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# *LIGHTHOUSE*

Winter 2008, Volume 12, Number 1



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Batten Disease Support and Research Association

## FROM THE EDITOR

The holidays of Thanksgiving, Christmas, Winter Solstice, Kwanzaa, Hanukkah, and others with various customs and celebrations are now behind us. The New Year has begun and we are looking ahead to Valentine's Day, Lent, and Easter celebrations, Passover and the beginning of Spring. There will always be birthdays and other special days we want to observe and remember. It might be necessary to create some new traditions and ways to celebrate our lives as we continue on the journey of grief from the death of loved ones.

Although these holidays that are ahead of us are of a different meaning, they will nevertheless require some planning and thought as to ways we want to institute in our lives, and families, meaningful traditions. Let us remember that the New Year and Spring is a time of new beginnings. We will have constant reminders of this in the natural world around us. And, Nature will sleep in grayness and cold awhile longer, just as some of us continue to have periods of crying and sadness as we search for understanding and significance in the grief process. Perhaps for some of you this is the ideal time to begin to take the next step in your individual journey of grieving. Do not be concerned that everyone around is at this step. Try to remember that every person and every life is individual.

I have tried to submit a variety of articles written by persons familiar in counseling and alternative ways that others deal with grief. This is in no way intended to influence or be judgmental of any person's method of handling their own grief. It is simply intended to present ideas for those who are possibly at a crossroad in their life and searching for healing of their own grief and loss.

In this February 2008 issue I have several articles submitted by family members whose children or siblings have died. I want to thank every one who has taken the time to express their feelings and thoughts to share with us through their articles. As you read through this issue I hope that you may want to express yourself in some way—a story remembering your child/children, a poem, or sharing a book or article that has been helpful to you. I welcome anything that you wish to contribute and encourage you to attempt to put your feelings on paper. There is no right or wrong in expressing your emotions/feelings, or sharing something special that you remember about your child/children. Please feel free to send your contribution, (or those of your children or other family members to me. You may send them to Ann Salladin at either my email: [aswildchild@yahoo.com](mailto:aswildchild@yahoo.com) or to my attention for THE LIGHTHOUSE, B.D.S.R.A. office or email: [bdsral@bdsra.org](mailto:bdsral@bdsra.org). Again, if you wish to speak with me please call me, or leave a message, at (614) 755-2986. To submit it directly to me at: 1194

Foxcreek Lane, Reynoldsburg, OH 43068. Please try to submit it to me by mid-April for the May issue.

May the New Year bring you peace, comfort and solace to your aching heart.



Cry. Your tears testify to your love. And tears that spring from love help bring healing and renewal.

#### REFLECTIONS FROM CONNIE

It's an amazing thing how grief for a child who died 39 years ago can suddenly surface. I'm thinking of Christmas morning 2007. The clan was gathered, 13 of us, in the family room. Peach, my 15 year old granddaughter in a Santa hat, was distributing presents. "Here's one for you, Gram", she said, passing me a small package from my daughter Cathy.

I could feel the frame and glass under wrapping paper. "A new photo of my grandkids", I guessed. What was this? My eyes gazed in wonder at a picture of Mary holding her son Jesus, a baby, perhaps three months old. Her shadowed face depicted a mother's love as she tenderly kissed his cheek. He responded with a little smile and sparkling eyes. Mother's hands, drawing him close, spoke of her strong protecting instinct.

Suddenly I was drawn into the scene. I was holding newborn Karen, born Dec. 12, 1968, my first child, a miracle of delicate beauty. The poem, published in the last *LIGHTHOUSE*, described the love and hope and awe I was feeling. Tears flowed, unchecked. I was speechless. Laurel, my new daughter-in-law, looked over at me, eyes brimming. I knew she understood.

Now I am holding in my hand the artist's portrayal of Mary and baby Jesus. Was there a shadow of suffering to come....At the child's

dedication in the temple. Old Simeon had looked directly at Mary when he prophesied: "A sword shall pierce you own soul, too."

That Christmas morning kinship happened between Mary and me. It was the bond of pain and love that only a mother who had lost a child could feel.

