The Illuminator

Batten Disease Support and Research Association
Volume 14, Number 2 April 2003

“ A Light in a World of Darkness”

Linda Sivulka
Special Young Woman
USA

Kristof Nemeth
Special Child
Hungary

2003 BDSRA Conference - Detroit - July 31 - August 3

The Cure Depends on US

Everyone who has a child/grandchild/brother/sister/niece/nephew/friend with Batten Disease wants a cure. Can it be achieved? YES!

BDSRA has become a driving force behind promoting, funding and supporting research. The scientists that are funded by BDSRA are working hard and are dedicated to finding the cure, but they need help from all of us.

BDSRA awarded almost $400,000 in research grants in 2002. If we could double or triple that amount over the next couple of years can you imagine how much more research could be done? How much closer to a cure we could be?

The other important aspects of BDSRA are the family support services provided. More programs and services can be offered if the amount of funding for the organization was doubled from last year.

We can do it. It isn't that difficult if everyone takes part.

There are 850 families in BDSRA worldwide. Only one of every 25 families (about .04%) are either raising awareness or raising funds to support BDSRA and research on a regular basis. Are you passionate about BDSRA and finding a cure for Batten Disease? This is the year to join up and make it happen. Take part in the force that will find a cure.

What can you do to help?

First, help to raise public awareness of Batten Disease and the BDSRA:

Call BDSRA at 1-800-448-4570 or email - bdsra1@bdsra.org to request a copy of the Public Service Announcement (PSA). When you receive the PSA tape, take it to your local television station to get them to broadcast it. All television stations designate a certain number of minutes each month for Public Service Announcements, so they should not have any problems with your request.

Purchase a lapel pin for yourself, and each member of your family. Wear them often and take advantage of opportunities to talk about Batten Disease and BDSRA when people ask you about the pin. Consider using the lapel pins as a chapter awareness campaign. The pins cost $2.00 each and covers the cost of the pin and postage. The pin is pictured on the cover. Call or email BDSRA to place your order.

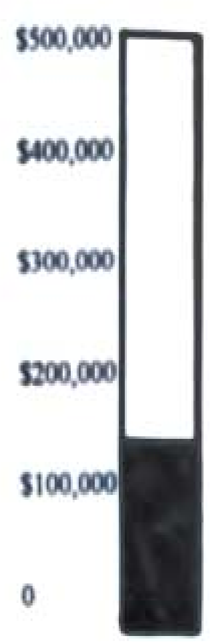
Second, get your chapter, family and friends involved in a fund-raiser in 2003. Imagine if each family raises $1,500 during 2003, we would be able to double the value of the research grants and double the operating funds for programs and services. How do you do this?

A resource book of fund raising ideas has been prepared and is available to help get you started. You will find ideas that are very simple to implement. Call or email BDSRA to request your copy.

No one is more interested in finding a cure, and expanding the programs and services offered through BDSRA than we are. No one else is going to provide the support and programs for our children. No one else is going to find the cure. We are the ones who are passionate, driven and have the desire. There are no limits or boundaries. **The cure depends on US!**

Research Funds achieved through

February 2003



On March 3, 2003, BDSRA issued the Annual Request for Proposals. The "RFP" can be viewed on BDSRA's website: www.bdsra.org

Research grants will be awarded at the annual conference in Detroit on August 2, 2003.

Molecular Diagnosis of Neuronal Ceroid Lipofuscinoses

Peter N. Ray, Ph.D., FCCMG, FACMG
Head, Molecular Genetics
The Hospital for Sick Children, Toronto, Canada

With the very generous support of the Canadian Chapter of the Batten Disease Support and Research Association, the Molecular Genetics Laboratory at the Hospital for Sick Children has begun to develop advanced molecular diagnostic tests for efficient detection of mutations in genes causing neuronal ceroid lipofuscinoses (NCL). I would like to take this opportunity to inform the families who support our research on the progress we have made.

NCLs are the most common neurodegenerative disorders of childhood, with an incidence of about 1 in 25,000 births. Several subtypes of the disease are classified on the basis of age of onset, clinical features, and detailed pathological examination of patient tissue with electron microscopy. Recent research has identified eight genes which can result in NCL. Six of these have been cloned and more than 100 different mutations that can cause NCL have been detected. With this knowledge it is now possible to develop molecular tests for these mutations and provide accurate diagnosis of NCL.

Why do we need a molecular diagnostic test for NCL ?

The current clinical and pathological tests for NCL are very good but there are important advantages to molecular tests. Most importantly, the molecular test looks directly at the mutation causing disease and not at the symptoms of disease. As new therapies are developed for NCL, especially those based on protein replacement, it will be essential to know which gene is disrupted in the patient before therapy can begin. Molecular tests can be used to diagnose an individual before symptoms emerge. This may be very important because treatment will probably be most beneficial if it is begun at the very earliest stages of disease. In addition to the diagnosis of patients, the molecular test can be used to determine who in a family is a carrier of NCL and at risk for having affected children. Molecular testing can also be used for prenatal diagnosis at 10 weeks after conception.

How do we test for NCL ?

Because mutations in at least eight genes can give rise to NCL molecular diagnosis can be very complicated and very expensive. For comparison the molecular test for breast cancer which looks for mutations in two genes costs over $3000 per test. However the situation with NCL may not be so bad. Although more than 100 mutations have been shown to cause NCL eight mutations are seen repeatedly and are responsible for ~80% of the disease in patients. Thus we have developed a rapid and relatively simple test to look for these eight common mutations. With this test we will be able to accurately diagnose the majority of patients. For patients who do not have one of the common mutations we are developing a comprehensive screening method to examine all of the cloned genes leading to NCL by denaturing high-pressure chromatography and DNA sequencing methods. We will use detailed clinical information on the patient to guide us in selecting which genes to examine first in order to maximize the efficiency of this analysis. While this second stage of testing will be complex and expensive we expect that it will be required in only a small subset of patients. Thus the combined strategy will provide an efficient but comprehensive molecular test for presymptomatic diagnosis and confirmation of diagnosis in patients with NCL, carrier testing for the relatives of these patients, and the possibility of prenatal diagnosis in families at high risk of having affected children.

Where are we now ?

The development of the first part of the test, looking at the eight common mutations, is complete and we are in the process of validating the test on patient samples. The development of the second stage of the test designed to examine all of the cloned CLN genes for rare mutations is about to begin. This will be more complex and take longer to establish and validate but we expect to complete this within a year. The complete test will then be ready for use in diagnostic service labs and will be available to all families with NCL.

For more information please contact the Molecular Genetics Laboratory at The Hospital for Sick Children. (leslie.steele@sickkids.ca)

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BDSRA has provided $8,000.00 in emergency bridging funds to A.N. Siakotos, Ph.D., Indiana University, to maintain the English Setter dog colony. The funding will help to maintain this important large animal model for NCL. Dr. Siakotos' work with the English Setter model involves dietary supplementation to reduce ceroid concentrations in the brain.

