

A speech delivered by Bodhi's mom, Sarah, at the Scott Hicks Memorial Event on June 12, 2025

*My family is a lightning rod for the rare and unexpected.*

*At the time that our son Bodhi was diagnosed with 1p36 deletion syndrome, a rare chromosomal disorder, we were also caring for my mom with a rare, aggressive form of easy onset dementia. With the help of friends and family, we were able to balance Bodhi's daily therapies and appointments with my mom's increasing needs.*

*Then, like a strike of lightning, a few weeks after my mom's passing, we found out we were pregnant with twins. Again, we leaned on our community for support as we grieved her loss, welcomed our two girls with their own health challenges, and continued to provide Bodhi with everything he needed to thrive.*

*We've spent the better part of five years now sitting on our proverbial front porch watching the lightning storm, and we've learned a few things.*

*We've learned, cliché as it is, to dance in the rain. Put on your raincoat and boots, prepare as best as you can, and embrace what life is throwing your way. Can't change it, might as well enjoy it.*

*We've learned to face the power and beauty of the storm without fear, but with reverence. Bodhi's diagnosis is complex and overwhelming at times. We've had, and will continue to have, some really hard days. But a hard life does not mean a bad life.*

*And we've learned that you can't weather the storm alone. Our community has continually shown up for us, metaphorical umbrella in hand, to keep us dry when the storm gets a little too rough.*

*If you're here, it means that you also recognize the importance of coming alongside families like mine, not with pity or derision, but with a genuine understanding of what community means.*

*With all of those lessons in mind, we have been working with our Make-A-Wish team to dream up a special space for Bodhi.*

*Bodhi's Backyard Bungalow, as we've named it, will be a shady play space tailored to his medical and sensory needs that we can all enjoy together as a family. We were overwhelmed in the best way when a dozen members of our East Ridge community showed up in our backyard a few months ago to start the process. Contractors, landscapers, an electrician, a roofer, someone introduced to me as a "concrete guy" and more, all sharing the same heart for service, all showing up for my kid.*

*Bodhi is the coolest five-year-old you'll ever meet. He loves Elton John and The Beatles, is a patient big brother, and has an incredible sense of humor. He tells you he loves you by snuggling in close and has the most infectious smile. And you wouldn't know it by looking at him, but he eats like a linebacker. He has logged hundreds of hours of therapy, working hard for every independent movement and each moment of expressive communication. He has endured countless medical procedures and always faces them with grace and strength beyond his years.*

*In short, he deserves the world.*

*Make-A-Wish is giving him a little piece of that, with a space that will bring him comfort and joy for as long as we get the honor of walking with him on this earth. And that's what it is, an honor. Not everyone gets to bear witness to a lightning strike every day, with its power and wonder and devastating beauty.*

*From the bottom of our hearts, thank you. By being here, you have all shown up for families like mine who are in the middle of storms of their own. The impact of your contributions today will be long-lasting and life changing.*