

*The*  
**LIGHTHOUSE**



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## Reflections

“Special Child” in the Illuminator touches and amazes me. There’s always a story of the struggle of diagnosis; the grief of always seeing a dear one stripped by Batten Disease of all abilities; and the challenge of giving care to the very end. What shines through and remains intact is the spirit of our child. Our children, in their helplessness, shaped us into persons of strength and hope.

I think back to Karen (1952-1968) with her friend Joyce in the dayroom of Newark Developmental Center, around them were profoundly impaired residents. The girls, blind and limited, wove potholders and reached out to others. Alice in her 70’s stopped by. “Bad heart,” she told them. “I’m afraid to die.” Karen and Joyce prayed for her. Right where they were placed, the girls had a ministry of caring. “Bloom where you’re planted” was the gift Karen gave me.

Jon (1958-1984) gave me the rare gift of gratitude. After his first seizure at age eleven, I struggled to accept his going down with Batten Disease. We took him to a healing service. Frequent prayers, laying on of the hands, but were there any changes? In the backyard later the evening star twinkled bright and pure in the sky.

“What do you see when you look up?” I asked Jon.

“Just the black night,” he answered. I began to cry. “What’s the matter, Mom?” He put an arm around my shoulder.

“Oh Jon, I wanted your eyes to be healed tonight.” “Hey, Mom, I’m OK” His voice was firm. “I have my friends at school, my tree fort, everybody in the family-and Jesus in my heart. I’m fine just the way I am.” I was the one who needed healing.

Jon taught me something important - to be thankful for all that I have.

David, (1967-1996) the youngest of my six children, knew his destiny when he began to lose his sight at age five. Smart, angry, fearful- he rebelled against the disease. Violence landed him several times in Psych Centers. For him, God was far away. A change began when Dave received Bible tapes from his Aunt and Uncle. Calmness came as he listened instantly to the New Testament stories, told with music and in

contemporary dialogue. The turning point happened when he learned about life after death. I was ironing one April morning and listening with him to I Corinthians 15. “The bodies we have has embarrass us, for they become sick and die.” Dave stopped the tape. “Listen to this, Mom.” I joined him on the floor. “Yes, they are weak dying bodies now, but when we live again, they will be full of strength.” He turned to face me, a smile lighting up his face. “Guess what? I’m gonna have a new body.” Tears were sparkling like diamonds in Dave’s blue eyes. “Mom, Jesus loves me. I love the Lord,” he solemnly announced.

That day my son taught me the power of God’s word. The gift he gave me was the calm that comes in believing.

With Valentine’s Day coming, it’s good to think back on the blessings our children’s bequeathed us. I hop this edition of the Lighthouse will stir memories. Grieving is long and hard, needing to be punctuated by gratitude. May you find help along the way throughout the poems, remembrances and articles in the following pages.

Connie Jackson



Remind yourself of your reasons for living. You have a future worth enduring for, and you deserve to find a renewed sense of purpose and pleasure in your life.

Nannette Habershaw beautifully shares the lessons she learned from her son.

### **Preston-What a Gift.**

He taught me to love unconditionally,

To find joy in the smallest things,

To gain understanding and compassion for those with less potential than ourselves.

How to respect everyone's best effort even if it appears less than ours.

To give merit for merit.

He opened my eyes to other worlds than I was previously exposed.

He taught me to respect myself, even if no credit or acclaim was given by others.

He showed me the way to stick to one's goals and promises through thick or thin.

He stretched my stamina beyond the unthinkable.

He challenged my creativity in every way.

He helped me to understand that all life is precious.

That living is a joyous event.

Every challenge taken is a reward to one's spirit.

There is no effort that is failure, the only failure is not to try!

Preston met all sorts of challenges every day for years.

He never gave up! He never felt sorry for himself.

He knew that his job was to be the best he could be as long as he could be.

He was brave, courageous, loving and had a great sense of humor.

He was so proud of his siblings, and boasted of their successes as his own.

He was always an equal member of our home.

Now he will be an angel to look down on our family and

Help us to continue to live and love and laugh with his unique energy and spirit.

God Bless You, Our Beloved Preston.

Austin Habershaw gave this powerful tribute to his brother at the memorial service for Preston (11-19-80-11-13-02)

### **Eulogy**

Hello, and thank you all for coming.

