

The

LIGHTHOUSE

Summer and Fall 2009, Volume 12, Numbers 3 and 4



A Publication of BDSRA –
Batten Disease Support and Research Association

LETTER FROM THE EDITOR

This issue of The Lighthouse is covering both the Summer and Fall issues for 2009. It includes articles relating to the recent July 2009 BDSRA Conference in St. Louis, as well as looking ahead to the holiday season.

A number of families have requested to not be included in the mailing list anymore and there will be some changes implemented in the mailing of this publication. This will help address the concerns of many who are now further along in their journey of grief as well as the newly bereaved. In addition it will help eliminate unnecessary expenses associated with the printing and mailing for those who have indicated that they feel they no longer wish to receive it for whatever reason. Instead of receiving The Lighthouse quarterly indefinitely we are planning to send a total of four issues over a period of one year following the death of a child to a family. This would encompass the first year of bereavement. Many of you who are receiving issues currently will no longer be on the mailing list and this will be your final issue. If you have questions or concerns please contact the Home Office at 740 927-4298 or email us at bd سرا1@bd سرا.org. Your input is important to us.

Summer has slipped away. Fall, resplendent in glorious leaves drifting through the air represents a special season. The fallen leaves on the ground, wet or dry, occasional smoke blending in the air from woodstoves and burning leaves, chilly air forecasts dropping temperatures in weeks to come, less daylight and longer, dark nights are all reminders to many of us. The season is beautiful, however presents time of reflection and often sorrow to those who are experiencing the loss of a loved one. We are aware of the holiday season ahead and an empty chair or more at the table. You will find suggestions in this issue that might help in your holiday planning and reassure you that it really is OK to follow the way that you feel this year. Perhaps some of them may help to bring some comfort to you and your family in the days ahead.

Personally, Fall is the season of greatest sadness for me. During the months of September and October the losses of my loved ones have occurred except for two. At this stage of my journey in grief I see the colors more beautiful this Fall. I now look forward to the beauty and solitude of Winter and eagerly anticipate rebirth in Spring. I have the belief and faith that this will happen and thus far have never been disappointed. In spite of adversities the year has brought I rejoice because I am blessed with support of a few very caring special friends. Nature's Cycle of the Seasons continues, a very real part of life. I cannot avoid it, but thanks to the passage of time I have begun to adjust to the change. It is necessary to make choices which will determine the remainder of my life. It is important to allow yourself and others this important time. Give this necessary, special gift to yourself, the unique person that YOU are, as well as to others in your family. Recognize that they are each a special individual and try to respect that in their journey of grief as well.

May the New Year bring continued awareness with Peace, Comfort, and return of Joy to you and yours.

Reflections from Connie.....by Connie Jackson

The first meeting of a grief support group met in my living room yesterday, only 4 of us. The opening question was: "What brought you here? How are you feeling?" The answer? "Anxiety"! Each of us could identify edginess and fear. "What will others think if I cry? But if I don't get help, how can I make it?"

One and a half hours later, after sharing the initial shock and grief of a loved one's death, and after looking at ways to care for our tattered selves, we joined hands in prayer. As we invited God into our lives, the Ultimate Comforter, peace and hope touched our spirits.

It was 14 years ago that Davy, my youngest son died of Batten disease at age 28. His birthday was recent, Aug. 8th, a day spent recalling his time on earth, written in my book "Nothing Can Separate Us". Seeing his brother Jon decimated by Batten disease right before his eyes, reminded him that early death would be his destiny.

Can good be born out of tragedy? YES! In our support group we touched on this. One mother, whose son died in an alcohol related car crash, is ready to share his story with the high school crowd. I keenly remembered how being part of "Yoke-fellows", a small group had helped me through Karen's illness and death. For me offering a support group to grieving people is a calling. Out of our suffering can come healing. How have you been able to reach out to hurting others? Your understanding and compassion is a gift from God.

Perhaps you'd like to read my book, "Nothing Can Separate Us". Send \$7.00 in a note with your address. I'll see that you receive a copy. That's another blessing that has emerged from pain: the story of Karen, Jon, and David.