BDSRA has also awarded $5000.00 to Ines Noher de Halac, M.D., Ph.D., Children's Hospital, Cordoba, Argentina to help with a symposium for pediatric clinicians, neurologists, pathologists, geneticists, and scientists from South America. The purpose is to introduce, teach and promote awareness of Batten Disease in South America. Following the main symposium there will be a five day course for graduate students covering clinical, morphological, biochemical and molecular aspects of NCL. The main symposium is scheduled for Sept. 18 - 20 and is open to parents, clinicians and scientists worldwide.

Tissue Donation: The need for tissue for scientific research continues to escalate. BDSRA's families have responded amazingly. The most recent request for pancreas was phenomenal and the results will be forth coming in a latter issue of The Illuminator. Thank you to all who helped. BDSRA's Tissue Donation Program is a service that provides families the means to make tissue donation for research in a simple and easy way. By signing up beforehand all that is needed when the time arrives is one phone call to place the wheels in motion. For more information contact BDSRA office.

Special Young Woman - USA

Our daughter, Linda, was born on Dec.9, 1964. Up until the age of four she developed normally in every way. At that time, about a month after her fourth birthday, she had her first grand mal seizures. She spent a few days in Children's Hospital of Wisconsin in Milwaukee, was put on an anti-seizure medication, and we were told she had a seizure disorder which she would probably out grow by age 11 or 12.

At that age and in the 6th grade she came home one day and said she had flunked a math test because she couldn't see it. I took her to the eye Doctor and he told us he was pretty sure she was faking. She had to be able to see, as he could find nothing wrong. At the same time I noticed that her penmanship had become very shaky and her speech had become slurred. So we took her to the neurologist. They did numerous EEGs and other brain tests, but we still got no answers, just severe seizure disorder. And we were very frustrated.

At this point we began a very difficult 3 years; Linda's middle school years. The school district in Racine, Wisconsin decided Linda did not belong in special ed classes, so she was placed in regular classes where she became increasingly frustrated. She had so much trouble writing and speaking, but no one seemed willing or able to help. During this same period we took her to Madison, Wi. University Hospital and also to the Mayo clinic in Rochester, Minnesota. We didn't learn anything new and every few years she would have a couple grand mal seizures and spend some time at Children's Hospital, usually a change in medication and then sent home again.

Then came high school. Though by this time she was having trouble walking and her speech had become very slurred and slow, she received extra help, and an aide went to classes with her to take notes for her. Then in June of 1983 she graduated from J.I. Case high school in Racine. We were all so proud and happy for her. But now what?

She loves little kids so she was able to volunteer for a while at a day care center. The school decided to hire her part time. Was she thrilled! But it was not to be. She started having more seizures, which became harder and harder to control. At one point the doctors put her in a coma for a few days and the seizures stopped. Her neurologist at the time decided to do a skin biopsy: When the results came back we were told that she probably had Battens. Of course we knew nothing about the disease, but we quickly learned . Linda wasn't a typical Battens person, as the progression of the disease has been very slow. She remains quite stable for a few years at a time. She has been confined to a wheelchair since the late 1980s, her vision deteriorated, but she is still able to watch TV and lots of videos. It is about the only thing she can do to pass time. Up until 2 years ago she lived at home with us and attended an adult day cadre 2 or 3 days a week. In April of 2001 we had to do about the hardest things anyone should ever have to do.

Linda moved to a long term care facility about 15 miles from our home. The first year was very difficult for everyone. Linda was in and out of the hospital 5 times. Many times I almost brought her back to our home, but I knew we could no longer care for her. We take her out frequently, and visit her 2 or 3 times a week.

So now at age 38, Linda is one of the oldest people living with Battens. So we will try to go on, Joe and I, Linda's brother-37, and sister-36, a neice-9 and a nephew14. She enjoys spending time with our large extended families. And she is loved at the care facility. It is small at only 72 beds, and she knows everyone.

Sue Sivulka (Mom)

Special Child - Hungary

Our son, Kristóf was born on February 23, 1996. We had been waiting for him for 2 1/2 years and so we were very glad of his birth.

He was a cheery small boy, he was interested in all of the things and he was not afraid of anything. He was more active than the average, he always used to move and wanted to do new things.

He grew until the age of 2 1/2 without problems. Because of difficult starting of his speaking and because he could talk just with syllables we turned to doctor (in the near hospital we have an acquaintance, who is child neurologist). She examined him and found no problem. Although he is hyperactive, but he can understand everything and his speaking will develop probably in the future. She suggested us to take him to a community. After that we started to bring him to a day nursery. We spent there an hour daily. It had a good effect of him, he got calmer, but unfortunately his speaking did not develop.

Our son had the first epileptic attack in the day nursery in January 2000, it happened when he was one month before the age of 3. We were frightened. We went to hospital, where we were quieted that it was just a fever attack and probably it will not occur again. After two weeks we got into hospital again because of new attacks. The diagnosis was still fever attack. The real cause was not found out. In spite of it he got drugs in order to avoid the attacks, then came a 3 month period without attacks.

After having attacks even without fever in May (after an EEG examination), the diagnose was changed to epilepsy. Then they stated to handle him with drugs, which brought unfortunately only temporary success. Although his mental skills were still developed, the coordination of his moving started to decline from September 2000. (it was explained as side-effects of the drugs). He had loss of appetite and fell down several times. Because of the continuing epileptic attacks (he had about 30 attacks from September 2001 till January 2002) we got into a hospital in Budapest (our capital) in February 2002. Here came up immediately the possibility of ceroid lipofuscinosis, which was unfortunately confirmed through an electron microscope examination of a biopsy sample (it was strengthened by a DNA test in January 2003, the correct diagnose is late infantile). In order to prevent new attacks the applied drugs were changed rapidly, which seriously worsened the Kristóf 's condition. Directly because of this change in drugs he lost his ability to go, he had very strong muscle-jerks. Afterwards he won back his abilities partly, (e.g. he was able to go a few steps alone again) but he did not reach his former condition anymore. Unfortunately his condition started to decline gradually. Because of the continuing muscle-jerks the portion of drugs were increased slowly but gradually (today he gets 5 drugs, from 3 of the drugs he gets the maximum portion that his weight enables). We could control the epileptic attacks fortunately (he had only 5 grand mal attacks from March 2001)

After getting home from the hospital we tried to walk him by keeping him up to the scratch in order to keep his condition. He still kicked the ball for a while (he liked to play football) then he was not interested in it anymore. He used even his hands less. He said syllables last in January 2002. His seeing and ingurgitation were declining as well. From summer 2002 he has got no eye contact. He cried last in June 2002 (since then he is not able to cry, he reacts for the pain with excitation). We changed to feed him with pulpy foods gradually. In December 2002 a stomach-tube had to be implanted because of ingurgitation difficulties. Being in hospital again and the standing fever because of infections worsened Kristóf's condition a lot, he lost weight 3 kg from 20 to 17 kg. He laughed last in December 2002 in the hospital. At last we could walk here up to the scratch.

During the time in hospital Kristóf received lots of drugs. When we went home, we gave him a sedative, which was given to him earlier several times, and he reacted with a serious epileptic attack. Afterwards we took him to the intensive care unit of the local hospital, because we could not stop the attack at home (he had been on a breathing appliance for 3 days). The doctors told us that there is no hope. Thanks to God he got on and after 3 weeks we could go home. Unfortunately from January 2003 it is necessary to use a suction machine because of secretions. As we can feed him through the stomach-tube well, he thrives and now he is 25 kg.