Very few of you gathered here really knew Preston. He was, to many of you, Nanette and Geoff's son, Hilary's or Auston's brother. Maybe, if you were among the exceptional few, he was your student, or perhaps, your childhood friend. No matter what your relation to him, however, it was very likely a brief one. Preston faded out of our lives so gradually, and yet so suddenly. Certainly, it was a process of years that took him away from us, but I imagine that to many of you, the boy you knew all those years ago seemed to vanish in an instant. "Where is Preston?" you may have asked. Gone to another school? Switched to another class? Where is he? I remember him, all full of spit and vinegar, with the dimpled smile and throaty laugh. He's just a face lost in a crowd. If I look hard enough, I still think I might find him. I suppose that is the way it always I with someone as memorable as Preston.

I am Preston's brother. I would submit to you that I knew him better than perhaps anyone in this room. He was my best friend, my roommate, my partner in crime. When we were little, we fought and played as all brothers do. We invented fabulous worlds to inhabit, fiendish nightmares to defeat, we conspired to find new and ingenious ways to torture my mother. As he grew sick, I was with him. I calmed him so that he could go to sleep. I helped him to the bathroom when he needed it. I read him stories when he went blind. He was my brother, and I am here to tell all of you who and what he was.

I guess most of the stories you may have heard about him were about how boisterous he was. Before he could walk, he was knocking down playgates and climbing atop refrigerators. He used to chase my friends around the yard with an enormous wiffle bat, hollering and roaring like a wild Scotsman. Beyond his famous tempers and riotous antics, though, he was very sweet and very kind. He loved animals; he wanted to be a veterinarian. When I lay in bed with fever, Preston, totally blind, found his way out to the rabbit hutch to bring in my rabbit, Domino, to soothe me in my bed. He was a boy who hugged as fiercely as he fought. He was passionate and loving.

My brother was a great man. I do not say this out of kindness to the departed, nor out of any obligation other than I feel this fact *must* be known: my brother was a great man. No, he was not a great athlete or war hero, he did not invent something or help the poor. He wasn't rich or well educated. He was robbed of his chance to do any of those things. No, I characterize Preston as a great man for this simple reason- he was, without a doubt, the most courageous and defiant person I have ever known. When he was in elementary school, he managed to pass all of his vision tests despite the fact that he had *no frontal vision*.

When he went completely blind, he still insisted that he could see. He rode horses blind, he played hockey blind, he skied blind. He cut his head open by running into things more times that I care to relate, all the while insisting that he could see. As he lost motor control, he would try walking anyway, even if it meant falling. He would insist on eating on his own, even though his hands were losing their ability to grasp or even feel the food on his tray. Here was a child who knew what was happening to him-he *had to* know- and yet he *did not give up*. Even in the end, lying paralyzed in bed, a prisoner of his own mind, Preston fought to stay alive. He outlived his life expectancy by two years. He endured intense seizures, critical illnesses, and worse-things that had killed others with his illness without fail-and he would always rebound.

My family and grew so accustomed to his bizarrely stubborn constitution to the point where we feared that he wouldn't die until he was in his thirties or even older. I ask, who among you would have persisted as he did, clinging to a life that was barely worth it. I know I could not. I do not think I know anybody else who could.

I composed a poem a few years back, and I feel it is appropriate that I end with it now. It is entitled *On Surrender*.

*We all stand before the Ocean,  
The gently ebbing, flowing infinite,  
Whose blue green weight grinds the sky,  
and wears mere mountains into mortal meal.  
Yet, if you look to the shore's white edge,  
You'll see a single tree,  
Whose roots cling to salt—stained rock,  
Whose withered hands plead with the clouds,  
Yet it Stands, immortal defiant,  
and shall remain 'neath darkling tides,  
Staunch stubborn, ever struggling  
To wring the very blood of life  
From every passing breeze.  
And as you watch it fight and die,  
With hero-shaming passion,  
Think on thyself, whose own roots shall salt soon taste,  
Against a sea of troubles  
And with dignity lay you down.  
Goodbye Preston.*

Written by Auston Allen Habershaw, 24 yr old brother of Preston.

## LIFE GOES ON

This is the first in a series of interviews with family members who have experienced the death of a child from Batten Disease. Often there's a sense of purposelessness because the focus for care is gone. How have parents or siblings used their experience in meaningful volunteering or in a vocation?