*Peace and Joy,
Connie Jackson*

6571 Mossy Bank Rd., Bath, NY 14810

<< So Many >>

by Patsy Savoie

Did you ever stop to wonder, yesterday or any day
How many angels are up in Heaven? There are many!!

And if you are reading these lines I have written,
Undoubtedly, you must have lost an angel to "Batten".

That is the name given to this awful and deadly disease
That destroys our children slowly, till they become one of these.
But once the loss of sight, the seizures, and every painful happening
Ends with death, they are all angels and each one is smiling!

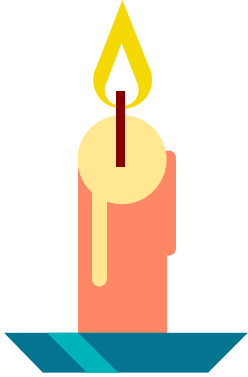
To those of you who have not reached the final day,
We, who have lived through it, think about you and pray.
Because, although we get tired and imagine it never ending,
Once it is over, it lasts so long, this empty, empty feeling.
My angel, Nancy, would have been thirty-three years old today.
Ten years, since she died, and the question remains come what may,
What would she have become if Batten had not taken her away?

Nancy

Born September 25th 1975 • Adopted November 7th 1975 • Died May 1st 1998

YOUR CHILD AND MINE

By Ann Salladin - September 2009



*My heart weeps for
Your child today
As it often does
For mine.
The years slip past
So silently
As the world forgets—
Goes on.
That torn, raw wound
Within us
Time mercifully
Has healed;
And in it's place
A hallowed spot
Where her presence
Dwells, reveled.
With the ever-passing years
She abides in
Memories and my heart
Until some day
We'll meet once more---
Never then
To part.*

For daughter, Victoria and children of friends who also died in the Fall of Batten disease.



FOR THE SIBS

I want to thank the Rev. Rob Matheus, Pastoral Associate, at St. Albans Episcopal Church, Bexley, OH for sharing the following thoughts with us for this issue. He shares, in retrospect, the personal thoughts of an adult as he describes the experience of the illness and death of his older sister during his childhood and the impact it had on his life. I have also included a poem written in March 2009 that Rev. Matheus composed for the memorial service of the son of a parish member. I am grateful to Rev. Matheus for his agreeing to participate with these unique pieces in *"The Lighthouse"*.....*Editor.*

Losing a Sister at an Age of Innocence

We are introduced to many people, many souls, at our birth. Our parents, pray God, first and foremost. Then to so many others....siblings, cousins, grandparents and godparents, come into our lives. We are changed by each one, helping to shape us and lead us on this journey of life.

When born I had an older sister, by three years. What I did not know was that she had been diagnosed with a brain tumor soon after birth. Treatment was limited and surgery was more difficult then. She often looked odd - a shaved head with fresh scars looked funny and a little frightening on my sister, in a time when shaving one's head was not so popular. I am sure they told me what was happening to Bonnie, but all I could comprehend then was how different she was. What her illness was to mean to me and my family or origin would not be revealed for years to come.

Most of my early years were spent with my grandparents in a valley of the Rocky Mountains, or with neighbors and friends of my parents who wanted to help. I learned to walk in my grandparent's living room, with many people other than my parents and sister witnessing my growth. People who loved me and were doing their best to shield me from the horror being lived out in my parent's lives.

My grandfather, Roy Joshua Day, a doctor of some skill in his time, taught me how to fly fish. I even had my own waders! When we were fishing in the peaceful mountain streams I could sense an uneasy desperation in him. He had lost a daughter and a sister in a car accident. His sister was driving, against his advice, on a mountain road at night. Tragedy was familiar to him, but now his first born granddaughter was dying and he could do little to help; except making sure his first born grandson was well cared for.

I am fortunate in that way - in the midst of death I was surrounded by love and life. In many ways I was spoiled by frightened adults feeling guilty about what was happening around me, wondering if I would be able to have a "normal" childhood. Very little was normal, although I did not realize it at the time. I understood at some level that Bonnie's life would be short. My heart ached to see her and my family strain under that tragic reality.