Now in February 2003 our son can just lie and he can expectorate the saliva swallowed apart more and more difficult. In order to help him to sit we sit behind him. So he can expectorate easier and still then he did not get a lung-inflammation. If he feels all right, he is scratching himself a lot and smiling.

We celebrate his 7th birthday now. We thank to God for every minute, when he feels all right, for every smile, and that he can be still with us, we can nurse him home and we have enough force and health. We hope to spend a longer time with him.

We would like to thank BDSRA for creating the web site of the foundation, where we can get lots of information, what we could not receive from other sources in Hungary.

Laszlo Nemeth (Dad)

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HHS NAMES 13 TO SECRETARY'S ADVISORY COMMITTEE ON GENETICS, HEALTH AND SOCIETY

HHS Secretary Tommy G. Thompson today named 13 doctors, scientists and other experts to the Secretary's Advisory Committee on Genetics, Health and Society.

The committee will be chaired by Edward McCabe, M.D., Ph.D., who is the executive chair of the pediatrics department at the University of California-Los Angeles and physician-in-chief at UCLA's Mattel Children's Hospital. The committee's new charge is an expansion of the mission of the Secretary's Advisory Committee on Genetic Testing to more broadly consider the impact of genetic technologies on society.

"This committee's members bring strong scientific, professional and personal backgrounds and an understanding of the serious health and ethical issues raised by new genetic technologies," Secretary Thompson said. "Under Dr. McCabe's leadership, they will provide sound and thoughtful advice to the department as we weigh the impact of these advances on the health and welfare of all Americans."

At the department's request, the committee may consider the broad range of human health and societal issues involving the development, use and potential misuse of genetic technologies and make recommendations as appropriate. The committee's charge includes considering the clinical, ethical, legal and societal implications of genetic testing and other technologies, and its members include experts in each of those areas, as well as consumer representatives.

In addition to Dr. McCabe, the newly named committee members are:

a.. Cynthia E. Berry, J.D., of Great Falls, Va., the general counsel and managing director for Wexler & Walker Public Policy Associates.

b.. Barbara Willis Harrison, M.S., of Washington, D.C., a genetic counselor and instructor both in pediatrics and in health care ethics at Howard University College of Medicine.

c.. C. Christopher Hook, M.D., of Rochester, Minn., the director of ethics education at the Mayo Graduate School of Medicine and an assistant professor at the Mayo Medical Clinic.

d.. Eric S. Lander, Ph.D., of Cambridge, Mass., director of the Whitehead Institute for Genome Research and a professor of biology at the Massachusetts Institute of Technology.

e.. Debra G.B. Leonard, M.D., Ph.D., of Philadelphia, Pa., an associate professor of pathology and director of the Molecular Pathology Laboratory at the Hospital of the University of Pennsylvania.

f.. Brad Margus, of Boca Raton, Fla., co-founder and volunteer president of the A-T Children's Project, which raises funds for research into a lethal childhood genetic neurogenerative disease called ataxia telangiectasia.

g.. Agnes Masny, R.N., M.P.H., of Roslyn, Pa., a research assistant and nurse practitioner at the Fox Chase Cancer Center and an adjunct assistant professor of nursing at Temple University.

h.. Joan Reede, M.D., M.P.H., M.S., of Cambridge, Mass., an assistant professor of maternal and child health at the Harvard School of Public Health and an assistant professor of medicine at the Harvard Medical School.

i.. Reed V. Tuckson, M.D., of Minneapolis, Minn., senior vice president of consumer health and medical care advancement at UnitedHealth Group.

j.. Huntington F. Willard, Ph.D., the incoming director of the Institute for Genome Sciences and Policy and Vice Chancellor for Genome Sciences at Duke University in Durham, N.C.

k.. Emily S. Winn-Deen, Ph.D., of Pleasanton, Calif., the senior director for genomics business for Roche Molecular Systems.

l.. Kimberly S. Zellmer, J.D., of Mission Hills, Kan., an attorney and mother to a child with Batten's Disease.

BDSRA Board member nominations

The Ad Hoc Nominating Committee is now accepting member nominations to fill 4 board positions. These board positions have a 3 year term, and will be filled based upon general membership elections held in May. The nominating committee is looking for qualified candidates based upon the following criteria:

1. Demonstrated commitment to BDSRA's mission
2. Ability to devote time and energy to board meetings and committee assignments
3. Demonstrated leadership skills
4. Ability to work and communicate with others

Nominations will be accepted until April 20, 2003. Ballots will be mailed out May 15th, and must be returned postmarked June 6th. To nominate yourself or someone else please contact any member of the Ad Hoc Nominating Committee.

Rick Godfrey -ricgodfrey@excite.com (847)695-5453
Vikki Schwartz - natey@ipa.net (417)881-8188
Eric Faret - eric.faret@kraft.com (631)586-4315

Equipment Exchange Program

The Equipment Exchange Program has been busy the past few months matching families with donated equipment. BDSRA has a good selection of equipment available. There is always the need for suction machines. Contact BDSRA office to donate or request equipment

Sibling Carrier Testing Program

BDSRA and the Sibling Group have developed a carrier and prenatal testing program that began Jan. 1, 2003. This program is for siblings age 18 and above who do not have any insurance coverage or are not covered by anyone else's insurance. The program provides financial and logistical assistance. Contact BDSRA office for additional information and application package.

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2003 BDSRA International Conference

Detroit, Michigan

Please join the Michigan Chapter in Novi Michigan at the Novi Hilton July 31st - August 3rd. Be sure to make your reservations early and return your registration form before June 30th. On line registration is also available. We have a great program planned just for you! Looking forward to seeing all of you July 31st. You will be welcomed Michigan style!

Michigan Chapter

The conference information package is enclosed with this issue of The Illuminator.

There will be limited stipends available again this year to help families attend the conference. Stipends are restricted to immediately family only and are for one room and four meals per person. Priority will be given to families attending for the FIRST time, Second time and third or more times, in that order Anyone interested in requesting stipend assistance must email or call the BDSRA office.

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Australia Chapter to Host 2nd. Family Conference

We are excited to announce that we will hold the 2nd Australian Batten Disease Conference on Saturday 18th October and Sunday 19th October, 2003.

The venue is Sea World Nara Resort on the Gold Coast of Queensland. Sea World Nara Resort has offered our guests a room price of $160.00 AUS per night. This standard room price includes 2 double beds. The chosen venue caters wonderfully to a family holiday (in case you would like to share this experience with your own family) and can be viewed further at www.seaworldnara.com.au

We would like to invite you to be a part of this very special event and hope that you can indicate your interest to me in due course. Please note early accommodation bookings are preferable - the length of your stay is completely optional.

Vanessa Anderson - gvjcando@ozemail.com.au

BDSRA Website

BDSRA will be adding new features to the website.

