



## Collin Cushman

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Every parent will tell you, that their baby is perfect. Collin was our perfect baby, meeting milestones early. Yet, being first-time parents, we didn't see the red flags until it was too late. At his 9-month checkup, we expressed our concerns:

- He hated tummy time; he was rolling over one day and then not able to do it the next.
- He could wave and smile one day and then he couldn't.
- He was hand feeding himself Cheerios and then he wasn't.
- He was becoming irritable and stiff.
- He was never able to sit up on his own.

Our diagnostic journey lasted 4 long excruciating months. Once we received the diagnosis of Krabbe disease, we wanted to learn everything we could about it. My family sought medical advice, Googled the disease, and reached out to other experienced families.

We carried on with life by doing everything we could to make his quality of life the best we knew how. We were Collin's advocate, his nurse, and his caregiver. We made sacrifices with our health, our marriage, our sleep regimen, and with our daughter, Kendra. Every Krabbe family has a slightly different story but, were all connected by the heartbreaking journey were forced to walk.

Caring for a Krabbe child is difficult. We experienced great difficulty early on when Collin's disease seemed to be progressing rapidly. I struggled with many things such as, learning about all the complexities of the disease, feeling emotionally drained, and ongoing thoughts of how to manage all of Collin's needs. I learned quickly how to pick up on the clues that Collin was giving when he was struggling, and I made a point to stand up for Collin when doctors seemed to have closed ears and minds –it's what I had to do.

I struggled to take care of myself, I struggled with my faith, and was very angry with life. It was not fair! It was not right! This was not the life I planned for Collin.

I know how challenging it can be to support someone who has Krabbe, that is the reason why I feel I can be a listening ear, a support when you don't know who to talk too, and someone who simply "gets it."

Warm Regards-

Kevin Cushman

