I realized my hands were going numb as my stepmother, Julia Rosado, and I pulled into a parking spot at the Houston MD Anderson Cancer Center parking garage. It was February 2023, and I could not feel the cold red exterior of the car door as I slammed it shut. We were on the seventh floor of the garage, so my stepmom guided me to a room of elevators near the car that would deliver us to the bottom of the building. Sunlight cascaded through an elongated window in that tiny room. Most people associate sunlight with happiness, but at that moment I felt nauseous and insensible in its glowing rays.

My mind flashed to August 2016. My father and I were driving to my high school volleyball practice. He was in the driver's seat of his car around 6:30 a.m., and the early morning sun was just beginning to reveal my angsty teenage face. It was my first week of ninth grade.

“You have to BE THE SHARK, honey,” my dad, Jeffrey Rosado, exclaimed from the driver's seat.

My dad had just started using this analogy, attempting to teach me to imagine being a shark so that other people and challenges are simply fishes in the sea. He was trying to uplift my 14-year-old brain as I learned to navigate the treacherous waters that accompany being a high schooler. I turned my head away from the window and toward the rearview mirror, where I knew my dad’s smiling face would be gleaming at me. I didn’t want to admit it then, but his positivity comforted me greatly.

For as much advice as he gave me, my dad didn’t teach me how to navigate the emotions I felt as I walked along the rusty-colored stone pathway that led to the hospital entrance. The trek was difficult, with feet that felt like weights pulling me down. I only finished the first portion of my journey as I looked into the gaping entrance and felt hospital air slam into my face. My knotted stomach tightened just a little more than I thought was already possible.

I attempted to keep a stoic face, but my hands twitched as we walked in. I folded my thumbs into my palms, then squeezed them as hard as possible repeatedly, as if I could pulp my anxiety into orange juice. A disorienting mixture of smells hit my nose and fogged my brain, signaling we were walking past the cafeteria. Coffee, pizza, burgers, Mexican food and baked goods felt like smells that should not be combined. We were suddenly in a hallway with eight elevators, four in a row and facing each other.

“It’s floor seven,” my stepmom told me softly.

This was the first time I’d be seeing my dad since I found out he was going to die. My chest felt heavy, as though every depressing and angry emotion inside of me was balled up tightly and pressing up against my heart.

Be the shark. It’s what I learned to tell myself before every major event, and it is what I repeated to myself in that moment before the doors opened to his floor.

During my hospital visits that week, he was taken off life support. He passed away less than a month before his 42nd birthday. The youthful age at which he passed has eaten away at my thoughts for several reasons. He had a genetic disorder called NF2-related schwannomatosis (NF2-SWN), formerly known as neurofibromatosis type 2.

NF2-SWN is a disorder that one can spontaneously have or can be genetically inherited from one's parent who has it. My father received the disorder from his dad. Then, me and my little brother, Ace Rosado, inherited it from him. As I watched this disorder take my father, I could not help but question what my fate would be. Since his death, I constantly grapple with the burdensome thought of whether I'm middle-aged at 21.

"Pure medical advancements give me hope for you and your brother," my stepmom said. "I don't have a fear of you dying because we all die at some point. I obviously don't wish for y'all to have a shorter life span, but I just feel like any life with you guys on earth outweighs not having you at all."

Understanding the disorder

To understand the full gravity of this disorder, it's essential to know how it works and runs in a family genetically.

Dr. Ted Mau, an otolaryngologist and vocal care specialist at UT Southwestern Medical Center, is well-versed in NF2-SWN. He treated my father for his vocal fold and throat complications and now treats me for mine. Mau does a good job explaining what NF2-SWN is in simpler terms.

"It is a genetic condition in which the nerve sheath cells can grow out of control and turn into a tumor, hence the term schwannoma since the tumors arise from the Schwann cells," he said. "These cells form around the nerves."

Medical research guarantees that the NF2-SWN gene change can either be inherited from a parent or appear spontaneously; every person with this gene change has a 50% chance of passing this change onto their child, according to Johns Hopkins Medicine, a renowned hospital for NF-related research and treatment.

Watching my father go through countless medical treatments and surgeries broke my heart but revealed how much love the human heart truly holds. Many people don't understand the value of things in their lives unless it's in jeopardy of leaving their grasp.

"The thing that was the worst for me— because of mother nature's amazing ways and being in tune with your motherly nature when you have a child— is that when Baylee came out of me, my motherly instinct told me my daughter had it. I knew it even when I was pregnant," said my biological mom, Carly Baldwin.

