions for our families concerning your children with Batten disease. Her goal is to be available in crisis situations with suggestions that may be helpful for you or your Physicians care of your children and to develop a knowledge base for a clinical database that will be helpful for new families along their journey. Nancy has also

published educational materials to help families care for their children at home including: Medications 2008, The Respiratory System, The Gastrointestinal System, Pressure Sores, Dental Issues & Mouth Care, Physical Therapy, Death & Dying: A Helpful Guide In Dealing With The Many "End Of Life" Issues, Dementia in Children with all Forms of Batten Disease – A Guide for Parents, Teachers and Care Professionals, and Pain Management. These books are all available by contacting the office free of charge.

Ann Salladin is a full time parent volunteer at BDSRA, past board member and NE chapter president. She is the parent of two LINCL children who have passed on with this disease and appreciates the work BDSRA does for other parents traveling this long and perplexing journey of Batten disease. She assists the staff to support our families through general but necessary tasks. She is the "go to" girl. She does everything… the important special projects and event planning, transportation of equipment and staff, mailings, data entry. She is the editor of THE LIGHTHOUSE, does conference preparation, awareness activities, and the all important task of ordering of lunch. Her life is fulfilled every day by volunteering here. She is glad to be of service.

Eric Leslie, Awareness Director, has 5+ years experience in community development and has a bachelor's degree in entertainment business and law. Expertise includes multi-media (creation and distribution) and public relations. He manages our website and social networks.

Donna Gunn is the Office Manager. Donna works part time, but gives full time service. She is our office prayer warrior and has been a staff member for over 5 years. Donna's responsibilities include handling donor acknowledgement and entry, all financial deposits, filing, updating family databases—keeping track of our new families and those who have lost children, and general administrative duties. Her prayer is that she will be an influence in the lives of families dealing with this disease and help them forge a less rocky road.

Amy Kirk Lombardi is our Family Service Coordinator. Amy currently works as our family service coordinator on a contract basis to provide information and coordinate service with local, state and federal agencies (such as SSI, Medicaid, NORD, et.al).

NURSES NEWS

Nancy Carney RN @ 877-642-5512

Psycosocial Assessment

1. The effect and understanding of the diagnosis and treatment on the patient and caregiver.
2. The meaning of the pain to the patient and family.
3. Significant past instances of pain and their effect on the patient.
4. The child's typical coping responses to stress or pain.
5. The child's knowledge of, curiosity about, preferences for, and expectation about pain management methods.
6. The child's concerns about using controlled substances such as Opioids, Anxiolytics, or Stimulants.
7. The economic effect of the pain and its treatment.
8. Changes in mood that have occurred as a result of the pain.

Food and Pain

Does your child with Batten Disease crave food? If so, are there particular circumstances when the craving is present? Do they eat only when

they are hungry? I am going to list a few things to think about when it comes to the food we give our children.

There are six classes of nutrients – *Carbohydrates, fats, proteins, minerals, vitamins, and water.*

- The macronutients are broken down by the digestive system – carbohydrates to glucose, fats to fatty acids and glycerol, and proteins to amino acids.
- Regulation of food intake involves the hypothalamus and a balance between the activities of the centers governing hunger and satiety.
- A weak satiety stimulus coupled with the body's ease to which fat is stored and a lack of exercise, leads to dietary related diseases such as obesity, hypertension, dyslipidemia (high content of fats in the blood stream), type 2 diabetes, coronary heart disease, stroke, gall bladder disease, osteoarthritis and cancers – all of which can be the cause of chronic pain.
- Fat in the diet is essential for: synthesis of cell membranes, some hormones including steroids, sex hormones and prostaglandins (based on cholesterol); absorption of fat-soluble vitamins (A,D,E,K); an energy store within the body
- Fat can induce relaxation and sleep, and has analgesic properties. Sweetened fatty foods can alleviate pain associated with stress.
- N-3 fatty acids in oily fish and plant oils (flaxseed, grapeseed, or wheat-germ and walnuts), lower blood cholesterol and the propensity for clot formation in circulation.
- Too much fat in the diet can lead to obesity and related problems and certain cancers.
- Carbohydrate in the diet is essential for: a ready source of energy (in the form of glucose) for all cells in the body; a source of soluble and insoluble fibre.
- Carbohydrate has analgesic properties – the sweet taste in the mouth stimulates the release of endorphins, and in turn triggers the postingestive analgesic effect of a meal rich in carbohydrate.
- A meal rich in carbohydrate can enhance the uptake of antioxidants in food and the medication Levodopa (used for the treatment of Parkinson's Disease)
- Protein in the diet is essential for synthesis of cellular structures, enzymes, hormones, plasma proteins and antibodies.
- Deaminated amino acids are a source of energy within the body
- Protein has analgesic properties – the amino acid, Tryptophan, is essential for the manufacture of the calming and analgesic neurotransmitter Serotonin, and Glucosamine and Chondrotin Sulphate have been found to alleviate painful joints.