Bob Wilhelm has found his niche in Cincinnati's Children's Hospital as a volunteer tutor. A retired math and science teacher, he is helping kids hospitalized with catastrophic illnesses to stay on top of their studies. "The future is not to bright for some of these children," he explained. "Part of my placement is because I'm at ease with the circumstances."

Experiencing the death of his 22-year old daughter Carolyn has given him empathy. He's helping to bring normalcy for some bright children. "I also work with a Down's Syndrome child," he commented, "It's certainly not one way. I'm getting so much from these kids. It's uplifting."

One little fellow Jason wanted to come home to die. Terrible headaches from the meds interrupted tutoring. "We don't have to do this right now," Bob offered, "Maybe you don't want to see my ugly face."

In his pain and weakness, Jason rolled his head to the side, looking at him. "You're not ugly," he said softly. With a look of gratitude, Jason whispered, "Thank you."

"He was whole inside and rooted in his faith," Bob recalled, revealed by pictures on the wall.

Bob's religious orientation gave another perspective to the sorrow of his daughter's death. Bob remembered how much receiving letters and cards from teachers and students meant to him and his wife Laura. "Never under estimate how it feels when you send those cards and letters, he advised. "Each and everyone is helpful.

Bob has a son David who is a college teacher with an MA in Math. Her knight in shining armor, he and Carolyn were best friends. Since his daughter's death, Bob missed caregiving. Being at Children's Hospital has helped fill the hole, a continuation of the loving care he gave to Carolyn. "I see the children I tutor as her buddies," he concluded.

**You can cry and close your mind,  
Be empty and turn your back,  
Or you can do what they would want;  
Smile, Open your eyes, Love and go on.**

## Becoming A Person Of Safety

The best thing you can do for your children is get comfortable dealing with and talking about death. If you are not comfortable the children will pick up on that discomfort and be reluctant to talk to you. If you are not comfortable talking about the person who has died it will also be difficult for them to do so.

Being comfortable with dealing with death means you feel free to cry even in front of the children. This can be carried to the extreme but most of the time we don't cry in front of them enough. We don't want them to see us sad, and we are afraid it will hurt them, but if we hide our grief they will hide theirs also. If we can build a warm, open and honest atmosphere where grief is talked about in the open, healing can take place.

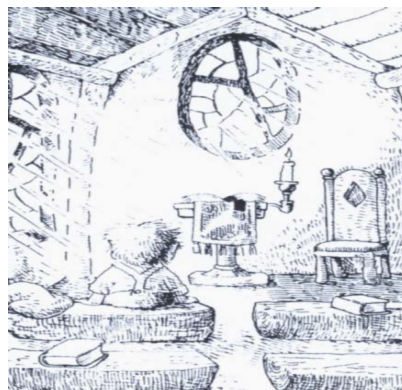
Being comfortable will help us avoid the mixed messages we tend to use. If we are afraid of saying the person died, we may tell the child the person is asleep, and the child may then become afraid of going to sleep. I have heard people say, "God took him because he loved him." I always wonder what the child will think the next time they sing "Jesus Loves Me" in Sunday School. It takes a great deal of comfort and courage, but telling the truth to our children is almost always the less hurtful choice.

We need to use all of life to teach children about death. There are so many opportunities to do so from the death of a pet to the falling of a leaf. They need to begin to see death as a natural part of life and not some feared horrible thing that happens as a punishment if we are bad.

They need for you to relax and let nature and grief take their natural course. They do not need you to make their healing a crusade, nor do they need someone constantly taking their emotional temperature. Right now, more than ever, they need normal and relaxed parenting.

They need reassurance that it is not their fault. Kids will naturally think they somehow caused this to happen. "Daddy died because I wet the bed," or "I wished this person was dead and then they died." We need to let them know it was not their fault without pressuring them for a confession. We do not need to ask them if they think it was their fault, just let them know it was not.

They need a world with not pressure. I have heard far too many grown-ups tell kids, "You have to be the daddy now", or "Be a big little man," or "Your daddy would not want you to make your mommy cry", or "You need to be brave for your mother." The child does not need to be strong, nor do they need to be afraid of making mother cry, and they cannot take the father's place and should never be made to feel like it is expected



**Your loss is not God's punishment or God's attempt to test you. Know that God shares the hurt in your heart and wants to lead you to new hope and peace; know that God grieves with you.**

## A Memorial of Love to the brave children taken by Battens Disease

Mother, please don't mourn for me;  
I'm still here, though you don't see.  
I'm right by your side each night and day  
And within your heart I long to stay.