As I reflected on this disorder, I thought back to a memory from the winter of 2014. I was 12, staring at my dad in his black jacket and business attire as we sat down in cushioned rustic leather chairs at Starbucks. A glance to my left was my stepmom, wearing warmer clothes too. I was facing both of them as if I were in an interrogation. A feeling of awkwardness overcame me; I knew something serious was going to be discussed with me. That's when they informed me that I tested positive for the same disorder dad had, and asked if I had any questions. As a fifth grader, my world was small and my perspective on NF2-SWN was even smaller. The disorder can affect individuals in infancy or much later in life. Every case is different, and for me, I was not affected at an early age so I didn't have questions at that time. I squirmed in my seat, a little confused as my small mind tried to comprehend if I would end up with the same disabilities as my dad. Then I was immediately distracted by my cake pop.

Living with the disorder

This disorder can be hard and slow, a dark cloud of a storm that meteorologists warn and prepare people for. But the anticipation of what could happen is an agonizing wait. It's considered dangerous to remove tumors because they often grow on cranial nerves, which have important functions such as balance, hearing, and swallowing. Removing these tumors often results in these functions being greatly affected or even sacrificed, Mau described.

He said nearly every individual with NF2-SWN experiences symptoms at some point in their life. The disorder most commonly affects hearing since the vestibular nerve and the auditory nerve travel together.

My dad was diagnosed with this disorder at 21, and through his health journey, he developed extreme balancing issues and other complications. He had his first brain surgery when he was only 24. This surgery was smooth with a quick recovery time. His second surgery left him with hearing loss and paralysis. These are common side effects for NF2-SWN patients post-tumor removal or debulking surgery. No one was expecting my dad to pass away because every surgery had ended with him having moderate to no complications.

Unfortunately, he had a specific tumor on his brainstem that had grown to the size of a lime. The surgery for debulking this took 17 hours, and his surgeon said the tumor had more blood vessels than he had ever seen in someone. Due to this, my dad lost 60% of his blood from those tumor vessels during the operation. This experience resulted in my dad being diagnosed with a traumatic brain injury because of complications. During the surgery his brain swelled so much they had to cut a piece of his cerebellum, which led to a coma he did not wake up from.

These tumors can have a strong effect on one's body. For me, it has resulted in struggling with invisible disabilities. I recall being in eighth grade as athletics season had begun. I tried out for different sports throughout the school year, and it was volleyball season. In the girl's locker room, I laced up my shoes and headed out the wooden doors toward our main gym. When we would begin to do cardio workouts during practices, I felt the uncomfortable sensation of being unable to catch my breath. By basketball season, this turned into me wheezing for air while exercising. Embarrassment trailed my every workout. I could not stop the gasps for breath and other girls would stare.

My biological mom has always been a major advocate for my health. When I expressed what was happening, she started bringing me to different doctors. After I received an asthma test and allergy testing, we still could not figure out what was happening. I saw multiple doctors and had a scan for lung issues in my chest, but they still didn't know the problem. This process infuriated me; it felt as though I was faking it because no one understood what could be causing this issue.

Finally, my mom took me to get a scope of my throat and vocal folds. My doctor was a vocal cord care specialist like Mau. A nurse numbed my entire airway, and with each spray into my nose, I was scared for the wired camera to reach into the depths of my nostrils and down into my airways. Luckily, the experience was worth it, as this would give me the answer to what I had been longing for.

"Yep, your vocal cords are paralyzed," said Dr. Kathleen Tibbets.

As I stared at the pink alien-like insides of my throat, I felt a tsunami wave of relief. Even though paralysis was not able to be fixed, I knew why I could not breathe. This was my first invisible disability. As years flew by, when I started college I developed a slow progression of swallowing complications. My throat muscles were having a tougher time being able to push down my food, so it got caught in my throat. I took a swallowing test, where I was informed that it takes three full swallows for food to go down my throat entirely.

Mau later explained to me that my vocal fold paralysis is due to a tumor on Cranial nerve X (vagus) and my swallowing is mostly affected by the tumor on Cranial nerve nine.

Coping with this disorder

Remember the dark cloud I said NF2-SWN looms as in my life? Well, this means that at 20 I was already deeply planning my future, wondering when I should get married or have children. I feel very lucky that I got 21 years with my father. If he had me any older, we would have had even less time together on this earth, just as he had less time with my younger siblings. At age 21, I feel pressure to have children earlier in the worst-case scenario that I would not be here long enough to watch them grow.

