

Grandparents

REFLECTIONS FROM A GRANDMOTHER...

By Kathy Cassista

Kathy Cassista is a member of the PSG who lives in Wapske, New Brunswick, located in the eastern part of Canada. Kathy's grandson, Michael, died of Tay-Sachs shortly before his third birthday on February 12, 2001. She was very glad to join the grandparents group and wanted to share her thoughts and feelings about her relationship with Michael and Michael's mother, Tanya Fournier. Kathy sent us a beautiful letter about Michael's life. Unfortunately, we cannot print it all here due to space limitations but we have taken excerpts to share with you.

On March 15, 1998, my beautiful, fourth grandson was born. It was a very happy day for all of us. I couldn't wait for him to get home so I could visit every day. When I wasn't working, I spent a lot of time helping my daughter, Tanya, with the kids, Michael and his older brother, Corey. Although Michael's life was very short, this little boy was truly loved. We have a very close family. We talk to each other every day and we spoil the grandchildren like crazy. They are all we have and we love them very much.



Speaking as a mother – always be there for your child. I witnessed pain in my daughter's face that I never dreamt could be possible. I was determined not to let her go through this alone, and to be by her side to the end. When the doctor told us that Michael had Tay-Sachs, we found out that we could have up to five years with him and we needed to make every day count. So from that day on, my goal was to put a smile on Tanya's face and help her to make the best of every day.

The most important thing is to be there for SUPPORT. Let your children know you are there to help them. You will never take the pain

away completely but you can help by relieving some stress. Try to attend doctor's appointments and every hospital stay. Take them shopping or do errands with them. Visit at least once a day, and offer to babysit. Play with the kids, help with the housework, or just keep things quiet so the parents can catch up on some sleep.

Gather as much information as you can, so you can be aware of certain symptoms. This will help your child since the responsibility for your grandchild's care is not all on their shoulders. Make your grandchild as comfortable as possible by learning how to care for him. For example, I always read *Lifeline* so I asked my daughter if I could open it when it came in the mail. Inside was a picture of a grandfather with his grandson. He purchased a small recliner chair for him. The little boy looked so comfortable that I told my husband, Terry, that we had to get one for Michael. Thanks to a picture in *Lifeline*, Michael sat very comfortably in his recliner with his Disney blanket.



Sometimes you have to put your worries aside. When Christmas rolled around, I wasn't sure if my daughter wanted to celebrate or just let it slide.

When Tanya told me that the Children's Wish Foundation had granted her family a trip to Disney World, I was so happy for them, but so sad for me. I couldn't believe I wouldn't be with Michael on his third Christmas. How was I going to get through that? I was going crazy knowing that he would be so far away from me. What if something happened and he had to go to the hospital and I couldn't be there? Then I decided I had to put my feelings aside and think of how happy this trip made Tanya. I realized that getting away was exactly what her family needed – time alone with Michael. Even though I still had the holidays to go through, that week went by very slowly waiting for him to come home!

Speaking as a grandmother – you must always make your grandchildren feel they are loved and wanted. Try and take as many pictures and videos as possible. Be there to capture every precious moment that you can. You can plan ahead, but you can never go back. This comes from the heart because sometimes I feel like I could have done more.

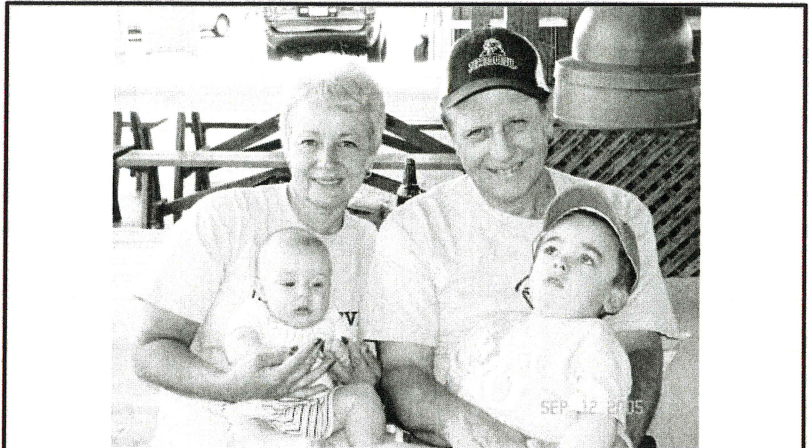
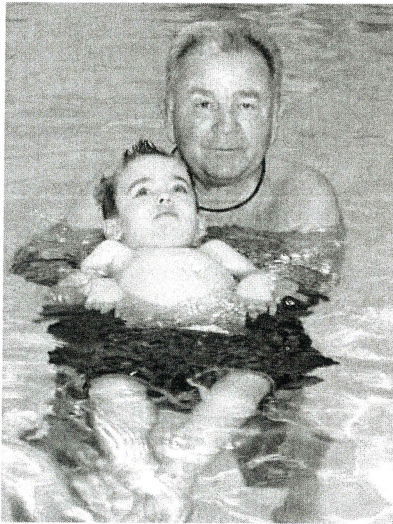
I know better than any one that there is nothing anyone can say or do to make the pain go away, but I do know there are lots of things that can be done to help keep the memories alive. When I found out my grandson had this deadly disease, I started a journal. I recorded everything and I

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Swimming with Grandpop

Every Wednesday DJ and I go for a swim at a local fitness club in Pennsylvania with his physical therapist, Shelly Case. It is the highlight of my week! Even though DJ cannot see, I can see in his beautiful blue eyes the pleasure and delight that he is experiencing. He truly loves to be in the water, which I tell him is his "big tubby." DJ is our very special boy. He has touched more hearts in his young life than any of us could equal in ten lifetimes! The way everyone gravitates to him is unbelievable. DJ is our Angel Baby. There is joy, and much sadness, and also abundant pride. DJ is my "Buddy Boy". He has shown me courage, desire, and will, which has made me "Just Believe".

– Pete
Hayes,
Dylan "DJ"
Manning's
Grandpop



Dylan Manning with baby brother Brady, and his Grandparents

Dylan's Nanny & Pappy enjoy spending every precious moment with Dylan and his little brother, Brady. He is a blessing from above and they treasure every day they get to spend with him! Dylan especially loves putting his Pappy to sleep while he sits on his lap, he has a magic touch for that! He loves the theme song from "Bonanza" and his special overnight sleepovers!

WE LOVE YOU VERY MUCH, DYLAN!
– Nanny and Pappy Godwin

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am really glad that I did. It has been four years now since he passed away and it still seems like yesterday that I was holding him. I think of him and say his name at least once a day. I have his pictures all around my house, and even in my car. Everywhere I go and see his name on something, I have to buy it. I make regular visits to his grave and I take something special there for him on every occasion. I place beautiful decorations around his headstone in the summer and at Christmas. I also buy a special ornament every Christmas for him.

In closing, I would like to say my heart goes out to everyone who is dealing with this as we speak. Remember you don't have to go through this alone. If you just want to talk, feel free to phone me any time at (506) 356 7250 or email me at ktmike@hotmail.com.

Calling all Men...

CONTRIBUTE TO LIFELINE!

For the cover of the Spring Issue, we are collecting photos of dads and husbands with their family members. We want to hear the male point-of-view from you! Send us your thoughts on how the diagnosis has impacted your job, your view of work, relationships, and your outlook on life. We would appreciate any advice you have to offer fellow members.

All photos and articles intended for *Lifeline* can be sent to:

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by email to

lifeline@djhomepage.com

or to : 2722 Payne Street
Evanston, Illinois 60201 USA

The deadline for the next issue is:
February 24, 2005.