

As I stand in a University of Pennsylvania Hospital observation room in the Genetics Department, listening intently to a patient's descriptions of frustratingly unexplainable symptoms, I cannot help but think about how much has changed since my brother went through this same process. 23 years ago, when my parents were iterating the slew of concerning traits displayed by their son, Jake, to apathetic physicians, they were given the same answer over and over: "He has CP [cerebral palsy]." These doctors ordered the bare minimum of testing, feeling sure of their diagnosis and eager to move on to the next patient. My parents were left to fend for themselves and find their own answers, knowing that Jake's symptoms were indicative of more than just CP. Bringing myself back to the patient in front of me, I am both relieved and motivated: relieved that there are doctors that genuinely care for their patients, and motivated to bring the highest quality of care to families that are desperately grasping at answers, like my own was over two decades ago.

After well over a year of painstaking research and countless appointments, my parents finally got the diagnosis that paradoxically offered them the news they had been looking for but never wanted to hear: my brother had GM1 gangliosidosis. An especially callous geneticist explained the prognosis by abruptly saying, "Your son will be blind in a year and dead in two." Despite knowing the risks of having another GM1-affected child, my parents bravely decided to have two more children. I was born three years after Jake, unaware that my life would be inextricably bound to one of the rarest known diseases.

Growing up, I knew that my brother was different. The feeding tube, breathing equipment, physical therapy, and vigilant, unyielding care were only a few of the clues that told me Jake was sick. I quickly became familiar with the sound of ambulances, advanced medical tools, and hospitals. I also knew that, in turn, I was to be no ordinary child. I traded play dates for doctor's appointments, Barbie dolls for books to read to Jake. I grew up much faster than most preschoolers, but I never resented any of it. I was intrinsically aware that my life had a purpose, a higher calling.

When Jake died at the age of nine, a void formed. Every day brought with it an unfathomable feeling that something was missing and could never be replaced. As I grew up, that feeling remained, but my belief that I was meant for something bigger than myself remained as well. I know that my purpose on this earth is to help kids like my brother and families like my own. This conviction has led me to incredible opportunities, experiences, and people, such as my job at Auburn University and my time shadowing Dr. Kallish, a geneticist at the Hospital of the University of Pennsylvania.

Choosing a college was rather easy for me: Dr. Doug Martin and other researchers at Auburn University were on the cusp of curing GM1 gangliosidosis, so Auburn was where I would go. Dr. Martin graciously gave me a job working at the Scott-Ritchey lab, contributing in any way I could to accelerating the discovery of a cure for the disease that had defined my life's calling. On top of my demanding class schedule to earn a degree in molecular biology, I work many hours a week in the lab, scanning tissue samples and making slides. Unlike many working adults, my job is the highlight of my day, because I know what I am doing, however small my contribution may be, is going to change hundreds of children's lives.