The day my parents came to get me, from yet another family who had taken me in during Bonnie's last surgery, I knew something was wrong. At the age of six I had developed an ability to sense what was not being spoken. My father lifted me to his knee and explained that Bonnie was not coming home. *She is in heaven.* I was sad and angry - why did she have to leave now? Was it something I did or did not do or say? And, I could see the pain in my parent's eyes. *This is not fair!*

After years of mostly silence about Bonnie's illness and death, I began to talk with my parents about her. I have heard many wonderful stories, life giving stories that have kept her real and present in my life. This experience has taught me many things, especially how precious each soul is that touches our lives. Each has something to teach us and their very presence shapes us in ways we may not be aware of at the time.

Bonnie taught me there is grace in vulnerability. In my faith tradition, Jesus is the ultimate example of God's ability to transform the most tragic of circumstances. Being willing to open one's life, becoming vulnerable, God's grace is given room to change lives. Bonnie's short life, vulnerable and filled with kindness, has been transforming for many.

In death life has changed, not ended. As survivors we have the joy of participating in this transformation. Coming to acceptance, it changes us and leads us on our journey with hope and peace.

Blessed be.....

Railroad to Heaven

I stand by the tracks
rails strong and straight
hearing the faint sound
of a train at its gate

Sounds speaking of times
I remember so well
And times yet to be
All aboard if you please

I say my goodbyes
boarding the train
remembering faintly
home's sweet refrain

Porters kind
smells so sweet
I sense my heart
Skipping a beat



Leaving the station
to a place still unknown
the rhythm comforting
once more going Home

Now I know
what this train means to be
my ticket to a heaven
yet unknown to me

As we ride along
I hear this song
*come home dear one
come home*

Carry me Home
Love I might embrace
life's final end
filled with Grace

The Great Conductor greets me
As I walk down those stairs

*Welcome home dear friend
To heaven's open gate*



GETTING THROUGH THE HOLIDAYS WHEN YOU'VE LOST A LOVED ONE


(With permission from Abbey Press: Excerpts from the article by
Darcie D. Sims)





The Holidays are coming and I'm not sure I'm ready. I'm not sure I'll ever be ready again. I tried making out my gift list today, but the tears kept getting in the way. It is so hard to think about gifts and fun and the holidays when a loved one has died.

As I get out the dishes and count the silverware, I am acutely aware of the empty place at the family table. I'm trying to find the holiday spirit, but when the family circle has been broken by death, the only things that sparkle this season are my tears.

Working Your Way Through

When you've lost a loved one, the holiday season can be a painful reminder of the terrible loss you are feeling - instead of bringing warmth, love, and excitement. The first few years are perhaps the most difficult, but even years later, the holidays may lack the joy they once held for you. There are steps you can take however, to help give the holidays new meaning. The holidays can become a time of peace and reflection, a time to cherish the gift your loved one has been – and continues to be – in the life of your family. Here are a few ideas that may help you begin the journey.

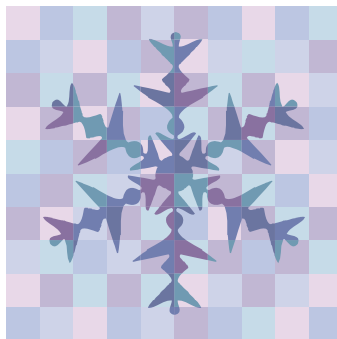
 ***BE PATIENT AND REALISTIC.*** Sometimes our own high expectations of the holidays make the pain and frustration more acute. We have a mental picture of how things ought to be, based more on fantasy than reality. Remember you are grieving. Be kind, gentle and realistic with yourself. Leave OUGHT out of the holiday season this year. It is difficult to be realistic while you are grieving, but it is also an important strategy for health and well-being. Plan ahead so that you are not overwhelmed by responsibilities at the last moment. When you are grieving it is difficult to concentrate, so make lists. Prioritize things. Decide what is important to YOU this season. Scratch the rest of the list this year and add them back on in years to come.