My body is gone but I'm always near  
I'm everything you feel, see, or hear.  
My spirit is free, but I'll never depart  
As long as you keep me alive in your heart.

I'll never wander out of your sight.  
I'm the brightest star  
on a summer night.  
I'll never be beyond your reach.  
I'm the warm, moist sand when you're at the beach.

I'm the colorful leaves when fall comes around  
And the pure, white snow that blankets the ground.  
I'm the beautiful flower of which you are so fond.  
The clear, cool water in a quiet pond.

I'm the first bright blossom you'll see in the spring;  
The first warm raindrop that April will bring.  
I'm the first ray of light when the sun starts to shine,  
And you'll see that the face in the moon is mine.

When you start thinking there's no one to love you,  
You can talk to me through the Lord above you.  
I'll whisper my answer through the leaves on the trees,  
And you'll feel my presence in the soft summer breeze.

I'm the hot, salty tears that flow when you weep  
And the beautiful dreams that come while you sleep.  
I'm the smile you see on a baby's face.  
Just look for me, Mommy, I'm everywhere!

**The Beauty Of The Moment**

Since I didn't expect to see anything with the day being so gray and rainy, I almost missed seeing the flock of wild turkeys standing in the field. They were beautiful!

I realized that much of life is like that when working through grief. It is so easy to get caught up in the gray and cloudy feelings that the beauty of the moment can be missed. There are ever times when we are reluctant to see the good things around us. I find myself doing that.

I catch myself worrying about how people might react to feelings I want to share, how family and friends respond to me as I seek to heal relationships. By worrying how others will react, I am denying myself the opportunity to get my own needs met. I have to do what I need to do for my growth and healing and let others do the same for themselves.

What began as a journey through grief has had much larger effects. Sometimes I am not sure I would have started my quest if I had known that it would lead me on such a difficult path. But I have grown. I have a better sense of myself and place a higher value on my relationships. Yet working through grief and the changes that come has its own measure of loss. For as some relationships grow, others will dwindle. This is scary, but it is also beautiful. The path to healing often hurts before it brings peace.

So, I spend more time looking for the beauty of the moment. I am not always successful, but I keep plugging away.

Dottie Chilton

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*There will come a day  
When you would have live  
your life  
All the way through.  
Mine long gone.  
And peace will descend then.  
Such a great peace, like a  
breath  
Moving those pines, moving  
Even the stone.  
And then, then I can let go.*

David Ray, *Sam's Book*

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Restoration is promised. That is the first and basic truth to hold onto. It doesn't take away the grief...but it does make it endurable. The truth is that we will be reunited. My mother is in heaven now, and she is with my little brother who died She only lost him for a time, and even though it was a long, sorrowful time, they are together again.

David M. Knight, *Priest and author*

Kathleen Cornelius wrote two moving prayers when her son Chris was very ill. These were the words he would pray if he'd been able:

"Dear God, I pray you will look down on me when I hurt all through my body. Please God have mercy on me and take the pain away. God, I cannot talk or ask for help. My ears are not broken like the rest of my body.

Some day, God, when I die, I won't need anyone's help, for I know I will have a new body. If only others could see that I'm ready to go. I'm only waiting for you to call my name. Amen."

Here is a mother's prayer for her dying son:

"Dear Lord, Please take time to look down on Chris. He has a rare brain disease and needs a helping hand from you. His body is weak and worn; he seems to get worse daily.

But God, only you can make the stars shine. You can open his eyes and let him see the sunshine. Lord; please just give Chris a smile. He has lots of friends and family who love him. Please, Lord. Send a light to guide him home. Thank you. Amen."

Kathleen wrote after Chris's death (9/22/78-9/24/02).

"My son was one of the many who died this year with Juvenile Batten Disease. He was a beautiful child and a handsome young man. Today I thank each person who is a member of the Batten Support Group." "My son is safe now, and never has to suffer anymore. Today I feel him looking down from heaven to say, "I've made it home"."

Memories Are Forever

As I once watched my son's body deteriorate,  
I know as the stars shine on a clear night,  
My sons love lives on.  
He has left this world of pain,  
Now his days are filled to the limit,  
For he is not sick.  
His body no longer lies in his bed,  
Waiting for someone to stop by.  
As I saw my son's body, after the life was gone,  
I felt only peace in my heart and mind.  
My son's journey here is at an end.  
But life begins again as he is needed  
By loved ones who have already made  
Their journey through heaven's gates.  
I can only imagine what it will be like  
To see my son in perfect health again.