1. Education Bulletin Board - A place for families to share information, problems and solutions regarding educational issues. It will also be a place for teachers and other educators to also ask questions and share information.

2. Homeopathic/Natural Supplement Bulletin Board - This is in response to many families request for a place to ask other families about natural supplements, etc.

   BDSRA is providing this as a service only and it does not indicate that BDSRA is in agreement or promotes any natural supplement or homeopathic remedy.

3. Links - The current "links" section on the website will be divided into two sets of links. The newer set will be composed of Family Links. Many families in BDSRA have their own websites. BDSRA will have a set of links to those websites. If you wish to have your website linked, email webmaster@bdsra.org. The other set of links will contain education, other organizations, etc., just as it does now.

Note: Many people have asked why they don't find anyone in the CHAT Rooms. People come and go from the chat rooms. If you want to meet someone there, it is suggested you make arrangements ahead of time.

BDSRA is also looking at scheduling specific topics for a chat room on a regular basis, perhaps twice a month.

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What is SUPPORT ?

The name of your association includes the word "support" ? What is it ? What does it mean to you ?

BDSRA considers support to be whatever is needed by a child or family at any given time. What may be needed today is not what may be needed tomorrow or the next day, next week or next month. It may be information, education, help locating services and assistance, networking with others, help finding answers to medical and research questions or emotional support, i.e. someone to talk with. It can be anything.

Support begins on or before the day of a child's diagnosis and never ends.

BDSRA started in 1987 with a primary support effort. Over the years BDSRA has added more and more effort and time into the research side of the disorder. Support remains just as strong effort as it ever has in the past.

BDSRA provides support through several different avenues. These include:

The Illuminator
Annual Conference
Website
Family Directory
The Lighthouse
Chapters
1-800 telephone number
Medical Referrals

Publications:

Batten Disease: An Easy to Understand Guide
Batten Disease: Insights for Parents
Teach and Be Taught: A Guide to Teaching Students with Batten Disease
Batten Disease: Coping for Careproviders
Handy Helpful Hints for Careproviders
Will You Walk with Us? - Batten Disease and Hospice Care
Medications
Respiratory System
Gastrointestinal System

Programs:

RN Family Medical Liaison/Educator (Nurse)
Parent Mentor Program
Bereavement program
Sibling Program
Tissue Donation Program
Diagnosis Review Program
Equipment Exchange

Unfortunately, all of this takes funding, too. We know everyone gets tired of hearing about the need for funds. We get tired of asking for it. The bottom line is the bottom line. We ask for more because we recognize the need to do more. Some examples are more awareness, more help for families with social services and programs, etc.

BDSRA's operating ration is 9 % for this upcoming fiscal year. In other words, for every dollar that BDSRA receives, 66 cents will go to research, 25 cents to support (programs and services) and 9 cents to the actual operation of the association.

Please consider allocating a portion of your fund raising event, or donations to the support side of the association.

Note: BDSRA's IRS Form 990 and annual audit is available upon request.

From the Nurse's Corner

This issue, I am going to tell you about the educational materials that I have written and the availability of them.

- Medications – this book includes most of the medications that children with Batten Disease take as to drug administration and safety of giving medications; anticonvulsants, antispasmodics, antibiotics, antidepressants, reflux, laxatives, digestion, drooling. dystonia, sedation, anti-anxiety, anti-psychotic, fish oil, carnitine, melatonin, vitamins and a small piece on vaccines. It is available in paper form or on a disc.
- The Respiratory System – this book starts with some anatomy and physiology of the respiratory system, assessment of the lungs, diagnostic testing, oxygen, humidity, inhalers, nebulizers, pulse ox, postural drainage, bipap, cpap, prevention of respiratory infections, then goes into more details as to specific different respiratory problems that our children are subjected to, example – asthma, bronchitis, pneumonias, and then includes treatments for each. It includes chest physiotherapy, suctioning, and CPR. It is available in paper form and also on a CD for your computers.
- The Gastrointestinal System – this book also starts with the anatomy and physiology of the Gastrointestinal tract, why you need to assess the gastrointestinal system for your child/children, diagnostic testing, when to make a decision as to the insertion of a feeding tube to avoid aspiration pneumonia, and all of the problems that may become evident in our children throughout their childhood and teenage years, its treatments and some solutions. It includes information on different feeding tubes and tube feedings with suggestions to correct problems that may be a problem for you. It is available in paper form or also on a CD for your computer.

All three of these books, are designed with Batten Disease in mind and how these body symptoms are affected by Batten Disease. A lot of the information is from families who have offered insight into situations which need resolving and corrections to the problems. They each contain a glossary and a bibliography. If you have received any of the information and would like to or have other solutions to problems, please let me know and I will include it in the next printing of the books. I am basically updating as needed and not printing too many too far ahead.

I can be reached at 1-877-642-5512 (toll-free) or 1-740-927-4315 or my email address is nancycarney@bdsra.org.

Nancy Carney RN
Medical Liaison/Educator
BDSRA

"Watching Lily"

Pagan Family's Story in April Issue
READERS DIGEST

In the April, 2003 issue of Readers Digest is the wonderful story of Felix and Anabel Pagan, one of our families in BDSRA, who tell of their struggles with children, Maria Sofia, age 11, and Danielito, age 8, who suffer with Batten Disease and little Lily now 5 years old, who at the age of 4 was tested by skin biopsy to see if she, too, would have to fight this fatal disease. After 3 long months of waiting, in March of 2002, Felix and Anabel find out that Lily is "clear" of cells affected by Batten Disease. Anabel now can imagine Lily in kindergarten and growing up all the way through college. She exhales, smiles, and thinks for the first time, to look into Lily's future.

BDSRA Families Now Able to Receive Special Hotel Rates

BDSRA, Tharaldson Communications, and Lynne and Curtis Olien have developed a program which offers special room rates to parents and caregivers of children with Batten Disease..

We are currently working with 3 Lodging groups: Tharaldson Lodging, The Summit Group and White Lodging.

WEBSITE: http://www.batenshotels.com

To reserve a room at a hotel owned by Tharaldson Lodging dial 1-888-651-7666.

This number will be answered by Travel Travel. Just mention you want the Battens rate. You can also book airline tickets and rental cars with Travel Travel. There are no special rates available for airline tickets or rental cars.

To reserve a room at a hotel owned by White Lodging or The Summit Group please dial 1-888-937-6081. Lynne Olien will answer this number.

Some of the hotels are: Marriott, Courtyard, Residence Inn, Comfort Inn, Fairfield Inn, Town Place, Springhill Suites, Sleep Inn, Mainstay Suites, Econolodge, Holiday Inn, Hampton Inn, Homewood Suites and Country Inn.

Heart of America Chapter Elects Officers

Elected on January 17, 2003, were:
Kim Zellmer - Pres.
Vikki Schwartze - VP
Caryll Schultz - Secy
Todd Zellmer - Treas.

The Heart of America Chapter will be hosting the 2004 BDSRA Annual Conference in Kansas City.

President’s Message

Dear BDSRA families and Friends,

The BDSRA Board of Directors met for our Winter meeting at the Novi Hilton, Novi, Michigan, the site of the 2003 Family Conference. Also present were the Sibs Leaders who had a meeting of their own.