-  ***LISTEN TO YOUR HEART AND ACKNOWLEDGE YOUR LIMITS.*** Spend some quiet time before the rush of the holidays listening to your heart. Become aware of your needs and express them to family members and friends sharing the holidays with you.
-  ***REMEMBER THAT IT IS O.K. TO SAY NO.*** You do not have to accept every invitation or fulfill every responsibility that comes your way this holiday season. Accept things only as you have the energy and desire to do so. Do what you can and let that be sufficient.
-  ***TAKE CARE OF YOURSELF PHYSICALLY.*** Grieving is hard on the body and is a great source of stress. Eat well and wisely. Avoid overindulgence in the season's many culinary delights. However do not deny yourself the pleasures of good food and companionship out of a sense of obligation to the deceased. Remember that your loved one would want to see you smiling, happy and surrounded by those whom you old dear. If you are alone this year as a result of your loss, find a way to share a part of the holidays with others. You may find yourself forging new bonds out of shared losses.
-  ***ADAPT CHERISHED TRADITIONS.*** When loss and grief overwhelm us at the holidays, we are sometimes tempted to scrap the whole thing. To do absolutely nothing. But you can keep traditions alive in ways that make sense given the new reality of your life. Purchase a gift that your loved one would've liked and give it to a charity in that person's name. Hang the stocking, or not, place a wreath or balloon, toy or memento on the grave if it seems appropriate. Try a new twist on old traditions. Have Christmas dinner or open presents on Christmas Eve, New Year's Day or the Sixth of January. Do whatever feels right for you and your family. If you are alone this year as a result of your loss, find a way to share a part of the holidays with others.

1. *ALLOW THE TEARS TO COME, BUT LOOK FOR JOY AMIDST THE PAIN.* As you unpack the holiday decorations along with the warm loving memories, you will be unpacking some heartaches as well. Don't deny yourself the gift of healing tears. Try to remember all the wonderful moments of your loved one's life. Write all the gifts your loved one has given you on strips of paper-joy, laughter, affection, companionship. Put the strips of paper in a stocking, a gift box, a memory book, a private drawer or use them to decorate the tree. You are celebrating the joy your loved one has brought into your life.

2. *FOCUS ON THE SPIRITUAL DIMENSION OF THE HOLIDAYS.* When you are ready, and it feels right, one way to refashion the holidays is to focus on the underlying religious meaning. In the Christian tradition, Advent can be a time of quiet reflection and spiritual preparation. In this season of light, remember the light your loved one has brought to your life. Light a special candle-not in memory of a death, but in celebration of a life and a love shared. Give thanks for having loved and been loved by this person.

3. *TAKE HEART.* Right now, you may feel like the scattered pieces of a broken puzzle. Honor that feeling, but take comfort in knowing that the pieces of the puzzle can be reshuffled, re-arranged and pieced together to form a new picture. As you learn to create a new reality for yourself, temper your expectations with compassion and gentleness. You will heal, but only as you allow yourself to experience the full range of emotion on your journey through grief. Try to focus on your loved one's life-not the death-and that can make all the difference. May love be what you, too, remember the most.



CONFERENCE 2009

This year at the conference we started a new program for those who have lost children to Batten Disease. We wanted to have a meaningful program for those who have lost children in the past several years and for those whose children have been gone for quite some time. With many hours spent on working through different ideas and with the help of Doug Cluxton who works with the Ohio Hospice and Palliative Care Organization, we came up with a program that we felt would meet the needs of our families. We wanted to invite those to attend who have lost children but also include others: some who may not yet have lost their child/children, but coping with Batten Disease begins at the moment of diagnosis, so we wanted to include any families who felt they wanted to learn what to anticipate; also grandparents, aunts, uncles and any other family members or caregivers.