Assessment & Measurement

If **Pain** is not assessed, appropriate management is impossible. Pain is a multidimensional human experience and thus requires a comprehensive, holistic evaluation. Each new pain report requires a systematic assessment, appropriate treatment, and follow up. A complete pain assessment includes the following:

1. Site: If possible your child identifies primary sites on his or her body or on a diagram. Remember also, that your child may have several sites of pain – his stomach may hurt, may have pain from contractures and may have

a headache; it may be helpful to number "pains" to organize assessment, interventions and evaluations.

2. Character: Use the child's own words if he is still able to communicate; a careful description will lead to the diagnosis of pain type and assist in determining appropriate analgesics (i.e., sharp shooting describes neuropathic pain syndromes). If your child is no longer communicative, then you have to rely on finger pointing or the Batten scale for pain.

3. Onset: When did it start? Did (or does) a specific event trigger the pain? Carefully distinguish between new and preexisting pain (i.e. contractures, chronic low back pain).

4. Duration & Frequency: How long has the pain persisted? Is it constant or intermittent?

5. **Intensity:** Intensity is commonly defined on a 1-10 scale. However it must be adapted to the patient. Many children use the smile-sad scale. Ask your child to rate their pain intensity "now" at its "worst" and at it's "least". Note that ratings of pain intensity are the most important pain assessment data to collect if time is short; pain intensity directly correlates with interference with the child's quality of life.

6. Exacerbating Factors: What times, activities, or other circumstances make the pain worse?

7. Associated Symptoms: What other symptoms occur before, with, or after the pain? Nausea is frequently associated with pain and often attributed to pain medications and not the pain itself. If nausea occurs at the peak of the drug (highest drug level in the blood), it may be drug related; if it occurs at the end of the dose, it may be pain related.

8. Alleviating Factors: What makes the pain better? What treatments have been successful in the past? What treatments have been unsuccessful? Remember, that treatments that did not work in the past may work now if the previous dose was inappropriate or the type of pain problem is different. Include a thorough medication history, especially for the past several weeks.

9. Effect on Quality of Life: How does the pain affect the child's ability to perform activities of daily living? How does the pain affect relationships with close others? What does the pain mean to the child and family? How has this pain affected them? How much do they know about pain? Do they have the expectation that it can be relieved? Are there emotional and spiritual components to the pain? Does unrelieved pain lead to increased fear or anxiety, or to fears that death is imminent?

10. Child's Goal for Relief: Consider using either a pain intensity score or a goal, for example, the ability to walk without pain. What would you like to do that your pain is preventing you from doing? What pain score would allow you to perform that activity?

11. Physical Examination: Observe the site of the pain, and validate with the child the pain's location, if possible. Note skin color, warmth, irritation, integrity, and any other unusual findings.

12. Other effects of pain: Assess for the presence of depression, anxiety, and other emotional aspects of the pain experience.

13. Keeping a RECORD of when medicated and the effects of the pain medications, whether helpful or not.

Medications

- **Non-Opioid analgesics** – are the **NSAIDS** – (Nonsteroidal anti-inflammatory drug) which possess Analgesic, Anti-inflammatory, and Antipyretic (fever) properties. **Major side effects with this group of drugs is:** GI bleeding (ulceration), kidney & liver issues and platelet issues, as well as nausea/vomiting, bloating, heartburn and/or constipation. Before long use of NSAID's is began, ulcer prophlaxis should be initiated with drugs such as Prilosec, Tagamet, or Zantac. Some of the NSAID's include: Tylenol, Aspirin, Motrin, Ibuprofen, Naprosyn, or Celebrex to name a few.

ABCDE Approach to Pain Assessment and Management

A. Ask about the pain regularly. Assess pain systematically.

B. Believe the patient and family in their reports of pain and what relieves it.

C. Choose pain control option appropriate for the patient, family, and setting.

D. Deliver interventions in a timely, logical, and coordinated fashion.

E. Empower patients and their families. Enable them to control the course to the greatest extent possible.

- **Adjuvant Analgesics** – There are 3 classes of drugs that are usually used in this class – **Antidepressants, Anticonvulsants,** and **Corticosteriods** to enhance the primary analgesia or to provide relief from the side effects of the primary analgesia, whether it be an NSAID or an Opioid. Several factors should be considered when considering choosing a specific adjuvant medication including the pathophysiology of the pain, medical and analgesic history of the patient, Opioid poorly-responsive pain, and the adverse events being experienced by the patient.
- Several **Antidepressants** that have been used especially in the setting of neuropathic pain are: Amitripyline, Pamelor, Remeron and Effexor currently. Although their exact mechanism of action is unknown, they are thought to exert an analgesic via their ability to prevent the synaptic reuptake of the neurotransmitters Dopamine, Serotonin, and Norepinephrine.
- For **Anticonvulsants**, Neurontin is an excellent choice for neuropathic pain or burning pain, and sometimes Carbamazepine is used. **Some side effects** include: nystagmus (back and forth movement of the eye), dizziness, diplopia (double vision), lightheadedness, lethargy, somnolence (prolonged drowsiness), ataxia (defective muscular coordination), and fatigue.
- In the **Corticosteriods** line, Dexamethasone (Decadron) or Predisone is usually used in this situation to reduce swelling or their anti-inflammatory properties in the brain for children with Batten Disease. They can also have the added benefit of mood elevator, appetite stimulator, and antiemetic activity (for nausea and vomiting). **Side effects** include hypertension blood pressure increase), hyperglycemia (sugar level increase), immunosuppression (immune system being compromised),psychotic reaction and cognitive impairment.
- Sometimes **Stimulants** are used to counteract the effects of the Opioids like Ritalin, Adderrall or Concerta.