Some of the items on our agenda were:

- **Chapter Development:** a new Chapter: Missouri “Heart of America”.
- **Educational:** Wendy Bills showcased a video featuring Roma Downey (“Touched by an Angel”) as narrator. Teaching professionals will use this video to learn better ways to teach children with Batten Disease. This is a project funded by the BDSRA.
- **Medical Liaison:** Eric Faret reported on a meeting he and other Batten parents attended regarding the closing of IBR (Institute for Basic Research) in New York. BDSRA has a real concern in this as we have funded many research projects at IBR as well as providing resources for a Cell Bank and the Batten Disease Registry.
- **Nominating Committee:** 4 positions are up for re-election. Rick Godfrey and his committee are busy getting the bios and information ready for the election.
- **Memorial Committee:** Vikki Schwartze reported that the Committee is currently working with NC State University Design Team to develop concepts and hopefully scale models will be available at the Conference for you to preview.
- **Personnel:** It was determined that we need to increase our resident Nurse, Nancy Carney, from 20 hr./ week to 30 hr./week. Our goal is to get Nancy on staff full time.
- **Nurse’s Report:** Nancy Carney reported that she has completed another book; The Gastrointestinal System. This book will help families better understand the internal working of the GI system.
- **Research:** The Board agreed to allocate funds to help with a Symposium on NCL for South American Doctors. We have funded research in Cordoba, Argentina and are hoping this Symposium will further increase awareness of and research on Batten Disease.

We also discussed some **long term planning** for the BDSRA. Our organization is a Support and Research association. Too often people forget about the many types of Support that is offered: From the beginning, after a family receives a diagnosis and they make contact with BDSRA, we have a **Parent Mentor** program. BDSRA provides **information, medical specialist referral,** and **sibling support.** We have **Chapter affiliation, annual 3-day conference** for information and networking, **Quarterly newsletter,** opportunities for **participation in research, genetic testing/counseling referral,** and **bereavement outreach.** In addition to those services, we have a **Nurse** on staff who can answer many questions and give invaluable help to families. This is just a sampling of what we have to offer.

When I look at the many different aspects our organization encompasses, I often think of how much more we could accomplish in the areas of support if we just had the funding. One of our goals is to establish a steady income stream for the Operating and Support side of BDSRA. The Board will be looking at different ways to achieve this goal.

Best Regards,
George Maxim, President

Send Flowers America

Over the past year and a half BDSRA has promoted using Send Flowers America. BDSRA received a portion of all orders. Please be advised that **Send Flowers America has gone out of business.**

The Batten Week 2003

The Batten Project joined efforts to celebrate The Batten Week from March 3 to March 8, 2003. The week began with a symposium celebrated at Carlos Albizu University and presented by two of our members, Javier Negron and Gypsy Rios-Serrano. On Tuesday, the first Chess Tournament was launched . Students from the university as well as members of the community joined efforts to support the activity. The first, and second place winners received trophies. On Wednesday and Thursday, we had a Bake Sale.

On Saturday, the “First Family Walkathon and Sport Day” was celebrated at the Kendall Indian Hammocks Park. Erika Spaide, one of our poster children attended the event, accompanied by her mom and friends. We held the first basketball and volleyball tournaments. The first, second, and third place winners received trophies donated by a local vendor “Italian Trophies”. Another local vendor and supporter of our mission donated the sports equipment “Play It Sports Again”. This family day was filled with fun activities for the entire family, including raffle drawing for great surprises.

Our Grant Marshall of the week was Jose Antonio Alvarez, a radio announcer from Amor 107.5, an important Hispanic Broadcaster in South Florida. Several radio interviews were conducted through out the week to inform the community about the disease and to promote the weeks’ events. Dr. Maritza Fuentes and, Raul Gonzalez prominent members of the Hispanic community joined our efforts by promoting the disease and supporting our efforts.

Editor's Note: The Batten Project group has a "Talent Show" fund raiser planned for July 25 in Miami.

Fishing Derby Again Successful

The Annual Fishing Derby was held at Pyramid Lake, Nevada on March 7 & 8. 800 people participated raising an astounding $49, 701. Derek & Kristie Allbee, family and friends held this event and proceeds are being divided between BDRSA and Make A Wish Foundation.

Alabama Dart Tournament

Becky Lucas held her annual Dart Torunament at the Roebuck Lodge of the American Legion on February 22. 57 players participated and raised $ 2187.

Family Christmas Auction Proceeds to BDSRA

The Scwab Family of New Jersey held their 3rd. Annual Christmas Auction and for the second year the proceeds were donated to BDSRA. In lieu of buying everyone in the family a gift, they go to the dollar store and purchase three items that are then auctioned off within the family. They had a lot of fun during the auction and feel that making a donation of the proceeds added meaning to Christmas.

Restaurant Fund Raiser Does Very Well

The Fairfield, Calif., Youth Commission held a fund raiser on January 16 at Chey's Restaurant. 20% of all meals purchased was donated to BDSRA. The event raised $450. Many thanks to Joe & Kathy Allio for helping make this happen.

New Southern Cookbook

The Alford Baprtist Church in Many, La., has put together a cookbook of favorite recipes. The cookbook is being sold and proceeds benefit BDSRA. The cookbook is filled with great southern rcipes. To order one, please contact Donna Sandifer at 318-256-2879.

Batten the Bear

For your fund raising

Batten the Bear, 2nd and 3rd Edition are ready and waiting to help you with your fund raising. These Bears will come to you in any quantity you request at a cost of $5.00 per bear. This cost includes the price of the Bear plus shipping. No profits are made at this cost. You can give them away for any donation amount you wish. For example is you got a $10.00 for a Bear, you would make $5.00 for your fundraiser. The 3rd Edition is a white bear with red and blue stars on its wings and a blue and red nose.

To order either the 2nd or 3rd edition please contact Katie or Rick Godfrey at ricgodfrey@excite.com, or (847)695-5453

Daily Grind Divas

The Daily Grind Divas CD is now available. Look back to your January Illuminator for the story. The CD sells for $15.00 each, BDSRA will realize $10.00 per CD). Can purchase outright for $5.00 each +postage to be mailed to any organization for sale to benefit BDSRA. Can purchase per CD for private use for $15.00 + postage. T order send request to:

Daily Grind Divas
PO Box 811
Pullman, WA 99163

Upcoming Events

Upstate New York Chapter

April 26 is the date Norma & Mike Angelo and the Upstate New York Chapter have a Chicken n' Bisquit Dinner planned at the Busti (NY) Church of God. The dinner will be followed concert featuring several local group and individual singers. For more in formation email Norma at njangelo@madbbs.com

Minnesota Chapter

Joni & Pete Metcalf and the Minnesota Chapter will hold their annual Walk/Run May 3 at Lake Phelan in Minneapolis. This is an annual event that is hugely successful each year bring in funding for research. Participation and help is needed. Contact Joni at joni_metcalf@hotmail.com

Lousiana Chapter

David & Carol Rickman and the Louisiana Chapter will be holding their $th. Annual Batten Walk on May 3 in Pass Christian, Ms. This event has over the past few years raised the most money for research. For more info email: battenresearch@aol.com

1st Annual
Freed-Hardeman University SGA 5K Fun Run

WHEN: April 26, 2003
WHERE: Freed-Hardeman University
PARTICIPANTS: Our goal is to have 500 student runners Our goal is to have 500 student runners and 500 community runners from congregations within 100 miles of Freed-Hardeman.
DIVISIONS: *Open Division* – This is just for fun and is not timed.
Team Division – This is a race. There will be individual and team prizes.(Teams consist of 5 runners; times will be averaged.)