We started off with a session for the more newly Bereaved entitled “A Portrait of Grief” where Doug went through the cycles of grief and tried to help those in attendance recognize where they were in the grief cycle. We had a session on Resources for Grief which talked about books, tapes, other groups, such as Compassionate Friends, that were helpful for those who have lost a child. We had a table that had 20-30 different books on the subject that could be purchased at a reasonable price from Barnes and Noble. And also in that session they talked about how do you accept help from family, friends and neighbors? If you would a listing of these books or a copy of Doug’s handouts, please contact us. Ohio Hospice and Palliative Care also have a program entitled “Bobby’s Books”. Childhood is a wonderful time. A child embraces the joy of each day. Sometimes though, sadness, fear, illness and loss enter a child’s life. If you know a child who had to make such a journey, would you know how to help? One way is to use children’s books to help kids deal with difficult issues. Using children’s literature as a springboard for conversations will give kids the chance to express their feelings and tell their own stories. It is also important that children have access to a variety of books that

show a broad range of emotions and feelings. This helps kids see that they can act independently, assume responsibility for their actions, tolerate frustration, approach new challenges with enthusiasm, and be proud of their accomplishments. Use books that help kids feel good about themselves. Use a book and conversation to help a child deal with a change in routine or a death of a pet. Use everyday happenings to build a child's coping skills. Keep reading. Keep talking. You and your child will both benefit.

For those who have lost children some time ago we had sessions entitled "Grief Now & Then": which dealt with looking at the grief cycle now that some years have passed, how they can help those who have just lost their children and how does grief change? They also talked about how can they stay connected and reinvest in BDSRA now that they have lost their children.

In the afternoon sessions, we split the men and women into two groups and held two sessions as to how men and women grieve differently, where did you find the strength to make it through the tough times of Batten Disease, what was the most difficult thing to face after the loss of your child, what is helping you mend, and how were your other siblings affected by the loss of your child. After they had time to discuss the items above, a spokesperson from each group reported on the topics discussed from each group and talked about recognizing Special Days – Birthdays, Anniversaries, Holidays, etc.

We then held a session "Living After The Loss of Your Child" no matter how long it had been for the attendees and discussed ideas of what some had done in the past. At the end of this session, everyone got in a circle and tied string around a wrist three or four times then gave the ball of string to the person beside you until everyone in the circle had done the same signifying that they were all one, had experienced the same grief of losing a child/children and now life goes on, but in the midst of it all, they all had each other to gain strength from and could contact each other in the time of need.

That session was followed by a wrap up session in which the idea of having regional meetings or an every second or third yearly meeting was discussed. We tried having a Winter Retreat for the Bereaved two years in a row and it was not too successful – not very many people attended, so we are working on some other ideas for this program. The group did not like the idea of having regional meetings, so we would like your ideas of what would be meaningful to you. We would greatly appreciate any input from our readers or a phone call because we truly would like to come up with a program for you soon. We will keep you updated with decisions made for this program.

Written by Nancy Carney, RN

On Sunday, July 19, 2009 the Annual BDSRA Conference held in St. Louis, MO concluded with the Memorial Service. Many in attendance included not only parents who had attended the Life Goes On Session and had lost a child/children to Batten disease, but also other parents giving support to their friends and other conference attendees. The following is from the service and was written by Carl Schwartze, Heart of America Chapter who presided at this moving Memorial Service which was held in a room where the beautiful Memorial Wall was an ever constant reminder of so many beloved children lost to Batten disease. Although some parents were unable to be in attendance their children were not forgotten. Thank you Carl and others who participated in its planning and presentation.

Remember

*Remember me not with tears and pain.
Remember me not like the wind and rain
Remember me not for the body that failed
Remember me not for the color that paled

Remember instead the smile on my face,
my glow, my laugh, my abiding grace
Remember me for the battle I fought
Remember me for the lessons I taught.*

*Remember me for the time that we shared.
Remember me in the way others cared.
Remember me for the sparkle in my eyes
Remember my persistence in repeated tries.
Remember me in all that you do.
Remember my courage, remember my flame.
Remember me now and speak my name.*

Following the reading of "Remember", Carl continued with the following thoughts which spoke the thoughts of everyone present.

"We gather together as a family. A collection of individuals separated by distance, time and personal experience. Members of a family, drawn together, not by choice, but through fate. Inseparably joined through a witness, to a journey made by those who were chosen for a reason unknown to us, to travel a difficult road. We followed along knowing full well that their struggle was our struggle, their gain was our gain, and their loss was our loss. We were entrusted with their care and expected to clear the way for their mission. We were to help where we could, and stand aside when there was nothing we could do.

