

Suzanne Chen - New York

Who's in your family?

I (Suzanne) am married to my husband Edward. We have three children: Parker (11) is our first and most easy going, loving, and determined child, who also has CHARGE.

Piper (8) is our spunky, confident daughter.

Pierson (4) is our outgoing, energetic, LOUD child.



What do you want people to know about your family?

We're a tight family. My kids are crazy. They can't get enough of each other. My kids know that their brother is a little different, but they don't treat him otherwise. They all embrace each others' uniqueness and abilities, and that's what I truly love about them.

- Edward is a Field Operations Manager for a telecom company.
- I (Suzanne) work part-time with the New York Deaf-Blind Collaborative as the Outreach Coordinator. I also work one day a week at Morgan Stanley Children's Hospital as a Parent Partner. I'm also the President of the New York Parent Association for Deafblind.
- We live in Queens, NY. My husband and I both grew up in Queens, NY and met in college (lived next door to each other in the same dorm hall, and that's how we met!)

What activities do you like to do?

- We hang out as a family, but also try to make time for each other. During the weekends you can find me with my kids at either a morning speech therapy session (drinking coffee), swimming lessons (drinking coffee), or we'll try to find family activities around NY to take the kids to, like the Hall of Science, or a children's museum, or the park.
- All of my siblings, and a lot of our family live in NY, so we try and get together every so often for lunch, or meet somewhere to hang out.
- Each year we try and have the kids also do their own thing (it's hard when you have multiple children, as well as a special needs child, to do that). Piper does a summer camp for siblings of deaf children, she also participated in Ninja warrior classes. Pierson does Chinese classes, and Parker participates in an inclusive Dance Class once a week (finally something NON therapy related!) after school.
- I am also on the PTA for two of my children's schools. I LOVE to be busy, and love meeting new families, and being social.
- At least once or twice a month I try and have dinner with friends. They keep me grounded, supported, and make me laugh.

Why do you volunteer with the Foundation?

- Ever since Parker was diagnosed in the NICU, and when he finally came home from rehab (he was 13 months old), I've always wanted to connect with other families who had children like Parker. I knew this would be a lifetime journey filled with highs and lows (since he was also 2 ½ months premature), and I chose to embrace, cherish, and hold tightly onto the highs.
- Every time I met a family, I asked for their contact info, and we had play dates, phone calls, we kept in touch, and that's how the NY parent support group grew and grew. It became a little less scary and alone, and my circle of support started to overflow with wonderful CHARGE families, who became friends and confidants.
- I volunteer with the Foundation, (and choose to support and fundraise), to make sure families that come after me, as well as the ones that I've met along the way, including myself- have a community, a place where we feel connected, and a resource we can share to anyone that wants to be educated about CHARGE Syndrome.
- You know that phrase "Find your tribe, and love them HARD"? That's exactly what I feel the CHARGE community is all about!

