

***Becoming Her Village:
Learning to Walk the Rare Journey Without a Roadmap***

When we received our daughter's diagnosis of a 'rare genetic mutation' the words felt super heavy.

"Rare; not much information; research group still studying the gene."

I think one of the hardest parts of receiving the diagnosis was the uncertainty that came with it; no clear roadmap or checklist of what to expect or what things to look out for. As a parent, I had to adjust to living with unanswered questions and living with concern and fear without letting it completely overwhelm life every day. I had to learn how to handle all the things that come with this diagnosis, many doctors' appointments, many therapies, IEP meetings, and so much time researching on my own.

But most importantly, becoming her biggest advocate through this whole journey... no matter the destination. I've learned along the way; advocacy is a form of love.

Nothing in life prepares you to get a diagnosis like this for your child, but one thing is for certain... she will never go through any of this alone. From appointments and therapy sessions to moments of frustration when she doesn't understand why things are harder for her.

Along this journey, I've realized she teaches me far more than I could ever teach her. Day after day, she shows me that love doesn't need words, that resilience can exist in its purest form, and that true strength and bravery often come in the smallest, quietest moments.

--Momma to a CHD-9 rare princess