- **Anxiolytics** counteract or relieve anxiety. Several examples are Valium, Ativan and Xanax.
- **Muscle Relaxants** are used to do just that – relax the muscles. Several are: Valium, Flexeril, or Baclophen.
- **Opioids –** narcotics are the cornerstone to treat moderate to severe pain. As a class, the Opioid analgesic have many advantages when used in the treatment of pain. There is no maximum dose associated with Opioids, there is no organ damage as seen with the non steroidal anti-inflammatory drugs. These drugs (Opioids) provide an excellent risk benefit for most of the children. Most types of pain respond to Opioids, however, the degree of response is variable. Neuropathic pain does better when you add an adjuvant medication with it. Opioids are very cost effective, and they can be used in the home situation where the costly hospitalization, can be at a minimum. Opioids can be dispensed in a wide variety of routes which makes it much easier for any child to be kept comfortable. Some of the drugs are: Morphine the most widely used; Codeine, useful in diarrhea; Dilaudid or Hydromorphone has a more rapid onset and shorter duration of action than Morphine; Fentanyl – good for breakthrough pain, good in patch form, good for short durations of action.

The most common side effects of Opioids are:

1. **Sedation** – usually clears in 1-3 days. If sedation persists, your child may benefit from a slight reduction in the Opioid dose and an evaluation for the need to add an adjuvant medication. Excessive sedation is often a sign that the pain syndrome is Opioid resistant. This assumes that an assessment has ruled out the potential contribution of other medications to oversedaton. Just be sure to keep in contact with your Physician or Hospice.

2. **Constipation** – This is common but preventable side effect. Regularly scheduled laxatives are almost always required. Start a bowel regimen before initiating an around the clock analgesic dosing schedule.

3. **Nausea** – Children usually become tolerant to the emetic effect after 3-5 days. In the interim, use an antiemetic, such as Phenergan, Compazine or Zofran. Persistent nausea requires further assessment for other etiologies (reasons).

4. **Confusion & Excitability** – Evaluate for the underlying cause. Eliminate other medications that may be reacting with the Opioids. If analgesia is satisfactory, reduce the dosage of the Opioid by 25%. Neurotoxic effects of Opioids can be seen in those children who have impaired renal function (kidney) and have been on higher dose or prolonged therapy. Symptoms manifest as delirium, myoclonus, agitation, and hyperanalgesia (too much pain medication). These symptoms may require a change in Opioid.

5. Less common side effects are: sweating, pruritis (itching) and urinary retention.

I also have some handouts that went with this presentation. One of them is the pain rating scale that Dr. Lynn Breau from Nova Scotia developed for Batten Disease. It is very helpful in determining whether a noncommunicative child (such as a child with Batten Disease)is experiencing by taking a couple of minutes to look over this rating scale and decide very quickly if your child displays any of the given data listed. If you want a copy, either email me or give me a call.

RESEARCH NEWS

Lisa A. Weston, LisaWeston@BDSRA.org

BDSRA is excited to announce that four Batten Disease Centers of Excellence have been established across the United States. A Batten Disease Center of Excellence is available to all families interested in having their child seen by a team of professionals who have experience dealing with and treating all forms of Batten Disease. We are working to expand our number of Centers of Excellence over the next several years.

Each Center of Excellence has a designated "Clinic Day" that affords families the opportunity to receive care from the lead pediatric neurologist as well as other healthcare professionals such as a nurse practitioner, nurse, social worker, and/or genetic counselor. Patients will also be able to receive consultations from other medical specialists such as a cardiologist, pulmonologist, gastroenterologist, etc. It is a goal of the Centers of Excellence to ensure that patients and their families receive well-rounded and complete care for all their needs.