> **OUR GOAL IS TO HAVE A 5-MAN TEAM FROM EVERY CONGREGATION WITHIN 100 MILES OF FHU. WE ARE ALSO HOPING THAT ALL PREACHERS AND ELDERS WILL RUN IN THE OPEN SECTION. THIS WILL BE A GREAT DAY OF FUN, A GREAT DAY OF SERVICE, AND ALSO A GREAT DAY TO MEET MANY CHRISTIANS FROM AROUND OUR AREA._**

ENTRY FEE: If you raise at least $35, the entry fee is waved. For those who don't raise $35, there will be a $10 fee to cover expenses.

For more info: Robby Hatchett - 615-865-3619

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National Batten Disease Awareness Day in Australia

March 31 is National Batten Disease Awareness Day in Australai thanks to the efforts of BDSRA's Australian Chapter. In addition to raising awareness, the chapter is also selling miniature cricket bats, thus leading into the "In to Bat for Battens" logo for the National Awareness Day. The Indoor Cricket Foundation of New South Wales is helping to sponsor this special day. Posters are being placed in McDonalds Restaurants throughout New South Wales, Western Australia and Queensland.

Melissa Froio Foundation Schedules Annual Golf Tournament

The Melissa Froio annual golf outing is scheduled for June 20 at Maple Ridge Golf Course. Majority of the proceeds from this event are given to BDSRA for research. For more information contact Greg Froio at 856-435-0212.

Combined Federal Campaign

United Way

Each year the Combined Federal Campaign (CFC) and the United Way raise hundreds of millions of dollars for a multitude of charities nationwide.

One area CFC raised over $6 million. BDSRA received $12.34.

BDSRA is a CFC Agency (#2992) and in most cases can be a "write-in" agency for United Ways. This is an easy way to help BDSRA achieve much needed program and support funds. All that is needed is for government employees to be made aware of Batten Disease. Government employees include military, postal service, etc. Many of your family and friends give to the United Way. Ask them to consider BDSRA to receive their pledges.

The next CFC and UW campaigns will be this coming fall. Think about it and get out the word.

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2003 Annual Membership is payable. Membership is payable to your chapter or, if you are not in a chapter, to the national organization. Membership is $20. Include your current mailing and email address.

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

Memory of Corey Adams
Richard Wayne
Gloria Ann Coker
Atley & Teresa Ledlow
Dale & Sandra Hilton
Kathy & Randy Lee
Gloria & Wayne Coker
Jay & Beverly Buckley
Don Wade & Family
Sharon Volunteer Fire Dept.
James & Joan Woods
The Chisholm Foundation
Jerry Akerman
Southern Wholesale
Jerry J. Long
LeBlanc Orthodontics
Lott Furniture

Joseph Fail
Howard Industries
R.H. Watkins High School
Sharon Elementary School
Ellis & Walters Dentistry
Telepak, Inc
First Baptist Church of Sharon

Memory of Jessica & Corey Adams

Sarah Brent
Jim Collins
Sharen Fire Dept.
Walter & Patricia Sims
Jerry Akerman
Collen Cagel
Tracy & Angie Adams
Sharon Elem. School
First Baptist Church of Sharon
Alicia & Brad Holifield & Boys
Robert & Annie Adams
David & Diane Adams

Honor of Catie Allio

Larry & Renee Walker
Quick as a flash, Inc
Oldroyd Masonry
Isaac Anderson
Patricia Bales
Joseph Gagliardi
Mark & Hilda Schraer
Michael & Janice Radesky

Memory of Laura Anlauf

Peffer & Wallace, LTD
Mille Lacs Oil Co.
Johnson Oil Co.
Tri-State Petroleum, Inc.
Robert Gunderson
Michael & Judith Ziemann
James & Jeanie Young
Patricia Wolter
Carol Wolff
Mae & Dean Tonsfeldt
Pete & Julie Thiry
Alan & Linda Staples
Stamm Trucking
Donald & Beth Spears
Steve Schwarten,D.D.S.
Stephen & June Strom
Ken & Carol Sauter
Thomas & Keri Sahlmen
David & Lora Ruthenbeck
Timothy & Berghetta
Marcus & Cheryl Rolando
Mara & George Renier, M.D.
Gary & Jackie Peterson
Craig & Melissa Rossman
Robert & Rita Speichel
John & Lynette Munkberg
Linda & Ron Noyce
Mrs. Arthur Nusbaum
Roger & Donna McNear
Melissa Lupinek
Mary Beth Leitze
Joni Metcalf
P.J. & Carmen La France
John & Gretchrn Kramer
Ted & Ramona Klein
Collen LeBlanc
Neil & Amy Jennissen
Richard & Donna Humphrey
Le Roy & Merrie Ann Hesseiroth
David & Sally Richard
Dudley & Barbara Hanson
David & Marlys Fast
Richard & Christine Exsted
Ted & Sharon Haugen
Jeff & Debra Edbald
P.A. & Mary Dunbar
Keith & Merri Doral
Barry & Diana Engdahl
Cameron & Susan Conrad
John & Corrinne Colombo
Dennis & Cleone Clayton
Randy & Tammy Dooley
Suzie Carlson
Tim & Constance Carroll
Michael & Lori Beth Lind
Robert Carstens
Bob & Joyce Becklin
Lawrence & Ann Berg
Alan & Judy Berglund
Matthew & Jackie Berry
Jeff & Diane Anlauf
Kent Cummings
Vicki Raitor
Neil & Gwen Anderson.
Jim & Trudy Hunt
School District Office Staff
Community Education Office Staff
Lynn & Val Sulerud & Mindy
Cambridge Middle School Staff
MN Chapter of BDSRA

Memory of Jeffrey Balzer

Jeannie McCormick

Memory of Whitney Barrow

Mary Mapes

Memory of Jeff Bobby

Michael & Carol Bobby

Memory of Michael Boer

Honor of Amy Boer

The Springfield Foundation

Memory of Mary Alice Bortz

Elizabeth Flannery, PhD

Memory of Dylan Carr

Eric & Lisa Faret

Honor of Dominic Ceravone

Micheal & Heather Chappa
Tracy Ceravone

Memory of Margaret Chisholm

Giuliano & Sharon Lucatelli
Brian Finn
Lake Minterwood Beach Club, Inc,
Harriette Roger
Wendy Greg & Deanne English
Mary Chisholm
Judy & Don Mills
Kenneth Long
Hotchkiss Enterprises

