

# Meet the Roberts Family

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*Written by Karen Roberts*

I was asked to write about my family for *Vibrations*. It is very difficult to know where to start and how to limit this to just a few paragraphs. But if it weren't for Benjamin I suppose I never would have been honored with this request, (in fact, believe it or not, I don't think I would ever have heard of *Vibrations!*), so I will start with him.

I am convinced he is, and will be my ticket to fame and fortune. He has certainly enlarged my scope of friends, of knowledge, of personal growth and taught me without a doubt, what unconditional love is. And I will give up the fame and fortune for all of that. Because those are things anyone can have. Benjamin was born in August of 1997 and just had a whole array of things "wrong" with him.



What was supposed to be an overnight hospital visit to spit out number three Roberts child (and first boy), turned into five weeks in the neo-natal nursery with lots of scary stuff being said. But the bottom line is we finally got home, with a few more tubes than ever expected, and tried to find out what our "new normal" was going to be. Benjamin eventually was diagnosed with a rare syndrome called Opitz C. It is not one of the better ones (as far as syndromes go) but it wasn't like we could pick and choose either. He is the only known child with this syndrome diagnosed with deafblindness. **Our bonus!**

And thank goodness. I say that not completely facetiously. Because it has given us a niche. A place to hang our hats, an identity a place to start learning. There is so much out there about deafblindness. There is not much out there about Opitz C. Most Opitz C kids are not verbal and it takes awhile to figure that out. Time is lost. But once we put "deaf" together with "blind" (that diagnosis took a few months), we were able to begin our journey with a direction. And Alyssa and Caroline began their school careers (preschool and elementary school) just as he was born and I think that was a good thing because I was very consumed with his care. But their coming home at the end of the day gave me balance and perspective. And husband/dad is Jeff. We are very fortunate in that we have been able to stick these years out together, though it isn't always easy. The rest of life hasn't stopped and that can be stressful enough at times! I have been

extremely lucky to find incredible therapists to work with us. And I consider them members of our family. I have learned as much from them as I think Benjamin has.

As Benjamin hits the three and a half milestone he is healthy, and that is not something we take for granted. He is off of oxygen, he gained a feeding tube and a nissen funduplication, he is about to be fitted for contacts for his extreme myopicism (glasses would be too heavy), he has purple ear molds, we live in Denver so he is going to the Anchor Center twice a week for two hours (without me!), he is rolling and scooting on his back, he mostly likes to gaze at his left hand in adoration but is using it for functional purposes more and more, and he is happy. He will continue at Anchor for two more years and will hopefully start at Montview Preschool in the fall (where his sisters went). He will be (by far) the most involved child they have ever had. Sharon Prairie, our deaf educator will teach his class...how much more perfect could that be? But after that, I don't know, I am just beginning to explore our elementary school options.

When Benjamin was born, I thought my world was shattered. There was never any good news. It was surreal. I had a few strands of hope, one being that we were not the first parents to go though it. I take much of my strength from the parents that have and are raising a child with multiple disabilities. You are my heroes and I really appreciate learning from you and being able to draw on your knowledge and support. It has given a whole new meaning to the term "family" for me. I look forward to continuing to learn from you at summer conferences and through this newsletter. Thanks for hearing our story.

***Update:*** *As of September 2004, Benjamin was being educated in a first/second grade classroom at his home school. Contacts were a disaster and glasses have worked just fine. As Karen has gotten older, she has learned how much she doesn't know.*

*Life is a continuing education and she had begun exploring all the questions and possible answers with other parents of children with vision and hearing loss. To contact Karen, Family Specialist with the project, call her at (303) 329-8950 or [kdot62@comcast.net](mailto:kdot62@comcast.net)*



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