Many often question what having babies looks like for NF patients given it is passed down genetically. For women with this disorder, it is strongly advised to not get pregnant, as the extreme hormone changes during pregnancy can cause tumor growth that otherwise would not happen. My childhood neurologist informed me that NF2-SWN women such as myself can freeze their eggs and decide what they would like to do when they are ready to have children. Patients can also use donor eggs, or surrogates, or go the adoption route.

Hearing this in high school, as someone who identifies as a woman, I did feel a tiny piece of myself was just out of grasp. I always thought I would someday experience the wonders of growing a child in my body, but for many NF women, it can be a complicated process. It's a choice between sacrificing your health or accepting different forms of fertility treatment. The gratuity I feel to have a partner who accepts the hardships of my journey and willingly wants to do that together is something I will never take for granted.

My girlfriend, Megan Pappas, said when she met me and found out I had this disorder she felt confused and scared by her research findings.

"I looked up NF2 life expectancies, and it said 65 or 62. I was really shocked," she said. "I remember you telling me when you were little you would cry to Julia because you thought no one would love you since you have NF, but it never was something I would leave you over. It was more like, seeing you have to go through things will be so awful. It has nothing to do with how I feel. I don't want to see you in pain."

Just as Megan plans to support me in any way needed in the future, we both saw the taxing hardships of NF2-SWN on marriage. Near the end of my dad's life, the size of his tumor took a great toll on his ability to complete everyday tasks. I admired my stepmom's ability to take on the patience and role of a caretaker for him. She gave me and Megan advice and inspiration for our future.

"When your dad was dealing with everything he was going through after us having twins, a lot of people would come up to us and say they don't how we do it," my stepmom said. "And I do not understand how it could even be a choice honestly. That is something that really connected our energies together because we just didn't see a choice; you are going to get up and you're going to do it."

Two women know first-hand how much loss and grief NF2-SWN has brought into my family's life: my aunt, Elizabeth Rosado (whom I call my Tía), and my dad's mother, Nancy Lee (whom I call Nani). My Tía lost both her father and now brother to this disease.

"I felt very hopeful and positive when your dad got diagnosed because there had been so many medical advances since our father. And you know what? Your dad put up a good ass fight," said his sister and my Tía.

On the other hand, my Nani had to watch both of her children lose their father, who was her then-ex-husband. Now she has also lost her son. Since my brother and I inherited this, they both worry about us too.

Closure

Before my father went into surgery, he was featured on his coworker’s podcast for an episode as a co-host. I never knew a 46-minute and 16-second video could be one of the most valuable things I would ever incur in my lifetime. I remember when it was released, my dad sent it to me over text and I told him how awesome it was. But I had not clicked the link yet. It was released the day before his third major brain surgery and is the last message we ever exchanged with one another. Once he went in, my stepmom and some family members insisted I should watch the video because it had amazing advice. He talked so sweetly about his kids, especially about having me at the young age of 21.

Part of me wishes I had watched it when he sent it because I was not yet consumed with worry and grief. After he went into surgery and I knew the complications that had occurred, I couldn’t bring myself to watch this video. Seeing his bubbly face full of stubble dimly lit on my iPhone made my heart ache, and hearing his voice shattered me into broken glass.

Six months after his passing, in late September of this year, I was relaxing in my home late at night. I knew I healed to a point where I missed his voice, no matter how much pain it felt to hear it.

I grabbed my phone and approached my sage green duvet perfectly made on my bed beckoning me to relax in it. I curled up and tapped through each button-like obstacle on my phone to get to the YouTube link. My dad’s face once again is staring at me through the lit-up phone screen next to his coworker's face.

“Ep 403- How to Speak without Speaking and Talk Without Talking (w Jeff Rosado),” the video title read.

My fingertip lightly tapped the video image link, and I found myself at the start of his video. My stomach dropped immediately as I heard his voice. A ball quickly developed in my throat and my eyes misted like fog in the early morning of spring. I had not heard it in what felt like five years.

My reaction quickly morphed from shock and hurt to tears of joy and longing. Even though I was not watching him speak wisdom with a light-hearted sensation, I was hearing him with a heavy heart and a prideful smile. I only made it to minute 23 until the ache of wanting to make a phone call I couldn’t ever make again was too strong.

I accepted that my future consisted of moments like this, waiting for someone who would not be there to wait for me. No matter how hard grief is, I would not trade my dad for any other man to raise me. He is a hero to me and forever will be.