Memory of Anna Clendenin

Ronald & Jill Arbeiter
Donna & Curtis Clendenin
Mary Ann Bunselmeyer
Kathryn McClurken
Wilson's Funeral Homes,LTD
Shirley Malone
Deborah Todd
Jack & Betty Messerli
Mary Jane Karg
Charles Clendenin Children
Cecil & Sue Dunning
Gary Ahner
Harriett Kunce
Mr. & Mrs. George Downen
Mary Ann Bunselmeyer
Katie McClurken

Honor of Amanda Coats

Jim & Sandy Coats
Jim & Sandy Coats,

Honor of Ken, Laurie and Tommy Dockter

Mr. & Mrs. Albert Mezzano
Michael & Joan Baroz

Honor of Eliot & Jean Elliott

Wayne & Trina Kiefer

Honor of Robin Marie Flynn

Rob & Theresa Flynn,

Honor of Chris Gaines

Doug & Renee Jefferson.
Connie & Tony Cochran
Terry Milstead
Helen Huddleston

Honor of Joann Ganske

Wayne & Trina Kiefer

Memory of Eleanor Genepro

Ambrose & Marilyn Galli,Jr
Silvio & Nadine Vaccarezza,
Giulio P. Vaccarezza,
Rose Schmid,
John & Arlene Cooper
Tannis King & Rosa Heinrich
Grosso Financial Group, INC
Stephen & Toni Coughlin,

Memory of J.R. Godfrey

Richard & Kathrine Godfrey,
Dr. Matthew J. Gryzlo
Joseph & Melissa Rossa

Memory of Preston Habershaw
Diabetic Foot Management Center-Michigan,P.C.
Russell Khederian
John & Millicent Seymour
Golightly Companies
Rare Kids, Inc
Mr. & Mrs. Len Gorden,
Mass. Podiatric Medical Society
Geoffrey & Nanette Habershaw
R.F. & Mary Ella Jones
Kathrine Reese McGinnis
Steven & Kathy Quint
Eric & Lisa Faret,
Honor of Megan Harriman
Jane Remy
Honor of Austin Hein
Ken & Lexine Pranschke
Audrey & Robert Fink
Memory of Paula Hudson
Carter & Leticia Judy
Memory of Solange Marie Isnard
Debbie & John Diaz,
Honor of Jay Jensen
Jay & Karen Flynn
Memory of Jamie Jersha
Brian & Nancy Reese
Glenn F. Jersha
Eugene & Irene Jersha
Memory of Lorena Johnston
William & Nancy Scheerer
Memory of Thomas Kerr, Jr.
Ronald Greene
Central Transportation
Deann Jacobson
Rob & Karen Twietmeyer
Andrea Hoskins,
David & Deborah Hagen
Susan Heston
Curtis & Barbara Smith
Larry & Trudy Morris
C. V. Teacher Social Fund,
Cougar Valley Elementary
J. E. & Elveta Travelstead
Carol Farr
Brenda Jensen
Randal Vincent
Christy Gallardo,
Ralph & Elaine Parks
Kathleen Riley
Rhonda Douglas,
John & Donna Laha,
Robert & Elizabeth Ramm,
Johnny & Phyllis Bates
Cheryl Brooks
Memory of Ashley Kiefer
Wayne & Trina Kiefer
Todd & Diane Hill
Wayne & Trina Kiefer
Honor of Wayne Kiefer
William & Carol Frith
Memory of Levi Knowles
Linda Niemi
Memory of Patricia Lueng
Vicki Ramm
Memory of Brittany Mastronardi
Eric & Lisa Faret
Honor of Christopher McDonough
Mary Ellen Brown
Memory of Leah McFarland
Anne Olek
Marybeth Nesbitt
Tammy Shockow
Diane Barber
Payyi Mock
Betsy Armes
Gail Sielaft
Nancy Tesse
Karen Arnold
Regina Boyer
Tracy Tyra
Susan Pryntz
Marcia Olson
Christina Mancini
Marybeth Mackenzie
Maria Tantillo Muller
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John & Suzanne Onken
Arthur & Carol McFarlane
Reta Dolan
Lisa Leary
David & Leisa Strabel
Royce & Edna Coon
William & Jeanette Behnke
Vincent & Barbara Flow
Mr. & Mrs. Dale Smith
Mr. & Mrs. Richard Jewsbury
Lake Plains Dialysis Staff
US Postal Service Employees,
Tours 1,2and3
APWU
Peggy McFarland
Betsy Thurner
Bill Phillips
Eleanor Phillips
Joan O'Neill
Mr. & Mrs. Ed Barrett
Mr. & Mrs. Donald Pilger
Pam Dorschel &
Eastside Internal Medicine
Randall & Marilyn Elliott
David Pearce & Suzanne Nott
Michael & Lorinda Didonato
Richard & Sandra Race
Race Family Reunion
Larry & Sue Klafehn
John & Julie Picard
James & Kathy Bresnan
Eileen Jungbluth
Harvey & Cathrine Pollicove
John & Pamela Allen
Glenn & JoAnn Winkler
Lyle & Florence Crispell
Peter & Alice Yellitz
Gary & Lori Lorraine
Roy & Marlene Streetz
Todd & Stephanie Becker
Sandra Rowland
Marha Dieter
Stephen & Mary Ellen Seaman
Robert & Martha Hart
Joel & Roberta Johnson
Mark & Jill Groves
D.F. Goodwin
Rebecca & Wayne Hibbard
Judith Doan
The Krony's Wednesday Lunch Bunch
Richard & Patricia Suhr
James & Patricia Dusett
Debra Drennan
R.C. & Betty Wilson
Joni Metcalf
Roberta & Francis Norton
N. Stephen & Carol Castor
Howard & Barbara Kitchen
Gerald & Alyce Reamer
Robert & Sandra Wilson
Jack & Wendy Scull
Honor of Michael Metcalf
Connie Metcalf
Honor of the Milani Family
Jeffrey & Linda Van Spankeren
Memory of Helen Morgan
Howard & Ruby Robinson
Memory of Nathan Olien
Lynn & Curtis Olien
Nancy Mangum
Robert & Jeannie Paris
Phyllis Verworn
Ned & Shelly Rector
Stephen & Nicole Nelson
Scott & Brenda Kast
Memory of Meghan O'Neill
James & Aileen Reasoner
Memory of Merna Paris
Patricia Schipma
Lynn & Curtis Olien
Marla Nelson
Janet & David Baumbach
Laura Kesmar
Jay & Cheryl Stob
Honor of Adam Pederson
Ethel Brown

