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More Than a Name: Growing Up with Hear See Hope

I didn't always know what Usher syndrome was. I just knew that my brothers were deaf and that my parents were busy on the phone at night, working on something at home called "Hear See Hope" when we should have been going to sleep. I knew it was important; I just didn't know why. I knew that two of my brothers signed with each other. I knew that they had cochlear implants. I knew that my parents aided them in their pursuits, and I knew that we did things differently from other families. We left functions early in the middle of the week; we had doctor's appointments; we had to explain to strangers who didn't understand why my brothers never responded when they spoke too fast, yet to me, it was normal. This was life.

What I didn't know was how devastated my parents were in the beginning. When Conner was born, they were surprised and worried. When diagnostic testing came back that it was Usher syndrome, they thought that it was better than the alternative. Usher syndrome is progressive; it doesn't just take away hearing; it takes away vision, too. When people hear Usher syndrome, they think of an artist due to all the film/media representations. Yet at the time, there weren't many answers. There wasn't much good news to be had by the doctors. There weren't many avenues for support. My parents felt alone.

Thus, in 2004, they established the Hear See Hope Foundation to provide answers to families like ours. They wanted to raise money for research and grow a community that represented what it meant to endure such hardships. At first, the mission goal was simple: find a cure for Usher syndrome in Conner's lifetime. Then, when Dalton was diagnosed in 2008 as well, the mission became personal.

I was young through the initial years; I didn't comprehend the severity of the situation. But as I aged, it became clear that my parents were doing everything within their power to change the world around them, one research vote at a time. From meeting with doctors and scientists to fundraising events to speaking engagements and attending/conducting conferences, accessibility remained key. Sometimes they traveled hundreds of miles across the country, sometimes to a neighboring town to meet with other families and researchers. I never took notice, but these were all things they had to do without distraction.

But they didn't let it stop them. Conner is an incredible speaker and speaks at conferences, using his narrative to inspire and empower. He doesn't live his life out of fear. Dalton doesn't, either. He's been to D.C. to lobby and fight for additional funding for the deafblind to live more empowered lives. If he wants something done, he doesn't wait for someone else to do it; he does it himself. Cole, our brother, did something incredible for awareness and fundraising, too. He climbed Kilimanjaro. That's the tallest mountain in the world, and he used time and energy donated to Usher syndrome, which says a lot about these people.

As for me, I've been in the background, ready to help wherever I can. I'm not one to be behind the podium or climb Kilimanjaro, but I'm there, in person, for events, for awareness, and for cheerleading my family. I've spoken on our family's tale to outsiders that could contribute to why funding is critical for medical research. I don't do anything for accolades but for the opportunity to be part of something bigger than myself. It's a family fight.

Hear See Hope has changed over time. We've generated different pots of money that go directly to research. My parents helped form the Usher Syndrome Coalition, which has national recognition. This means families worldwide can connect with each other, validate their feelings, and receive assistance. Years ago, that didn't exist when my parents came on the scene. They created it.

Because of this progress, specific things have changed. Researchers have made progress in their findings; they're learning more about Usher syndrome and learning more about how to treat, even possibly cure it one day. That gives us optimism. Our family holds onto hope like the most treasured warmth in the world.

When I reflect on everything my parents have done, I'm humbled. They didn't take no for an answer. They didn't accept what the doctors said and let mediocre life or a drop in quality of life take its place. They punched back, blended their blood, sweat, and tears into a foundation, and united community members to change the tide for everyone. And now all of us boys are involved in that mission.

Yet it's not always easy. Sometimes, it's challenging to talk about. Usher syndrome is real; it's hard to bear; it's unfair sometimes. I despise thinking about what my brothers won't have one day; I hate thinking about how much they've had to fight for things that easily come to others. But that's exactly why the work is so essential.

