

Looking into the eyes of my parents, lit up by the red *Yarzeit* candle in the middle of the table, I can understand the constant struggle they have endured for the past two decades. The pain is especially present tonight-the 25th of October, which is always remembered as the day their sick little girl died in my mother's arms. I know that every day the void in their hearts aches where their baby daughter once resided.

My sister Mollie was four years old when she died of Tay-Sachs. I was only an infant, and even though I cannot recall life with my sister, her memory and story have stayed with me. I grew up in a very loving household of two parents and two brothers, so someone was always there to look out for me. I always took advantage of the fact that I was their only daughter, and I got away with more than I probably should have because of it. My parents saw me as a survivor. I did not know it when I was young, only that I was proud of my extra scoop of ice cream or new dress. I was their second chance to have a daughter, and I cannot imagine how scary that must have been for them. I grew up with my mother always telling me how she knew I was going to be a girl before I was born, and that she knew I had at least one of the Tay-Sachs genes. The doctors figured out that I would only be a carrier of the disease and I was born, almost exactly three years after my sister.

Pictures of my family are scattered all through my house, divided into unspoken categories we all know of as "before", "during", or "after Mollie." I clearly remember that when I was a little girl I would look at a particular picture in our living room of my parents. In the picture, my mom is sitting cross-legged on the floor, and my dad is kneeling behind her with his head almost on top of hers. The photo was taken in the months following my sister's death, and at a glance appears to be a normal family picture. However, my mom used to take the picture down from the shelf and say to me, "Look at our eyes: we were trying to smile for the picture, but you can see how sad we really were. Especially your father, he took it harder than anyone." To her credit, she made an effort to look happy, but for both of them, the picture helped keep the loss of my sister always present in their lives.

When two parents who are both carriers of the Tay-Sachs genes have children, the chances that their baby will have the Tay-Sachs disease is one in four. With two brothers, my sister, and myself, this is exactly what happened in my family. I have great respect for my mom who, making the best out of a tragic situation, served as President of the National Tay-Sachs & Allied Diseases Association to raise awareness and to fight against Tay-Sachs for two years while raising three children. It was amazing to accompany her to the conferences and see the support that everyone received from fellow members.

Mollie's brief, but cherished life, serves as a reminder for my whole family that we need to spread awareness of this terrible disease. I know that the Tay-Sachs disease will always be with me and will affect life-changing decisions that I will make. I know that my family's experience has given us a unique perspective on life, and that we will do the most we can not to take a second of it for granted.