

My mother has a picture of me playing hockey when I was seven. Underneath it resides the following quote “You can’t be brave if you’ve only had wonderful things happen to you.”

When I was seven I was diagnosed with Chiari Malformation, a condition caused by a portion of the brain--the cerebellar tonsils--extending beyond the base of the skull and into the spinal column. The end portion of my young brain descended twenty millimeters into my spinal cord, which compressed the brainstem and nearly caused a stoppage of spinal fluid to the brain. Only through decompression surgery would we be able to relieve this pressure and reopen passageways.

After a painful recovery from my surgery, I went shopping with my mom at the Paper Store. While walking around the store, I picked up a book. It had a bright blue cover with a picture of a snowman on it. My mom saw me reading the book and said she would buy it for me. As I walked towards the register I told her that the kids in the hospital would really like this book. Without another word, my mom bought every single book at every single Paper Store within the Greater Boston area and Share with Shane was born. For the past ten years, Share with Shane has provided gifts to countless young patients at Boston Children’s Hospital during the holiday season and it has allowed me to give back to the hospital that has given me so much more. My goal every year with Share with Shane is to bring a smile to the face of each patient that gets a gift. I know that it is not easy for them to smile during such a terrible period in their young lives. But if a stuffed animal or a toy truck can make them smile for even a minute, my goal is achieved. For me, that is what Share with Shane is all about: helping people through traumatic times by comforting them and putting smiles on their faces.

When I think back, I still remember my parents sitting me down to tell me I was going to need to have surgery. They explained to me a little about the surgery, talking about my head and neck, not really mentioning my brain. They were honest, saying it would be painful, but they would take care of me. Painful it was. Having to go through an experience as intense as brain surgery taught me that I could conquer anything. Marcus Luttrell, a Navy Seal and the author of *New York Times* Bestseller *Lone Survivor*, once said “No matter how much it hurts, how dark it gets, or how far you fall. You are never out of the fight.” I have fallen far and felt intolerable pain but I now use this experience to fuel the fire inside of me. I preserved through the pain, the complications, four years of physical and occupational therapy. I was able to play at recess again and eventually hockey and baseball. I compensated for the things the Chiari took from me and I made adjustments accordingly with school and sports. I am at the top of my life journey succeeding and competing. But, I still know that every time I take another step forward I am blessed to have that opportunity.

Chiari Malformation does not define me. However, my journey with Chiari has most definitely shaped the person I have become in a positive way. Bobby Jones was known, despite his illness, to always carry himself with character and perseverance both on and off the golf course. I take pride carrying myself with these traits. Therefore, being a recipient of the Bobby Jones Open Scholarship is a great honor and I appreciate the generous support towards my academics. My family and I are thankful for the mission of the American Syringomyelia &

Chiari Alliance Project in research, education, and support. Families and patients rely on this support as they continue to fight their battles against Chiari Malformation and Syringomyelia.