Our dreams for them were many and varied. Our hopes for their accomplishments were grand and glorious. But it was not to be. The course of their journey had been determined before they were born. We have borne witness to difficult lives lived without fanfare and without notice, except by those closest to them.

We come together, not in mourning, but in celebration. Celebration of the lives of our Angels. With gratitude for the time we were granted, thanks for the gift we were given. We have been witnesses to their battles and lives. Battles met with courage and strength. Losing battles well fought. Lives lived with grace and purity. Short lives lived well.

They taught us the things we needed to know. And compelled us to teach others. Their lessons to us were simple; Learn, Laugh, Live, Love.

They taught us to learn to be flexible. To adapt to daily changes, to look for different ways to handle routine situations. They were patient with us when we resisted change and pulled us along gently until we learned and were open to learning again. We learned that sometimes a good day is the best you can ask for, and a bad day, was still a day together.

They taught us the true value of a laugh or giggle, which is immeasurable to us now. Those laughs are our strength in difficult times and our therapy forever. We wait for that special moment during a movie that would illicit that giggle. For that sound, that joke, that voice, which would bring the sparkle to their eyes. We take solace in that laughter. Confirmation that in the face of tremendous struggle, we can find happiness.

They lived each day, each moment, to the fullest. Taking joy in the simple, little, things of daily life, a special song, a favorite movie, the glimmering sunshine, a swim in a pool, a big purple dinosaur.

They taught us to live each moment for the moment. To take encouragement from even small achievements, a word, a grasp, a smile, a hug. We etched these events in our minds, knowing full well, that someday we would have only our memories of them, and hoping and praying for just one more.

They taught us that love truly does conquer all; that neither distance, nor time, nor absence can diminish that to which we cling for strength; that love is the one constant thing in our daily lives; and that love lasts forever.

Memories of difficulties and hardships fade with time. But the joys and happy moments burn brightly and fresh in our minds.

The impact of their presence on this earth is unmatched. They looked into our eyes as if to say, "There's so much more to life than you can see". They possessed knowledge of things beyond life on this earth. Their footprints are forever in the sand. To have been touched by them was to be touched by greatness for they walked with God, and allowed us to touch His face.

We held them with us for as long as we were able. When their work was accomplished, when their time was done, we released our grip on their physical being, and clung to their spirit. Freeing them to return to the heaven from which they were sent.

Now, we watch as they go high on that mountain, and we smile, because in our mind's eye, we see them dance.



In Memory of the Children We've Lost in 2009

Curtis Anthony, son of Paul Anthony & Donna Kapper, Dublin, PA

Born: 09/17/02 - Died: 01/20/09 Late Infantile NCL

Megan DePew, daughter of Phyllis DePew, Stanwood, MI

Born: 05/22/87 - Died: 01/22/09 Juvenile NCL

Carl Bergam, son of Jeff & Robin Bergam, Arlington, WA

Born: 07/30/96 - Died: 02/03/09 Late Infantile NCL

Thomas Schultz, son of John & Caryll Schultz, Leawood, KS

Born: 06/16/96 - Died: 02/10/09 Infantile NCL

Melanie Pichette, daughter of Gilles Pichette, Grand Falls, NB and
Jackie Violette, Edmunston, NB, Canada

Born: 11/25/76 - Died: 03/02/09 Infantile NCL

Caroline Nichols, daughter of Ron & Gail Nichols, Virginia Beach, VA

Born: 05/01/98 - Died: 03/08/09 Late Infantile NCL

Melissa Froio, daughter of Gregg & Paula Froio, Sicklerville, NJ

Born: 09/29/94 - Died: 03/18/09 Late Infantile NCL

Haylee Prater, daughter of Jean Prater, Busselton, WA

Born: 1989 - Died: 12/05/08

Tianna Theobald, daughter of Fran Theobald, Essex, England

Born: 10/26/98 - Died: 02/01/09 Late Infantile NCL

Jay Theobald, son of Fran Theobald, Essex, England

Born: 11/16/96 - Died: 03/10/09 Late Infantile NCL

Jesse Hackett, son of Amanda Hackett, Brisbane, Australia

Died 03/26/09 Juvenile NCL

Saul & Savannah-Rose Fraser, twins of Mark Fraser & Alana Addison, Dundee, Scotland