We are proud to have the following Batten Disease Centers of Excellence:

Nationwide Children's Hospital - *Columbus, OH*
Lead Physician: Emily de los Reyes, MD - Pediatric Neurologist
Clinic Day: Second Monday of each month
Contact: Sally Steward, RN, MS, CNP
Phone: (614) 722-4629

Massachusetts General Hospital - *Boston, MA*
Lead Physicians: Katherine B. Sims, MD & Marsha Browning, MD - Pediatric Neurologists
Clinic Day: Third Thursday of each month
Contact: Kellie Burke, Clinic and Lab Coordinator
Phone: (617) 726-5732

University of Rochester Medical Center - *Rochester, NY*
Lead Physicians: Jonathan W. Mink, MD, PhD & Jennifer Kwon, MD - Pediatric Neurologists
Clinic Days: Friday mornings
Contact: Amy Vierhile, PNP
Phone: (585) 275-4762

Oregon Health & Science University/Doernbecher Children's Hospital - *Portland, OR*
Lead Physicians: Robert D. Steiner, MD – Pediatric Neurologist; Amira Al-Uzri, MD – Pediatric Nephrologist
Clinic Days: Third Tuesday of each month
Contacts: Jessica Adsit, MS / Sothea Ros, Clinic Coordinator
Phone: (503) 494-6524 / (503) 494-7859

We are very privileged to have this level of care and expertise available for our families. We welcome any questions by either calling the BDSRA office (800/448-4570) or by directly contacting a Center of Excellence.

COMMUNITY DEVELOPMENT

Written By: Adina Ryan, aryan@bdsra.org

2009-2010 BDSRA Conference Recap

In July, we celebrated our annual conference in Chicago, IL with the theme "Take Me Out To the Ballgame". Our time spent in Chicago was one for the record books with many memorable moments including the Kids' Parade and the opportunity to learn about research first hand from the scientists conducting it. As always, families had the opportunity to catch up with one another, and new families had the opportunity to meet fellow BDSRA families for the first time.

During Saturday night's award banquet, BDSRA was honored to pass out research awards in the amount of **$273,826!** The research abstracts will be available on the BDSRA website. Those

individuals who received the awards are as follows:

RESEARCH AWARDS

Su Xu (Peter Lobel, PhD)
Center for Advanced Medicine and Biotechnology/Rutgers University
$31,500
"*Intrathecal Enzyme Replacement Therapy for LINCL*"
(Also a BDSRA Predoctoral Studentship)

Martin L. Katz, PhD
University of Missouri
$37,326
"*A Possible Canine Model for Infantile NCL Therapy Development*"

Sunita Biswas, PhD
Massachusetts General Hospital, Boston
$40,000
"*Generation of Human NCL iPS cells for study of NCL disease biology*"
(Also a BDSRA Postdoctoral Fellowship)

During Saturday night's banquet, we also awarded families, individuals, and chapters with fundraising awards.

In the category of Fundraising for Research, the winners were:

1) Mike & Diane Carbrey -- $51,000
2) Eric & Christine Thelen -- $45,000
3) Joni Spaulding/MN Chapter -- $30,000

In the category of Fundraising for Programs & Services, the winners were:

1) Charlie & Wanda Leffler/Debbie Lowther -- $10,100
2) Lorie Williams -- $10,008
3) Joe & Kathy Allio -- $8,000

In the category of Combined Chapter Fundraising, the winning chapters were:

1) Australia Chapter -- $116,000
2) Southeast Chapter -- $52,000
3) Heart of America Chapter -- $51,000

Workplace Giving: Opportunities to raise money for Batten Disease from where you work.

Many companies offer matching gift programs to encourage employees to contribute to charitable organizations. Typically, the employer who has a matching gifts program will contribute (match) dollar for dollar the employee's contribution. Some will even double or triple the amount. Some will also match volunteer hours.

To find out if your company will match gifts to BDSRA, you may contact me to do a search, or check with your company's human resources department. If your employer does have a program, you will complete a matching gift form and mail to BDSRA for certification.

We have nothing to lose, and twice as much to gain through your contributions in these programs.

Are you a Federal Employee? Now through January 15, 2011, all Federal employees will be given an opportunity to contribute to your favorite charity through the Combined Federal Campaign (CFC).

BDSRA is among the more than 2000 charities that you can contribute to this year. Each year, we undergo an extensive review to qualify as a charity for consideration in this program. The dollars you contribute through the CFC campaign will be dispursed directly to us /throughout the year. You may contribute through payroll deduction or a one time gift.

If you would like to participate in this campaign as a representative for BDSRA at an agency fair in your area, please contact me as we are currently participating in fairs wherever possible to spread the word of Batten disease.

Why join BDSRA? The BDSRA national headquarters, and your local chapter, is your most vital link to information, support, and encouragement for families with children who have Batten disease. BDSRA is also the largest private source of funds for international research on Batten disease. . We ask each individual to pay **$40 for annual dues** at the beginning of each new year. We hope you will plan to continue your membership with BDSRA, or perhaps join for the first time.

For more information on how you can get involved and hold a fundraising event, visit http://www.bdsra.org/fundraising.html or call Adina Ryan, Development Director at 866-287-7233.

The Equipment Exchange Program is available to any BDSRA family needing equipment. If you are in need of a certain piece of medical equipment or medical supplies (i.e., feeding tube supplies, suctioning supplies, dental supplies, wheelchair lifts, etc.) please contact Lisa Weston (lisaweston@bdsra.org) to see if BDSRA has the equipment available. Equipment is shipped at no cost to the family.