*Connie Jackson*

Life after 5-09-07

May 9<sup>th</sup> is the day that we lost our beloved Angel Linda to the Lord. She had Battens, of course, but in the end, sepsis is what she succumbed to. Thinking back, what a blessing that she went the way she did. God knows best, but he must have known how we were all suffering with Linda and no more seizures. The morning of the 9<sup>th</sup> she arrived at the hospital not breathing, but was resuscitated. Within 2 hours the doctors told us what was wrong and she probably wouldn't live through the day. Though all through that awful day the nurses were never able to get a blood pressure or pulse, during the first few hours she lay with her eyes open holding our hands and responding appropriately with a nod or shake of her head. So our last memories of Linda will always be those beautiful blue eyes, so clear and free from seizure activity, looking at us as if knowing she was going to die and wanting to say see you later. What a beautiful thing it was.

So now we go on with our lives, learning to live in a different way as before our lives were always planned around Linda. I miss it still, even though at the time lots of times it was so hard. She was 42 when she passed away, and lived in a long term care facility for 6 years. That was a daily challenge, as well, as she was there because we were no longer able to care for her, but wanted to be as much a part of her life as possible.

Most of my support during this grieving process has come from reading many books, both religious and inspirational; maybe one of the ones I enjoyed the most was "Chicken Soup for the Grieving Soul". I went to a few grief support group meetings but found them not to be as helpful as I had hoped so found my own ways. Joe, my husband found his most helpful thing was WORK. He has always been what I call a work-a-holic, so that's how he dealt with losing Linda... On what would have been her 43<sup>rd</sup> birthday, we all gathered at her gravesite, sang Happy Birthday and released purple balloons, her favorite color. At Christmas we changed things around a bit by going to a different mass than we usually did. We have a 21 month old grandson, and he was a wonderful help by just being himself. What a great thing it is to see little children's eyes light up during this most special time. We also have a 18 year old grandson and a 14 year old granddaughter, AND a new grandchild expected in July. So these all made the Holiday Season a little bit easier to get through. We decorated her headstone and gravesite as well, and I made ornaments to give to all of our relatives and friends [2]. I also made the Christmas cards we sent out. We

received many special cards from friends and family, but one especially was sent by the 9<sup>th</sup> grade CCD class at our Church.[1] Now it's 2008, a new year and new challenges, but we will deal with them as they come.

I hope this has helped someone deal with their grief, and I would be more than happy to talk to anyone who would like to share their stories of their loved ones. Oh, what heartache it is to endure, but I wouldn't change anything if it meant I wouldn't have had all of the happy times that we did have with Linda through the years. She will be forever missed and in our Hearts.

Mom, Sue Sivulka  
262-835-1364  
soo43@msn.com



Stay connected to others. You need their presence, their support, their concern, their listening, their hugs.

*In Memory of My Precious Son, Michael*

*Each year as I anxiously approach the anniversary of my son's death I desperately hope to honor his memory in a special way. On January 11<sup>th</sup> it will be 11 years since his death. As the day approached this year, two significant things happened that allowed me to do just that, honor his memory...*

*On Monday of this week I was presented with my "10 Year Pin" in recognition of the years that I have served the very population that my son was once a part of, and it was even presented to me in the very building where he attended school for many years. What perfect timing. And the second was to submit my story. The last thing any of us want is for our child life to be forgotten. They were here, they were and still are loved, and their lives did and continue to have purpose!*

*So today I have the privilege of continuing to live out the legacy of my son and many others before him. They fought the good fight. Michael was my teacher and my hero! He taught me the true value of life, that it is a gift from God, and is to be lived with purpose and appreciation. We are to honor our Creator with this gift of life. We know too well that there are no guarantees and that we must not take the precious lives of our children for granted. They are a blessing, a very different kind of blessing.*

*I consider it a privilege to do the work that I do working with children with special needs. Each day is a new challenge and a new opportunity to be a part of building up these children and assisting them in reaching their highest potential. It is also very important to me to reach out to parents with respect and empathy, for I was once there. I have felt the frustrations and fears that they have felt day to day. I feel I am more able to connect to the hearts of the families because of my own struggles. I know they want so much for their children, but must continually accept that they are limited. I am forever thankful for those who came along side of me to guide me through. I hope I can pass this along in my work. This is one of many gifts from Michael, the gift of empathy.*

