

When my sister Brooke was diagnosed with Tay-Sachs Disease, I had no idea that my life would never be the same. At six years old, I understood that my sister was sick, but couldn't fathom at such a young age how Tay-Sachs was going to influence my life. Being in kindergarten with two other younger brothers on my dad's side of the family, I didn't understand why my sister couldn't crawl or sit upright. Over time, as I witnessed Brooke regress physically, I began to realize the full extent of my baby sister's condition. Eventually she was placed in a full skilled nursing facility called Broward Children's Center. Some of my most vivid memories from first and second grade were visiting Brooke and reading and playing with her. I remember my mom's words the first time that she took me to visit Brooke:

"Don't be scared...you're going to see kids with three heads and four eyes. It's going to be ok." My mom was trying to prepare me for what no child should have to witness. Until this point, the only sick child that I had ever seen was Brooke, and her symptoms were still relatively mild. I honestly believed that I was about to see someone with three heads and four eyes. Luckily, my mom was only trying to mentally prepare me, and I was able to visit my sister that day. I continued to visit her at least once a week until she passed away on December 24, 1998.

At Brooke's funeral, I remember promising to my mom through tears in my snug blue blazer that I was going to cure Tay-Sachs Disease. It was an ambitious statement for an overemotional seven year old.

Today, as I sit in my dorm room typing this essay after spending several hours doing chemistry practice problems, I am no closer to curing Tay-Sachs Disease than I was at Brooke's funeral – but I am on the right path. I am now a freshman pre-med Biology & Psychology double major at the University of North Carolina at Chapel Hill. After volunteering at the annual National Tay Sachs & Allied Diseases Conferences the past three years, my professional goals remains the same—to cure Tay-Sachs Disease and to become a doctor helping families in need.

Three years ago, I began my work with NTSAD by volunteering for the Youth Retreat. I helped chaperone events such as karaoke, dodge ball, and the ice cream social on hotel-grounds as well as go with the kids on field trips to engaging places such as the Boston Science Museum, Tampa Zoo, Lucky Strikes Bowling Alley, and Tampa Aquarium. I had a great time working with the Youth Retreat and was able to provide guidance for several kids going through tough times with a sick brother or sister. Even throughout the year, I still communicate with several of my group members. For my work with NTSAD, I was recently honored by the Sun Sentinel Newspaper with Honorable Mention in the Silver Knight Awards for community service.

In addition to having a great time working with the kids, attending the annual conferences has reaffirmed my goals in medicine as well as with Tay-Sachs. Seeing Tay-Sachs babies, the

families struggling with the pain caused by Tay-Sachs, and adults afflicted with Late Onset Tay-Sachs Disease has been very impactful.

At the last conference in Boston, I spent an hour in the affected childcare room holding William Marquardt. It was a magical hour—he didn't cry the entire time that I was holding him. When I left William, I felt on top of the world. I knew at that moment that this was what I was meant to do and that I would become a compassionate doctor.

I still have several years to go, but I will do everything possible to continue on this path and to fulfill my goals, as well as stay active within the NTSAD community. If my schedule permits this spring, I will be at the conference in April working with the Youth Retreat and spending time with my friends in this wonderful organization. For at least an hour when I have a free moment, I will be holding a baby in the affected childcare room, thinking about my baby sister. I love you Brooke.