

Samie DuVall

NTSAD- Gottlieb Scholarship Essay

29 September 2012

### Unforgettable Smile

Having a little brother with Tay-Sachs disease impacted my life in the most beautiful way. The day I found out I was going to be a big sister was one of the best days of my life. As a 3 year old, I was determined to be the best big sister ever. I couldn't wait for the day when Nicki could run and jump with me. I was excited to play catch and ride bikes together. When I was told that my new baby brother would never be able to run or dance with me, I was devastated. I soon learned that there was more to being a good big sister than riding bikes and playing catch.

Being a good big sister means you help your sibling with the things they can't do and are there for them when things get rough. For some it may mean tying their shoes or helping with math homework but for me it meant feeding him through his g-tube and holding his hand through seizures. It wasn't glamorous but it was how we spent our time together and I wouldn't change it for anything.

As a four year old, I learned how special Nicki was and how lucky I was to have a brother like him. Some may wonder how I can consider myself lucky having a brother that wouldn't live past four, but I know that growing up with Nicki in my life made me the person I am today. He never spoke a word to me but I learned

more than one can imagine from him in three short years. He taught me that life is short, and you have to enjoy it one day at a time. You can't take anything for granted. I learned that we need to cherish the little things. It's the little things that get you through the day. It was the big smile he got on his face when I danced around him, or the way he giggled at the sound of the potato chip bag. It was little moments like those that I cherished the most. Nicki taught me that life isn't always going to be fun and it isn't fair, but you have to take what you're given and enjoy it while it is here.

I was so young when Nicki was alive so I don't remember a lot of little details. It's hard to distinguish between actual memories and things that people have told me about having him around. There is one memory that I do remember vividly. One morning I was lying in his hospital bed with him, holding his hand, and whispering in his ear. I told him that he didn't need to be afraid of dying. I told him that Jesus would take care of him and that when he got to heaven, he wouldn't be sick anymore. He could run and play just like me. I have hope that that is exactly what happened. Jesus did take care of him because the moment he passed, he had a huge smile on his face even though he had not smiled in a long time.

Even after Nicki has passed away, going to the NTSAD conference is still the highlight of my year. The time I spend with those special children and their families, are the times I love the most. Whenever I get to go to the NTSAD conference I always volunteer in the "affected childcare" room to take care of the children. Being with those children, melts my heart. In a way, it feels like we're all part of a family.

Because of Nicki and my experience with Tay-Sachs disease, I decided to go to Morningside College to study nursing. After my four years of nursing school, I hope to continue my education and become a pediatric neurologist, for obvious reasons. I believe I have the heart to love all the special children in this world. They say, "If you love what you do, you will never work a day in your life." I love these children and really have a passion for helping them. I hope to touch the lives of children affected by neurological diseases and their families as much as they have touched my life.