*On June 22<sup>nd</sup> 1976 I gave birth to my beautiful son, what a joy! And what a blessing! It's difficult for me to imagine that Michael could be 32 years old. Sometimes I imagine his peaceful presence and I am comforted. Some days I miss him so much I can hardly stand the pain of knowing he was here with me and then he died. There will always remain a void in my life, but I know I will see him again, and until then I hope to continue to honor his life and give thanks to God for the precious gift of "him".*

*His life was complete; his purpose is being lived out and continues to be through me and those who loved him.*

*I no longer hold him in my arms but he is safe and free in the loving arms of his Creator...*

*I Love you Michael, forever unto eternity*

The above was submitted by Lita Ciacciao. I am so grateful to her for sharing her thoughts and memories with us.

As you read **TODAY'S INSPIRATIONAL STORY** from Beliefnet.com you will find things that have both helped and not-helped a grief counselor at the death of her own child. Perhaps you might be able to relate to this and they could become suggestions that you might ask of your friends and family at the appropriate time in your journey.



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.

### **GRIEF COMES TO THE GRIEF COUNSELOR**

A pediatric chaplain receives helpful tips on grieving the death of a child. By Norris Burkes

It's a terrifying and morbid thought, but in my line of work it's sometimes impossible to keep it at bay: I've wondered what I might do if one of my children were killed. I've wondered if I could somehow miraculously remain a minister and comfort those who were also grieving horrific losses? I'm grateful I haven't had to endure that experience but I still wonder.

I'm sure my friend Sue Wintz wondered too. Like most of us who serve as pediatric chaplains, Sue has long known the meaning of the scriptural admonition foretelling the "rain on the just and on the unjust" (Matthew 5:45 NKJV), but somehow she'd always managed to carry a good umbrella.

Then, on December 2, 2003, Sue's seventeen-year-old daughter, Sarah, was killed in a car accident. As they struggled to survive this unimaginable blow, Sue talked to me about the ways she and her minister husband, Mike, have learned to better align their professional roles with the lessons they've learned from losing a child.

In the days and weeks after the accident, Sue said, "We didn't sleep or eat; we felt like we were in a fog. I had absolutely no idea how deep and dark the hole of parental grief would be."

Yet, despite the fog, the Wintz family knew, from her professional perspective, that their "feelings were normal and OK," she said.

But the heartbreaking ordeal also demonstrated to her that some professionals “just don’t get it sometimes.” In fact, a day after the accident, one colleague told her, “You aren’t reacting very professionally.”

Some even told the Wintzes their grief should be “over” in a matter of months, and soon those acquaintances stopped mentioning Sarah by name. Unbelievably, one colleague even told Sue, “The honeymoon year” is over, so you should move on.” Sue described these people as “toxic” and noted that grieving parents become very adept at recognizing the ones who are helpful “and the ones who should be avoided.”

Gradually Sue has regained some of her former confidence. “I was a good chaplain before my daughter’s death,” she said, “but through our experience I’ve learned some things that did and didn’t help.”

Twenty-five days after Sarah’s death, Sue listed those things in her journal. And now, she’s asked me to share part of that list with you.

**HELPED:** People who checked on us without an agenda and took care of details like answering our phone, keeping lists of what people brought, cleaning our house, and making sure our cars were running well.

**DIDN’T HELP:** Trying to micromanage aspects of our grief by telling me when I needed to eat and rest or take anxiety medications.

**HELPED:** Food brought every other day, beginning the second week of the accident.

**DIDN’T HELP:** So much food brought all at once.

**HELPED:** People telling me, “My child died too. I’m here for you.”

**DIDN’T HELP:** People claiming to know how I feel because their father/friend/dog died.

**HELPED:** The hundreds of people who came to the service and our amazing son, who put together the slide show of Sarah’s life.

**DIDN’T HELP:** Giving me advice on when I needed-or didn’t need-to go through Sarah’s room and things.

**HELPED:** Carolers and Secret Santa gifts. Sara loved Christmas.

**DIDN’T HELP:** Telling me I needed to realize there are also “others having a bad time in their lives right now.”

**HELPED:** The people who listened and never told us to stop crying.

**DIDN’T HELP:** Questions asking us who was at fault in the accident.

**HELPED:** Taking me out to lunch and back into the world.

**DIDN'T HELP:** Asking when we're going to get our "lives and work back to normal."

**HELPED:** All the wonderful donations to the memorial scholarship fund, the live plants reminding us of Sarah, and the flowers brought to the site of the accident.