Mom, Kathleen Cornelius

Claire McLean writes from Austin, Texas:

“On the bright side: I supplement our income playing piano for five assisted living and care centers. “I’m hoping to receive a scholarship for Music Therapy Certification.

“I recently introduced Batten Disease to a young Optometrist at an eye facility next to the hospital. I also met at a care center a kind elderly lady who recently went blind. I told her about Emily (1977-1994) and Erica (1974-1989).”

“As sunshine hit my face in a certain way, I felt my angels close by. My lovely princess children are near to their mom and brother.”

“James (son with Down’s Syndrome) and I say prayer every night- I review my 12-step program, a book for adults with ADD. Through personal prayer I know that God lives, our children too. At the Second Coming of our Savior Jesus Christ, they will be resurrected, whole and joyful. Someday we will understand it all. Our tears will be lovingly and tenderly wiped away as we embrace our beautiful children again.”

### **Handling the heartbreak of a Child’s Death**

*by Andrea Gambill, (used by permission)*

The phone rang at 6:35 am. “Hello,” Jim said apprehensively. We had been dreading this call for a long time. “I’m sorry,” said the voice on the other end. “She died suddenly at 6:30 this morning.”

Almost mechanically, we got out of bed and tried to think what we should do next the early January morning was bitter cold and dark. What an amazing contrast to the sunny August morning in 1975 that had changed our lives forever.

Our beloved Judy was 17, bright, pretty, and very mature for her age. “Bye, Mom she called as she left in our station wagon. “I love you. See you at 2:00.” Two minutes later, in an intersection close to our home, the car stalled. A huge lumber truck couldn’t stop in time. There was a crash and an explosion. Judy suffered a critical head injury and third degree burns.

For five months I sat with her every day. I rode the roller coaster of hope/no hope, prayed, believed, talked to her. Finally, on the night before she died, I came to terms with what must be. Her temperature was 108; she had pneumonia. No longer could I deny that she would die. I told her again and again how much I loved her, how she would soon be well. I promised her I would be OK and that I wouldn’t be far behind. I just couldn’t imagine lining after she was gone.

The next morning she began a new life and we began a new journey. Yes, though I walk through the valley of the shadow of death...” took on a whole new meaning for me.

### **Working your way through**

*A child is dead!* Our minds reel at the jarring impact. It can’t be true! It’s not fair! The death of a child is a jagged piece in life’s puzzle, a discordant note in its symphony. And for the survivors who were bonded to the child in love, there is soul-gnawing, shrieking pain, pain beyond measure.

Thirteen years have passed since Judy’s death. There is sunlight again, and I’m still here. As I look back, I am completely in awe of what I’ve learned. Judy’s death was tragic, but she would be the first to agree that it would be a greater loss to fail to grow from it and show care for others who are hurting. So I’d like to tell you some of what I’ve learned from sharing with other bereaved parents.

### **Find help; wait for healing.**

When a child dies, usually both a mother and a father are grieving. Because you felt and expressed your love for your child in different ways, and because your roles were different, you will also grieve differently. Neither of you can completely understand the pain of the other, and each of you may even believe your pain is greater.

Many issues are likely to complicate your relationship during grieving: sex, finances, other children in the family, in-laws, plans for the future- the list is endless. Although one parent rarely “blames” the other for the child’s death, each might be envious of certain elements in the other’s relationship with the child, or of the support and attention the other may receive. Suddenly you might find yourselves clumsy at comforting each other. Parents who have lost a child might be compared to two skiers on a mountain, each with a broken leg. No matter how much they care about each other, they can do little to help each other. Each is disabled and consumed with pain. They must simply wait for help or healing, whichever comes first.

Parents who link up with an active, ongoing support system have a major advantage in their healing and in preventing complications in their relationships. This could be an established support group, or it could be a strong support network through your church, extended family, neighborhood, or social group. Talking to or reading about other families who have survived similar circumstances is probably the best “safety net” you can find. Nobody can understand in quite the same way as somebody who’s been through it.

