

Hannah Stephenson

NTSAD-Gottlieb Sibling Scholarship Essay

22 September 2011

Having a sibling with Tay-Sachs impacted my life in the most dramatic way imaginable. Every prospective older sibling looks forward to teaching a new brother or sister everything he or she knows. However, for those of us with siblings who are affected by Tay-Sachs, Sandhoff, Canavan, or any of the other allied diseases, our dreams of becoming the best older sibling are shattered all too soon. It's a drastic shock to adjust to when being the best sibling means exchanging baseball gloves and Barbie dolls for suction machines and feeding tubes.

Just keeping Molly alive required constant vigilance. Immediately after coming home from school, I was placed on "Molly duty." I began her vest and breathing treatments, followed by drawing up her exact dosage of three to four different seizure medications, and then fed her through the G-tube – a constant reminder of one of the many things that my little sister couldn't do. Though my daily routine was chaotic and did consume most of my time, I was happy to spend all the time I had with Molly Grace. I knew that we didn't have many days left with her, so I took every one as a golden opportunity to let Molly know how much I loved her. Although she couldn't express it, I knew that she loved me, too. Having to give up my teenage freedom to become a responsible big sister was not something that I was prepared for, but I wouldn't trade one second I had with Molly Grace for the world. When Molly was here, my family was constantly being consumed by the everyday tasks that were required to keep her alive. It was emotionally, mentally, and physically exhausting. Even though every spare minute we had was spent taking care of Molly, I know that we would all give our new-found freedom back in a heartbeat if we could just spend one more day with her.

Many people look at children with disabilities and feel sympathy for their families. They question how hard it must be to deal with those complications every single day. What those people don't know is that we actually feel sympathy for *them*. They will never know the absolute joy that comes along with taking care of these kids. They don't understand what a blessing and honor it is to have the privilege of getting to be a part of their lives. I watched Molly Grace inspire families all over the world. It's amazing how someone who never spoke a word can touch so many people. I feel so blessed to have gotten to be such a huge part of Molly's life, as she was a crucial part of mine.

While having a sibling with Tay-Sachs was undoubtedly the most heartbreaking experience I have ever endured, it was also the most rewarding. In six short years I learned more about life than most people ever will. Learning to live every second like it's my last taught me how to appreciate life as a whole. I learned to never take life or the things that I can do for granted. Most importantly, I learned that if I dwell on what brings me down, it will only destroy me in the end. I have to keep looking for the light at the end of the tunnel so that I can climb my way out of the depths and become the person that I am meant to be.

To say that Molly Grace was the center of my world would be an understatement. I cannot begin to express how much I admire her for teaching me the most important lessons in life and giving me a reason to smile whenever things got rough. Molly gave my family something that we never would have had without her – the strength to persevere through any storm. For this reason, I will forever be thankful for the experiences I shared with my little sister. Although Molly has been gone for a year and half, her memory still continues to provide a salient presence that follows me everywhere I go and I know, in that way at least, she will always be with me.