I find it nothing short of miraculous that Sue remains in her job as a pediatric hospital chaplain. She says she finds in that work a gift for sharing with those who have endured similar losses.

She also says she finds a lasting lesson in Thomas Attig's writing about grief and how relationships with loved ones change after their death. Sue adds, "The truth is, it doesn't end; the relationship is miraculously transformed. I knew that concept before Sarah's death, but now it really hits home."

### **A MESSAGE FROM THE EDITOR FOR SIBS**

I am including several pieces of writing from a book by John Bramblett, *WHEN GOOD-BYE IS FOREVER: LEARNING TO LIVE AGAIN AFTER THE LOSS OF A CHILD, Chapter 7 Brothers and Sisters*. Mr. Bramblett has included pieces written by his other children after they experienced the loss of their little brother. I would encourage you to read these excerpts and hope that you might try your hand at expressing your own grief. Sara Thompson would welcome any thing that you might wish to share with others. She would send them to me to include in future issues of *THE LIGHTHOUSE* in this section for the SIBS. Sara, who is the SIBS Leader, can be reached at [sarathompson@hotmail.com](mailto:sarathompson@hotmail.com). Or you can send them directly to me in care of the BDSRA office, marked for THE LIGHTHOUSE.

I, too, had several other children. Now I realize, looking back over 30 years, that I do not believe that my other children were given adequate time or opportunity to express how they felt. I was too overwhelmed with my own grief, and they became the "silent mourners". I deeply regret this now that I realize the importance of what happened, in overlooking my other children's feelings at the time of the deaths of their brother and sister from Batten Disease. Therefore I encourage you to either contact Sara with your expressions, or ask a parent, grandparent or sibling to help you. (Sometimes we need help in actually writing our thoughts down and would like someone else to do it, or maybe we just need a little encouragement to express what we would like to get out.) It could be a poem or just thoughts about how you felt when your sibling died, similar to these thoughts from Mr. Bramblett's children.

## **MY FEELINGS ABOUT CHRISTOPHER'S DEATH**

**MEGHAN BRAMBLETT AGE 8 7/9/88**

**Megan was only 5 and in Kindergarten when her little brother died.**

### **FACING THE FACTS**

“Me and my parents stood there hugging until we looked like a sandwich. Then my brothers came home with red eyes. Brian, John, Mom, and me lied down on the couch as my Dad bravely called relatives and said “Hello...this is John...there's been a tragedy.” Then he would burst into tears. With faith we all prayed that the phone would ring because our grandparents were not home. Suddenly it rang...my Dad let it ring about five times and then breathlessly picked it up.”

### **MEMORIES**

**In the months just before her tenth birthday, Meghan wrote down some additional thoughts about her brother's death.**

About a month after Christopher's death I started wondering why God took him away. Every time I prayed at night, I asked God “When are you going to bring Chris back?”

Well, soon I found the answer to that question, and I didn't like it. I felt lonely and every time anyone said “Do you miss your brother?” I just stood and cried.

Things have changed a lot since I was in kindergarten. Now if someone asks that I just say “Yes, but I'll be with him someday.” I used to hope that I was just having a bad dream. The one thing I am glad about is I'll be with him soon.”

### **JOHN'S THOUGHTS**

**John was 15 1/5 when his little brother Christopher died.**

“Sitting in my dorm room in the spring of my sophomore year in college I am reflecting back on another very different sophomore spring. I will always view my sophomore year in high school as a turning point in my life. For the first time I had truly fallen in love and subsequently, as first loves often turn out, I was left brokenhearted. Although at the time I thought that I had suffered the loneliest and coldest moment that life could present me, I would be quickly and abruptly exposed to hard reality. Fortunately, my lost love's enduring friendship and support turned

out to be one of my greatest assets during the time I was struggling with Christopher's death.