IN LOVING MEMORY

FRED GOLL

Father of Kerry and Chris Goll (deceased), Treichlers, PA | Died: 7-2-10

MACAYLA SMOAK

Daughter of Jeff & Jennifer Smoak, Anderson, SC | Born: 05-22-01 Died: 05-22-10 L.Infantile

EMILY DUGGER

Daughter of Danny & Sara Dugger, Madisonville, KY | Born: 04-18-81 Died: 07-02-10 Juvenile

ZACHARY NOORDHOEK

Son of Tom & Julie Noordhoek, Wheaton, IL | Born: 02-08-97 Died: 07-07-10 L.Infantile

McKENZIE HOLDER

Daughter of Stuart Holder & Jocelyn Rowe, Mandurah, W. Aust | Born: 08-03-07 Died: 07-11-10 L. Infantile

BEN WEMPNER

Son of Carl & Brandy Wempner, Princeton, MN | Born: 09-21-03 Died: 07-23-10 L. Infantile

CHRISTOPHER ERB

Son of Terry & Wendy Erb,, Yorkhaven,PA | Born: 12-26-81 - Died: 08-24-10 Juvenile

SECOND QUARTER HONOR ROLL 2010 AS OF 6/30/10

HONOR OF JAKE MEDLEY & ALL THE BATTEN CHILDREN
Anna & Caroline Medley, Cousin Henry & Friend Clara

MEMORY OF MARY ALBAUGH
Mr. & Mrs. Richard Albaugh

HONOR OF DEON AMOSAH
Oxbow Elementary School Fund

MEMORY OF CURTIS ANTHONY
Great Grandpa & Grandma Anthony

MEMORY OF MICHAEL BAKER & HONOR OF JUSTIN PECK
Mr. & Mrs. P.G. Woods

HONOR OF REBECCA ELIZABETH HARRISON BARKER
Alyssa Torres & Kelly Knight

MEMORY OF LESLEY & LYNN BLAKE
Mr. & Mrs. Al Premo

MEMORY OF CARL BERGAM
Ms. Katherine Dilworth

MEMORY OF DANIEL BREUER
Mr. Daniel Breuer

MEMORY OF HANNAH CAULFIELD
Mr. Michael Caulfield

MEMORY OF ALLY CHANCE
Dad & Mom

MEMORY OF KELSIE CLYNCKE
Ms. Betty Marker

MEMORY OF KEVIN COPOUS
Rural Community Insurance Services

HONOR OF CLIFFORD DAHL
Dave's Home Roast
Friends of Chatham Library (Café)
Mr. & Mrs. Jack Waaler

MEMORY OF MR. KEN DECHANT &GRANDSON, THOMAS SCHULTZ
Wiedenfield & McLaughlin, LLP
JW Robison
Mr. & Mrs. James Johnson
Mr. & Mrs. Joe Goodman
Mr. & Mrs. Gerald Anderson
Mr. & Mrs. Mark Wackerbarth
Mr. & Mrs. Randall Rhy
Mr. & Mrs. James Dechant
Mr. & Mrs. Nelson Olavarria
Mr. & Mrs. Gary Johnston
Mr. Timothy Russell
Mr. & Mrs. Rolland Williams
Ms. Nancy Morgan
Mr. & Mrs. James Johnson
Mr. & Mrs. Lawrence Engel
Ms. Sally Dechant
Mr. Donald Wallace
Ms. Lisa Sumners-Gist
Mr. & Mrs. Robert Kuefner
Mr. & Mrs. Larry Zeiger
Mr. & Mrs. David Treimer
Mr. & Mrs. Kevin Bjornsen
Mr. & Mrs. Mark Collison
Ms. Carolyn Holland
Mr. & Mrs. Donald Midthun
Mr. & Mrs. Jeffrey Matchell
Mr. & Mrs. James Van Lew
Mr. & Mrs. Gary Davis
Mr. & Mrs. Jerry Jones
Mr. & Mrs. Bradley Chalker
Mr. Lawrence Crist
Mr. & Mrs. James Poulson
Doris Brockett & Susan Nelson
Billie Sucher
Mr. Russell Froyd