It's comforting to have gained experience over the years. When families hear "Usher syndrome" for the first time, they see my fear in my eyes and the confusion my parents may have had at the very start; however, now they don't have to go through it alone thanks to Hear See Hope or Hear See Hope Coalition. There's guidance; there's research to be found and supported by groups, and relative community is most important, what love and purpose allow you to do by sharing your story.

I've learned that advocacy comes in myriad forms. Some people write; some people speak; some create fundraisers; some show up like me and hold signs or hand out food at events or man booths or listen to someone vent. Every single aspect is critical because every single micro effort creates a macro goal, to help people with Usher syndrome live their lives and hopefully one day soon, find a cure.

One of the first times I really understood what advocacy was relates to a Hear See Hope fundraiser. I was pretty young and merely tasked with handing out programs and holding the door open. Yet, I remember sitting there watching Conner give his speech to the sea of adults standing in front of him, speaking softly yet assuredly about his life with Usher syndrome. As I glanced around the room and saw tears falling, not from pity but from a place of joy, I knew my life would never be the same. I realized, for the first time, that the power of a story transformed my brother from a brother to an advocate, a person who wanted to clear a path for others, and I needed to be his advocate.

Then, after I started attending more events, I realized how much work it took to make each planned endeavor a reality. My parents and our volunteer group worked late into the night coordinating auctions, sign designs, and donation inquiries. I learned how to set the table, load boxes, and check in guests. While seemingly menial tasks, they were all imperative. Each person who attended a Hear See Hope event walked away with a more comprehensive understanding of Usher syndrome than when they entered.

And events weren't the only thing to attend. I remember my family and I going to a research symposium. Although I didn't grasp most of the scientific conversations, I listened. Researchers presented their results on gene therapy and clinical trials, which showed me there are highly educated professionals in the world who voluntarily give their time and energy to the prognosis of Usher syndrome. That was positive to me. I wanted to work more regular hours because if they could do the science, we could do the advocacy. It's all connected.

But some of the most meaningful moments were on a smaller scale, quick, hushed interactions with fellow siblings or the parents who were new to Usher syndrome who pulled me to the side and said, "Thank you. Your family gives us hope." This is why we do it. We may never know if there will ever be a cure, but we know we can reassure people that they're not alone in this moment, and THAT STAYS.

It wasn't always easy to grow up in a family like mine. There were times I needed to be the strong one; I never articulated how it felt to watch my brothers have their vision parts taken away or how they've struggled when they knew I'd never have to. I wanted to project that I was strong, looking to the foreseeable future. But now, as an advocate, I realize that vulnerability is part of the advocacy process and a potent form at that. It's okay to be scared. It's okay to be hopeless. The only thing that matters is what you do after you recognize those feelings.

Growing up, I did not want my brothers to be "different." However, as time goes on, I realize that with a future of answers, treatment, and hope for all who present like them, they need to understand that they're not less than. They're more than, and this world just requires them to walk a different path, a reality that our society needs to honor. That's what my foundation does each day.

Hear See Hope was born because my parents felt like an island, scared, alone. But in the status quo, it's a vibrant, woven-in community across the country, and worldwide, of families, physicians, researchers, and advocates all with the same goal. And I am part of it. I will carry it on.

Thus, we have so much left to do. Yet, in this moment, reminiscing about everything we've done, everything they've done, I take great pride in our efforts. My parents had the option to succumb to the diagnosis and learn to live day by day; instead, they chose the fight. They chose to create a legacy that would one day benefit more people beyond just their offspring. That's the legacy I wish to carry forward.

And this is why I bring everything back to the start. Hear See Hope didn't mean anything to me before; it was merely a title. But now? It's transformed into more than just a name; it's a cause, it's a commitment, and it's my way of conveying that we're not done. We won't be done until there is a cure, we won't be done until each family has the means to get by, and we won't be done until everyone touched by Usher syndrome gets to be seen and heard.

This story started with my family, but it transforms into everyone's story who values community, empathy, and resilience. I did not choose this journey, but I am humbled to walk this walk.

And I'll keep walking, right alongside my brothers.

https://www.usher-syndrome.org