*“The longest life is short... and the shortest life is miraculous.”*

**-Joseph Gallagher, in *National Catholic Reporter***

You may find that some well-meaning people who have not been through it will actually add to your distress by poorly considered remarks: “At least you have your other children.” “I know just how you feel.” You might tactfully suggest to them that you really appreciate their presence more than their wisdom and advice.

**Tend to the needs of siblings.** Grieving children are unfortunately often misunderstood and ignored in the aftermath of death. They need answers, but sometimes they don't know how to ask the questions. They do know, however, that their world is dramatically different; the grown-ups are immensely sad; someone they love is missing. They overhear bits or adult conversation, and when they try to fit the pieces together they often come up with concept that are terrifying or heartbreaking (or, sometimes, funny).

Children need you to tell the truth in as much detail as their age and comprehension can bear. They need you to reassure them about their own security. (They frequently worry that they will die too or that their parent(s) will go away. As much as possible, they need to be included in planning and decision making. They need as much information as they can handle—usually more than adults think.

And, just as a parent may be suffering from agonizing guilt (“After all, “ we reason, “parents are supposed to always protect their children”), children can also suffer from guilt. They live in a magical world where what they wish for often comes true. The present lists to Santa and gifts appear under the tree; TV and movies show people who died last week but are now back on the screen. Consequently, when a child in a fit of anger or jealousy wishes —either aloud or silently—that a sibling would die, that child can easily believe that the wish actually caused the death.

Children can be deeply sad one minute and outside playing the next. Adults may think they have “gotten over” their grief, or they never really understood enough to grieve. Neither is true. Children’s minds (like adults) protect them from what is too powerful for them to handle. Their grieving episodes are shortened because they cannot rationally explore all their thoughts and feeling as adults can. You need to help your children work through their grief in healthy ways.

**Remember that grandparents grieve too.** Grandparents are truly the “forgotten grievers.” Doubly bereaved, the ache for their precious grandchild while suffering because of the pain of their own child. Support, if available at all, is usually riveted on the parents. Usually, this exclusion is not intentional—grandparents are simply overlooked in all the turmoil. Grandparents are rarely consulted regarding decisions about discontinuing life support, or funeral and burial arrangements. Sometimes they have strong feelings; yet they must swallow their pain and keep quiet.

Although grandparents have a special kind of wisdom and comfort to offer, their gift is left unwrapped if they are shut out of the grief process. Support groups specifically for grandparents are beginning to emerge, but they are few and far between. This is an area that definitely needs a brighter spotlight in our society.

**Let relatives and friends help.** The death of a child is a far-reaching tragedy, and its impact on the periphery of the family cannot be overlooked. These relatives and friends stand by on

the sidelines, feeling helpless, unable to contribute directly, but hurt and sad nonetheless.

Often these individuals fear their presence might be an intrusion. They care deeply, but they may turn away at the moment they are most needed. Afraid of saying the wrong thing, they say nothing at all. Typically, these people can offer the most help. Because they are a step removed from the immediate pain, their energy levels and objectivity are keener. If they can fine-tune their sensitivity, they can offer a grieving family valuable help.

They can assist with child care, run errands, go shopping, accompany a parent reluctant to go out alone, or just sit silently as a companion. They can be sensitive to the emotional needs of the family and advocate on their behalf when the parents are too devastated.

**Take heart.** The ultimate determinant in healing the horrendous wound when a child dies is love. Time, by itself, heals nothing. But time plus love fosters healing.

Someday, nurtured by sharing common joys and sorrows, we may take hand to form an eternal circle of caring, and thereby discover our energy renewed and our strength multiplied. Perhaps then, within the power of that community, we will grieve because we loved one who has died, but heal because we dare to love again.

In Closing:

Tears were mixed with joy as I put together stories, poems, and articles for this Winter 2003 Lighthouse. First hand contributions have made this a moving and honest edition.

Let’s keep your personal memories flowing. What was the gift your child gave you? What did you learn? You are helping others when you share your experience.

On a different note, are you in volunteer work or a paid position that utilizes your experience of children with Batten Disease? Let me know; I’d like to interview you.

Finally, I have a new box of books from Green Key, waiting to be sent. “Nothing Can Separate Us” (written by me) tells the story of how a family with three affected children, came through the loss. Mim, Rick, and Cathy, surviving sibs each have a chapter, too. The book is doing amazingly well. You can have your own copy for \$13.50, including postage, made out to BDSRA. Send me your request and I’ll get it right out to you.

Connie Jackson, editor.

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