My first recollection of the things that happened on the day of the accident was waking after two or three uses of the snooze bar on my faithful radio/alarm clock. Christopher's bedroom was located directly across the hall from mine and in the morning I would habitually pop my head in his doorway to catch a glimpse of his small figure. I don't know why I did it-maybe it was just because I needed to see an image of peace and innocence that was so far removed from the world that we all subject ourselves to every day when we make the decision to get out of our beds

----a voice penetrated the silence of a midclass dictation asking me to the office.---my brother Brian was also headed for the office. It was at that moment when I realized that something was seriously wrong.

---my brother and I were greeted with numerous painfully blank stares. We were quickly shuffled into the office of the vice principal----a conglomeration of the school's top officials and a state police officer. The classic line "You'd better sit down" was delivered, and my feeling that something was gravely wrong was reaffirmed.

"Boys, there's been a terrible accident...your brother has been killed." When those words were uttered, I felt my soul, as if it were an invisible inner suit of clothing, fall from my body and rest draped around my feet. Then there was a stillness that encompassed the room as my body was engulfed in a bizarre numbness.-----"Boys, your parents need you. I'll take you home" uttered the state trooper.

The next emotion that I remember feeling was sympathy...when I saw my parents (my father who I had never seen cry) oblivious to anything other than my brother's and my arrival and their own intense pain.

Soon after our arrival the house was a teeming mass of faces.....All I wanted was to be alone, so I fled to the seclusion of my room. While there I was visited once again by the state policeman, who had been the officer on the scene as well as my escort from school. He told me to think about whether or not I wanted and felt that I needed to view Christopher's body at the funeral home.

-----I eventually decided that it was important-if not a necessity-for me to go and see him. (I'm not suggesting that this is the best choice for all situations but that it was for me.)

It was at the moment that I walked into the funeral parlor and saw...a tiny white casket that held the broken body of my brother, that the reality of what had happened finally struck me for the first time. For that reason, if no other, I am glad that I did what I did-that I made the decision to Christopher for one last time.

The next phase was that which concerned the funeral and burial. My parents decided that Christopher should be buried in a family plot in Ohio. When I was told of this intention, I became irate. I

was upset that I had not even been “consulted” as to what my opinion or feelings on the matter were.-----This was one of the major “anger points” with which I had to deal.

I eventually came to peace with the issue by realizing that Christopher was not the tiny, blond-haired, blue-eyed frame of a child that we were burying in a distant piece of ground. He was instead, the joy, love, and memories, and a part of each and every person he had come in contact with during his short life. He was a special place in the hearts of those who had experienced his time with us—a special place that would always be with me no matter how far away he might be buried.

I had a difficult time writing this. Why? I’m not sure. I do know that through this experience I questioned my faith and through that questioning, I learned what it truly meant to me on a personal basis. Hopefully my relating these reactions will help someone who is dealing with or has been forced to deal with a similar situation.” A poem, one of three that John wrote just a little over 2 weeks after Christopher’s death follows:

### ***MEMORIES***

*Sometime in the future when I am old and gray  
I'll look back in time to when I was young and gay.  
I'll see you there, your white hair blowing  
And ask myself why you were so quick in going.*

*The love we shared has endured the test of time  
If I had a choice, it would have been your life for mine.  
I sit in my room and think of us as we were  
But then fantasy, sweet fantasy.....  
....fades and I am again without you.*

### **BRIAN’S THOUGHTS**

**Brian was 13 when his younger brother, Christopher, died.**

“My brother was puzzled as to why we were both being asked to the office.----Thoughts shot through my mind until the state trooper told us what happened. My mind was in a total blur. Nothing he said made any sense to me.

“----your parents and sister need you at home”, and took us out of the school to his car.-----My thoughts were too scrambled to feel sorrow. Not only was I confused and angry at the world, but most of all I was lonely.

When we finally got home, my parents came out the door in hysterics. It was at this point I thought to myself maybe this was really happening.---I needed some time to sit and sort things out so I went over to the living room couch and sat down.

I watched all our neighbors and friends trying their best to help us. That was the one good thing I could see.

I began to go into my own little world and think. I began to ask myself questions about Christopher’s death. Was he happy? Was he in heaven yet? Would I ever see him again? Why him? As I