Born: 11/15/01 -- Died: 03/17/09 Infantile NCL

Alexis Long, daughter of Martin & Martha Long, Oregon, WI

Born: 08/20/89 -- Died: 04/05/09 Late Infantile NCL

Matthew Crimmins, son of Martin & Jean Crimmins, Marysville, MI

Born: 06/20/76 -- Died: 04/13/09 Juvenile NCL

Sara Pfaller, daughter of Mike & Pat Pfaller, Crystal Lake, IL

Born: 07/17/92 -- Died: 04/14/09 Juvenile NCL

Stefani Puskar, daughter of Paul & Heidi Puskar, San Pedro, CA

Born: 05/14/99 -- Died: 04/18/09 Infantile NCL

Mark Szigetvari, son of Gabor & Marta Szigetvari, Budapest, Hungary

Born: 10/24/95 -- Died: 05/05/09 Late Infantile NCL

Sue Reynolds, partner of Lesli Hudson, N. Hampton, MA

Born: 04/18/75 -- Died: 05/08/09 Kufs (Adult NCL)

Sarah Whelton, daughter of Paul Whelton, Houston, TX

Born: 11/05/98 -- Died: 06/5/09 Late Infantile NCL

Terell Amosah, son of Philip & Tanya Amosah, Oxbow, Saskatchewan

Born: 07/14/01 -- Died: 06/13/09 Late Infantile NCL

Hilary Jones, daughter of Bobby Jones and Fred & Deb Mata, Callahan, FL

Born: 04/10/92 -- Died: 07/28/09 Juvenile NCL

Janine & Tracy Bullock, twin daughters of Marilyn Bullock, Thornlie, W. Australia

Born: 01/26/78 -- Died: 07/30/09 Juvenile NCL

Storm Carretta, son of Lynn Coll & Randy Carretta, Pittsburgh, PA

Born: 01/06/04 -- Died: 07/31/09 Cockayne's Disease

Dazlin Alexis Bates, daughter of Roderick Bates & Denecra Bates,
Nashville, TN
Born: 10/01/97 -- Died: 08/05/09 Infantile NCL

Elisabeth Johnson, daughter of Keith & Alice Johnson, Nevada City, CA
Born: 03/07/87 -- Died: 08/17/09 Juvenile NCL

Seth Holder, son of Jocelyn Rowe & Stuart Holder, Mandurah, Australia
Born: 10/10/02 -- Died: 09/01/09 Late Infantile NCL

Fielding Applegate, son of William Applegate & Deborah Applegate,
Watauga, TX
Born: 07/01/92 -- Died: 09/17/09 Juvenile NCL

Colton Green, son of Dawn Mizuguchi, Corner Brook, NL, Canada
Born: 12/15/01 - Died: 09/30/09 Late Infantile NCL

Blake Hux, son of Hunter and Heather Hux, Mendenhall, MS
Born: 04/10/98 - Died: 10/10/09 Unknown NCL

Jamie Mitzel, daughter of Roger and Sheri Mitzel, McCoy, TX
Born: 02/23/89 - Died: 10/08/09 Juvenile NCL

David Pfohl, son of Warren and Brenda Pfohl, Manlius, NY
Born: 11/02/88 - Died: 10/22/09 Infantile NCL

Josee Pichette, daughter of Gilles Pichette, Grand Falls, NB and Jackie
Violette, Edmunston, NB, Canada
Born: 03/28/78 - Died: 10/17/09 Infantile NCL

Brandon Smith, son of Doug and Cindy Smith, Winnipeg, MB, Canada
Born: 03/16/01 - Died: 11/01/09 Infantile NCL

Chelsea Garza, daughter of Aaron and Terri Garza, San Antonio, TX
Born: 09/10/92 - Died: 11/20/09 Late Infantile NCL