

## The Huson Family of Boston, NY

Meet Nick & Liz Huson and their three children: Paige -16, Gwyneth - 14 & Cole - 10.

A beautiful perspective shared by Liz, regarding. Her family dynamic and what it entails:

When we started our family, we knew having kids would be an adventure, however we never quite expected the journey we have been on. In 2010, my husband and I added our third child to our family, a son after having two daughters. We were ecstatic and living our happily ever after, three healthy kids, a house, a dog, and good jobs - life was good and according to our plans. Then, shortly after his birth, our son was whisked to the NICU as he could not keep his body temperature up. After a few days, all was well again, and we were sent on our way home. A few months later other symptoms emerged and eventually, Cole was diagnosed with Crohn's Disease and a Primary Immune Deficiency.

Since those first symptoms, much of our world has revolved around tests, treatments, illness, and preventing illness. Like other special needs families, we have made sacrifices and altered our expectations and dreams for what our family journey would be. Having a child with chronic, incurable medical conditions is draining emotionally and financially. With so many appointments and needs, I left my career behind. Over time, we learned others not only lacked understanding as to why we might cancel plans last minute or why we could not attend large gatherings in the middle of flu season but also lacked empathy for how hard the road was for every member of our family. The Covid pandemic magnified this for our children as they were not able to be a part of the things they normally would be. As life and activities picked up for many, they had to continue watching from a distance. As a parent, I expected to make sacrifices for my children, but never expected to have my children give up things for their siblings. For me, watching our daughters do just this throughout our road, especially during the last year and half, has been one of the hardest parts about having a child with special medical needs. The girls have experienced more nos, given up dreams, witnessed scary moments before we ran to the hospital, and faced more challenges than any child should. Yes, seeing Cole sick or at infusion has also been difficult, but he is seen as a hero and applauded by so many for his strength while outside of our family, our daughters are not seen by others for their strength and resilience. I don't think people consider just how hard being the sibling of a child with chronic illness is. The pride we have for just how gracefully our daughters have handled the ups and downs is just as immense as what we feel with the strength of our son with each procedure, they are all incredible warriors on this road.

Throughout the years, the unknown of what was coming next, the inability to plan too far ahead, the medical costs, the wanting to do what you could not, and the lack of understanding from others left us feeling so very alone. While I would never want anyone to endure the difficulties we have faced over the years or comprehend exactly what we were going through, I have been forever grateful to find our way to others in the special needs community who "get it." The caring, compassion, and lack of judgement from these kindred spirits has helped us feel seen and

no longer so isolated on this odyssey we sail in life. While it may not be easy or the road we expected, despite the hardships we have found many unexpected blessings and much love, and for that I am thankful each and every day.