Mr. & Mrs. Edward Braley
Ms. Ruth Fisher
Mr. & Mrs. Jerry Crow
Mr. & Mrs. John Tillman
Ms. Karen Beeler
Mr. & Mrs. Edward Cunningham
Mr. & Mrs. Robert Mitchell
L. Suckow
Mr. & Mrs. James Middendorf
S. Levine
Mr. & Mrs. Bill Long
Mr. & Mrs. Craig Snyder
Mr. & Mrs. Donald Poulson
Mr. & Mrs. William Skirnick
IMT Insurance Company
The Paul Schneider Family
Jen Yerhot
The Dan Cosgriff Family
Ms. Carolyn Cosgriff
The Steve Allen Family
Jennifer & Caley Jones
The Russell Gallimore Family
Mr. & Mrs. Robert Gastel
Ms. Meredith Ashby Family
Ms. Krista Clouse
Mr. & Mrs. Jerry Zimmerline
Ms. Phyllis Baur
Mr. & Mrs. Tim McCann
Mr. & Mrs. Gordan McCleary
Mr. & Mrs. William Stanford
Mr. & Mrs. Charlie Bessinger
Mr. & Mrs. Bruce Church
Gulf Breeze Hospital Auxiliary
Emerald Coast Women's Club
Mr. & Mrs. Tracy Thomas

MEMORY OF EMILY DUGGER

Ms. Sherry Hatchett
The Steve Watson Family
Mr. Bill Rudd
Mr. & Mrs. Charlie Chinn
Ms. Katie Hill

Mr. & Mrs. Charles French
Ms. Debra Wilcox
Mr. Allen Rudd
Mr. Danny Koon
Mr. & Mrs. Roscoe Porter
Ms. Mary Whitfield
Ms. May Watts
J. Craig Riddle Company
Mr. & Mrs. Thomas Frieburg
Mr. Robert Brown
Mr. & Mrs. Steve Brown
Mr. & Mrs. William Donan
Mr. & Mrs. K.E. Allen
Mr. & Mrs. David Roberts
Mr. & Mrs. Danny Sharber
Dr. & Mrs. Dan Baldwin
Mr. & Mrs. John Carr
Ms. Martha Jones
Mr. & Mrs. James Kerlick
Mr. & Mrs. Donald Robinson
Mr. Berry Adcock
Mr. & Mrs. Burl Milligan
Rhoads & Rhoads
Ms. Patricia Walters
Ms. Jacquelyn Calvert
Ms. Laurie Cox
Mr. Thomas Turner
Kenwyn Riddle
Mr. Charles Kington
Woodruff Supply Employees
Mr. & Mrs. Bob Sandidge
Mr. & Mrs. Charles Gillis
Mr. Chester Thomas
Manufacturers Supply Company
Mr. & Mrs. Terrell Lemond
Mr. & Mrs. Elige Palmer
Mr. & Mrs. Jesse Huff
Mr. & Mrs. Gerald Ragland
Mr. & Mrs. Gregory Bruce
Mr. Joseph Badgett

Mr. & Mrs. Bradley Myers
Mr. & Mrs. Philip Page

Mr. & Mrs. Wendell Rayfield
Mr. & Mrs. Steven Summers
White County Coal LLC
Mr. & Mrs. James Crick
Mr. Skip McGraw
The Cincinnati Mine Machinery Co.
Pakmix Inc.
Mr. & Mrs. Barry Eveland
Ms. Patricia Littlepage
Mr. & Mrs. H. Lee Owen
First United Bank and Trust Company
Mr. & Mrs. Ranveer Rathore
Ms. Denise Dugger Griffin
Mr. David Dugger II
Ms. Ginny Savidage
Ms. Karen Ladd
Avanell Sutherland
Mr. G. Ruffin Chandler Jr.
Mr. & Mrs. Herman Stewart
Ms. Kathy Pearce
Mr. & Mrs. Bill Winstead
Jorgensen Sales Co.,Inc.
Mr. & Mrs. Michael Hunt
Mr. & Mrs. Richard Rose
Mr. Rodney Long

HONOR OF ELNA FARET & GRANDSON, RYAN FARET
Mr. & Mrs. Andrew Valrosa

HONOR OF RYAN FARET
Mr. & Mrs. James Thomas
Mr. & Mrs. Eric Faret

MEMORY OF AMANDA FITZGERALD
Ms. Valerie Johnson

MEMORY OF JIM FRYE & PAULA WHITE
Ms. Tracy Frye

Mr. & Mrs. Bob Potter
Advanced Medical Equipment

MEMORY OF ANDREW GRIFFIN
Ms. Julie Bogarr

MEMORY OF FREDERICK M. GOLL
(Father of "Batten Angels" Kerrick & Chrismond Goll)
Ms. Beverly Goll

MEMORY OF COURTNEY GUNTHER
Mr. & Mrs. Melton Frederick

MEMORY OF MATTHEW HARGROVE
Lisa & Johnie Champion
Ms. Angela Lusk
Mr. & Mrs. Billy Hobbs
Mr. & Mrs. John Bolus

MEMORY OF ADAM HAWTHORNE
Ms. Janet Gasdal
Mr. & Mrs. Hugh McCarthy
R. Spurrel
H. Smith
L. Jeske