Blake & Janelle Johnson
Rebecca Wentler
Theresa Drexler
Sheila & Jon Fabre
Brenda Sandahl
Jerry & Kim Pederson
Honor of David Peterson
Lorraine & Michael Brown
Memory of Howard Pitts
Faye Reynolds
Honor of Stefani Puskar
Anneliese Vire
Christine De Cordovo
Memory of Brad Sandifer
Honor of Chad Sandifer
Alford Heights Baptist Church
Memory of Jered & Madison Savoy
Jennifer Thiebert
Honor of Collin Schmidt
Kent Schmidt
Honor of Thomas Schultz
John & Susan Wilson
Jack & Susan Wilson
Honor of Don Schultz
JW & Paula Robison
Honor of Kristin Smith
William & Diana Iltzsche
Memory of Shawn Smyser
Louie & Beverly Davis
Memory of Sarah Sproger
Cynthia Wadsworth
Memory of Gretchen Streett
Doug Leavy & Aleta Streett-Leavy
Memory of Tennessee Chapter Children
Tenn. Chapter of BDSRA
Honor of John & Mary Kay Tensing-(35th Anniversary)
Edward & Barbara Hayhow
Memory of Asa Tynes
Teresa Hjelle
Memory of Stephania Vela
Eric & Lisa Faret
Memory of Johana Van Meter
Sheldon & Daisy Bradley
Honor of Logan Warren
Memory of Tyler Warren
Frank & Florence Cole
Gary & Tammy Warren
Memory of Carolyn Wilhelm
Gary & Carolyn Ransick
R. Dennis Kelly
Victor & Barbara Boelscher
Gary & Carolyn Ransick
Tracy Ceravone
Tuhinabindu Rajupalepu

Annual Quilt Raffle

The BDSRA annual quilt raffle features a king size quilt and two pillow shams. The pattern is JENNA.

Proceeds from this raffle will be used to help families attend the 2003 BDSRA Conference.

Contact BDSRA at 1-800-448-4570 or email: bdsra1@bdsra.org for tickets. Tickets sell for a $1 donation each and must be returned by July 15, 2003.

In Loving Memory

David Seelye, son of Bill & Kathy Seelye, Tacoma, Washington, Born 5/17/85 - Died 1/21/02 - juvenile

Jefferson McGregor, son of Robert & Ann McGregor, Tulsa, OK, Born - 9/16/73 - Died - 3/8/02 - juvenile

Sara Sproger, daughter of Phil & Kathy Sproger, Fogelsville, PA - Born - 8/7/95 - Died - 4/1/02 - late infantile

Robbie Clements, son of Rob & Nita Clements, Lizella, Ga - Born - 11/1/96 - Died - 5/3/02 - late infantile

Hannah Lambert, daughter of Samantha Lambert, England - Born 7/15/92 - Died 4/10/02 - late infantile

Tressie Wells, daughter of Lester & Mary Wells, Seal Cove, Newfoundland - Born 4/19/61 - Died - 5/26/02 - juvenile

Dane Murdock, son of David & Fyffe Murdock, Lindsay, Ontario - Born 3/12/96 - Died - 6/2/02 - late infantile

**Jeremy Montana, son of John & Karen Montana, Little Rock, AR - Born - 12/1/74 -
Died - 6/4/02 - juvenile**

Jamie Killion, daughter of Al & Vicki Killion, Lake Bluff, Il. - Born 5/1/86 - Died 6/20/02 - late infantile

Philippa Heyworth, daughter of John & Robyn Heyworth, Mt. Claremont, Australia - Born 8/16/90 - Died 7/21/02 - late infantile

Alexandria Chance, daughter of Jody & Kim Chance, Prattville, Al - Born 6/1/98 - Died 8/9/02 - infantile

Meghan O'Neill, daughter of Mike & Cheryl O'Neill, Portage, MI. - Born 4/25/95 - Died - 8/21/02 - late infantile

Dylan Carr, son of Cliff & Sue Carr, Whitby, ONT., - Born 5/1/92 - Died 8/22/02 - variant late infantile

Kyle Oliver, son of Janice & Kevin Dart, Byford, Western Australia - Born 1/13/91 - Died 8/24/02 - late infantile

Paula Hudson, daughter of Dean & Carol Hudson, Chandler, AZ - Born 12/2/89 - Died 9/3/02 - late infantile

Christopher Cornelius, son of Jessie & Kathleen Cornelius, Blue Ridge, GA - Born 9/22/78 - Died 9/3/02 - juvenile

Corey Adams, son of David & Diane Adams, Laurel, MS - Born 8/15/76 - Died 9/19/02 - juvenile

Whitney Barrow, daughter of Trace & Renee Barrow, Bloomington, IN. - Born - 2/7/87 Died - 9/24/02 - juvenile

Cassandra Palmer, daughter of Wanda and Robert Steele, Lakeview, AR - Born 7/17/88 - Died 9/27/02 - juvenile

Laura Anlauf, daughter of Jeff & Diane Anlauf, Cambridge, MN - Born 8/8/83 - Died 10/7/02 - juvenile

Ethan McCord - son of James & Virginia McCord, Abbeville, SC, Born 7/5/90 - Died 10/9/02 - infantile

Carl Robinson, Jr. - son of Carl & Connie Robinson, Spring Valley, IL. - Born 2/18/78 - Died 10/26/02 - juvenile

Brooke Horsely, daughter of Matthew & Deborah Horsley, Australia - Born 2/11/97 - Died 10/30/02 - late infantile

Brittany Mastronardi, daughter of Tony & Eadie Mastronardi, Ruthven, Ont. - Born 8/3/91 - Died 10/31/02 - late infantile

Preston Habershaw, son of Geoff & Nanette Habershaw, Hingham, MA - Born 11/19/80 - Died - 11/13/02 - juvenile

Staphania Vella, daughter of Calcidonio & Monica Vella, Zabbar, Malta, Born 9/27/83 - Died 11/15/02 Juvenile

Patricia Lueng, daughter of Leigh Lueng, Houston, Tx - born 8/26/70 - Died 11/18/02 - juvenile

Siobhan Sowry, daughter of Stephen & Beth Sowry, Dapto, NSW, Australia - Born 2/18/95 - Died 11/26/02 - late infantile

Mary Alice Bortz, daughter of Terry & Mary Bortz, Janesville, WI - Born 7/25/84 - Died 12/2/02 - juvenile

Jordan Anderson, son of Graeme & Vanessa Anderson, Kilarney Vale, Australia, Born 8/26/93 - Died 12/15/02 - late infantile

Tom Kerr, Son of Thomas & Kelly Kerr, Bremerton, WA. - Born 9/9/81 - Died 12/21/02 - juvenile

Leah McFarlane, daughter of Kris & Tim Coon, Hamlin, NY - Born 11/8/87 - Died 12/26/02 - juvenile

Margaret Chisholm, daughter of Ian & Joann (Finn) Chisholm, Gig Harbor, WA - Born 6/29/86 - Died 1/10/03 - juvenile

Heather McNellege, Daughter of Michelle Kingston & John McNellage, Jr., Roberstdale, AL. - Born 2/11/88 - Died 1/21/03 - infantile

Steven Otto, Son of Lynell & Albert Otto, Frederick, MD - Born 12/17/92 - Died 2/4/03 - late infantile

Arlene Anderson, mother of Crystal Anderson (deceased), Happy Valley, Labrador - 2/11/03

Logan Warren, son of Gary & Tammy Warren, Park Hills, MO. – Born 4/21/91 – Died 2/28/03 – late infantile

James Lemley, son of Connie Conrad, Paris, MI. – Born 1/9/84 – Died 3/13/03 – juvenile

Wayne Zimmerman, father of Bonnie & Lynn Zimmerman (deceased), Wauseon, OH - 3/8/03