HONOR OF THE MARRIAGE OF SETH & KELLY HEIN
The Pranschke Family

HONOR OF JENNA HILL
Ms. Lyana Genovese

MEMORY OF JAMIE JERSHA ON HER BIRTHDAY
Grandma J & Uncle Glenn

MEMORY OF ELISABETH JOHNSON
Dad & Mom
Ms. Gretchen Serrata

MEMORY OF AUDREY JONES
Ms. Catherine Newton
Mr. Fraser Base
Ms. Barbara Ross

Mr. Cliff Carr
Ms. Mary Bullock
Susan Andrews
M. Rudkin
Irene Causton

MEMORY OF DANIEL KERNER
Ms. Monica Miller Walsh

MEMORY OF ASHLEY LYNN KIEFER
Mr. & Mrs.Wayne Kiefer

HONOR OF ZACHARY KILLINGER
Ms. Janis Shockley
Ft.Worth Housing Authority

HONOR OF SRI SRI RADHA KRISHNA
Mr. Lawrence Pass

MEMORY OF DENNIS P. LABARGE
Nick Brown & Alison Labarge

HONOR OF NOLAN LEI
Ms. Dawn Thompson

MEMORY OF ZANE MAXIMUS LEWIS
Ms. Sharon Grabill

MEMORY OF CARL LUTHMAN
Ms. Carol Guarino
Loretta Pasko
Brendan, Sean, & Ryan Murray
Mr. & Mrs. James Stevens
Mr. & Mrs. George Maurer
Ms. Ruth Kendzulak
Mr. & Mrs. John Mills
Ms. Linda Richards
Ms. Sally Scotti
Somerville Business & Professional Association
Mr. & Mrs. Charles King
Mr. & Mrs. T. Scott Asay
Mr. & Mrs. Theodore Stirling

MEMORY OF BRITTANY MASTRONARDI
Mastronardi Estate Winery
Dicarlo Produce Sales
Beth Yeh
Hejaz Entertainment
Bulldog Polymers LLC

MEMORY OF BILLY MILANI'S 21ST BIRTHDAY
Grandpa & Grandma Mikrut
Mr. Michael Foley

MEMORY OF HALEY ANN NICHOLS
Mr. & Mrs. Billy Moseley
Doris Jordan
C. H. Penney
Dr. & Mrs. William Roberson
Luminant Employees
Mr. Keith Sunday
Mr. & Mrs. Jerry Brannon
The Birth Place Employees
Mr. Sid AshbyFamily

HONOR OF ASHER NIKOLAJEVS
Berlin Milan Schools Teachers & Students
The Pamela Trautman

MEMORY OF ZACHARY NOORDHOEK
Mr. & Mrs. Richard Noordhoek
Mr. & Mrs. Douglas Noordhoek
Mr. & Mrs. Robert Noordhoek
The Thomas Noordhoek Family
Designed Alloy Products
Mr. & Mrs. William Brennan
Ms. Laura Roethler
Pragnesh Mehta
The Paul Gumila Family
Ms. Cathy Burns
The Michael Gogis Family
The Dale Schumacher Family
The James Kukla Family
Mr. & Mrs. David Exner
Mr. Ronald Kieft
Bosma Fabricating
Mr. & Mrs. Jack Beardsley

Mr. Ernest Bareuther
Mr. & Mrs. Joseph Jaruseski
Mr. & Mrs. Richard Anderson
Mr. & Mrs. Paul Gruenwald
Mr. & Mrs. Charles Lutz
Mr. & Mrs. Daniel Nottke
Mr. & Mrs. Daniel Curcio
Ms. Cindy Adams
The Cunningham Family
The Larry J. Ackerman Family
Ms. Jane Easley

MEMORY OF NATHAN OLIEN
Ms. Marla Nelson

MEMORY OF MELANIE, FRANCE & JOSIE PICHETTE
L. Hache
M. Martin – Morneault
M. Thorne
Caisse Populaire Lavalee
L. Casgrain
N.B. Liberal Association
Savoie Marine
A. Poitras
J. Pelletier
R. Godbout
A.M. Nowlan
Robert KirkPratrick
Lucille Collette
R. Vallilee
J. Nowlan and M. Lavoie
E. Foulem
C. Roy
G. Primeau
M. St. Amand
E. Daigle
J. Deschenes
J. Michaud
A. Martin
R. Pichette
L. Devost
G. Laforge
G. Nowlan
M. Levesque
Parish St. George
B. Morne Ault

MEMORY OF MICHAEL PINDER
Ms. Peggy Peterson
Mr. & Mrs. John Kaesssinger
Mr. & Mrs. Ralph Fromm

MEMORY OF MARCY, MINDY & MICHAEL PINDER
Mr. & Mrs. Penkunas

HONOR OF RICHARD & SANDRA RACE'S 50TH ANNIVERSARY
Ms. Sandra Phillips

MEMORY OF SHIV RANA
Mr. & Mrs. Showke George
Ms. Colleen Boskin
Mr. & Mrs. Timothy Webster
Dr. & Mrs. David Abbot
Abddreza Lman
Yuvraj Rajawat
Suman Chauhan
Mr. & Mrs. Deepak Dutt
Ms. Virginia Elgin

MEMORY OF NANCY SAVOIE
Ms. Laurine Hache

MEMORY OF DOUGLAS SCHMIDT
Ms. Sarah Kopp

HONOR OF MASON SMERDEL
Ms. Kathleen Fleming
Ms. Jill Page
Mr. & Mrs. Kevin Apanasewicz

HONOR OF EMILY SMITH & MEMORY OF SHELLEY SMITH & LORA SMITH (Hugh's Mother)
Mr. & Mrs. Douglas Roy

MEMORY OF LORA SMITH
Hope S.S.Class / Christ Way Com. Church
Mr. & Mrs. R.H. McCracken
Mayse Construction Company
Mr. & Mrs. D.S. Whittenburg
Mr. & Mrs. Drafts Murphy
Mr. & Mrs. Fred Vandergriff

MEMORY OF ANDREW SMITH & MICHAEL PINDER
Mr. & Mrs. Harry Smith

HONOR OF ERICKA SPAIDE
Mr. & Mrs. Rolando Barreto

MEMORY OF EMILY THOMPSON FOR HER BIRTHDAY
Ms. Bonnie Thompson

HONOR OF NOAH & LAINE VANHOUTAN
Ms. Patricia Konet

HONOR OF RACHEL VONTUNGELN
Ms. Melissa McCarthy

MEMORY OF MAYFORD WATSON & GRANDCHILDREN, BRITT ASHLEY & JORDAN DREW WATSON
Ms. Sherry Hatchett
Matthew Reasor Family
Maintenance Support-Planning
Mr. Michael Miller
Mr. & Mrs. R. Eugene Hensley
Mr. & Mrs. Gene Hatfield
Mr. & Mrs. Doug Bales
Mr. & Mrs. Larry Robinson
Edgemoor Baptist Church SBC
Ms. J. Jacqueline Cabe
Ms. Jennifer Lewis
TN. Chptr of BDSRA Members
Mr. & Mrs. Jerry Kear

HONOR OF ROSALIE WESSEL's 10th BIRTHDAY
(She requested donations instead of gifts)
Ms. Clara Granados
Ms. Brida Gibbons
Ms. Alexandra Patels
Ms. Maria Ferrey
Pelham Lindfield Roberts

MEMBER SERVICES & OPERATING

Mr. & Mrs. Jonathan Amyx (Vick's Mud Bog)
Kohl's
Former Members of CBOE Lessors Assoc.
Mr. Cliff Wilson
Mr. Dean Thomas Match
Ms. Tracy Frye
BDSRA NOR CAL
Ms. Pamela Merloni
Ms. Ginny Gossett
Ms. Joan Ditmar
Ms. Deborah Hoover
Ms. Pamela Merloni
Terry Lind
Ms. Sue Inks
Mr. Thomas Cornell
Ms. Alana Gayko
Ms. Kristin Coon
Ms. Sharon Mattison
Mr. & Mrs. Gary Griffith
Merck Partnership For Giving
Mr. Thomas Cummins
Mr. & Mrs. Vince Colarusso
Mr. Richard Tarburton
Ms. Sally Oliveti
Ms. Peggy Dicapua
Ms. Cynthia House
Anonymous
Kevin's Fund
Walmart
Ms. Paulita Pranschke

Ms. Mary Forseth
Ms. Sherrie Bonarigo
CustomInk
Jodi Clouser Erb
Lance Johnston
Sue Grandle
Ms. Jennifer Turk
Mr. & Mrs. Frank Conrad
Kroger
Mr. & Mrs. Andrew Dosick

CANADA
C. Fakeley
J. McCoubrey
Mr. & Mrs. Scott Cross
United Way (Whitby Ontario)
United Way (Ajax Ontario)
United Way (Toronto Ontario)

RESEARCH
Riverview Baptist Church
Mr. Thomas Cornell

INFANTILE
A Cure for Nick Foundation
Mr. & Mrs. Michael King

LATE INFANTILE
BioMarin Pharmaceutical Inc.
Fight For Nicholas, Inc.

JUVENILE BATTEN DISEASE RESEARCH
Rachel's Lemonade Stand
Ms. Kathleen Fleming

SIBS
Mr. & Mrs. Steve Thompson
Ms. Winnie Webb

CONFERENCE STIPENDS
Mr. & Mrs. Dennis Dahl
Ms. Sherry Hatchett
Anonymous

CONFERENCE
Kohl's

MEMORIAL
Kevin's Fund

EVENT SNAPSHOTS

Serbian Awareness Seminar | Novi Sad, Serbia

Miles for Michael Fundraiser | Westlawn, PA

UPCOMING FUNDRAISERS:

Please visit bdsra.org/calendar.html for details on events being held in your area:

10/08	Australian Chapter Conference (AU)
10/16	Arlington Police Association Fundraiser (TX)
10/22	Batten disease Golf Tournament (LA)
11/05	Blake's Purpose Golf Outing (CA)
11/06	Bowl-a-thon for Batten (NY)