



# Complex Child E-Magazine

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## You Are Your Kid's Voice: A Parent's Guide to Advocating by Rachel Nichols

I am my son's voice. I am his advocate. It's a tough job. The hours are long and the pay sucks. It involves hours of research, driving, phone calls, and appointments. I didn't get two college degrees to be a personal assistant to a one-year-old. However, it's the best job I've ever had. My boss and the rewards are amazing. I'm great at my job because I have to be; the consequences are too great if I'm not.

### Spencer's Story

We thought we were having a completely healthy baby. Doctors assured us that aside from a clubbed foot, Spencer was absolutely fine. My mommy-gut told me otherwise, so I turned to the internet. I spent hours researching conditions related to club foot and could ramble off facts about obscure genetic disorders by the hundreds. I'm a planner; naturally I hate the unknown, so I took comfort in Google. While most doctors recommend not looking on the internet for answers because of the horrors that lie within, I embraced it. The planner in me knew the worst case scenario and the best, which gave me peace of mind.

My mommy-gut was right. My fears were confirmed when Spencer was a day old and was rushed to the local Children's Hospital. We would find out later that Spencer probably has Say Barber Biesecker Young-Simpson Ohdo Syndrome (Ohdo for short), a rare genetic disease that causes physical and cognitive delays, congenital heart disease, cranio-facial dysmorphism, and muscular anomalies. In addition, Spencer was diagnosed with Pierre Robin Sequence with cleft palate, cranio-facial muscle weakness, and airway issues, all of which are common with kids who are diagnosed with Ohdo.

### Finding My Voice

We were in a whole new territory. Our world was filled with wires, monitors, and feeding tubes. We didn't even know how to parent a healthy baby, let alone one who was medically fragile. We trusted doctors to make the best decisions on our behalf because we assumed they had done this before. I remember feeling so intimidated during rounds and standing before a roomful of doctors who were using words I had never heard before. Spencer didn't feel like ours; the hospital was his parent. After we came home from the

hospital I spent hours on the internet each night. Every day the doctors told us a new diagnosis, and by the next morning I was an expert on it.

And then I got my voice. After a couple weeks of Spencer screaming his head off due to gas, we first challenged the numerous medical opinions pertaining to our son. He was constantly crying and the nurses weren't managing it properly. My gut told me that it was the formula that he was on, and when I voiced my opinion the nurses didn't seem to care. So when we had our first family care planning meeting, I went on a tangent about it. By that afternoon, his formula was switched and he was given gas drops around the clock. He got better.

I realized that if I didn't fight for Spencer, no one else would. I had power.

I didn't become a super mom overnight. I wasn't aware of the transition as it was going on, but I changed. Gone was the person who was afraid to speak up to doctors. The new me argued with them during rounds. I now look back at the person I was before Spencer was born and the mother I thought I would be, and then compare it to the mother I became. My transformation amazes me. Being Spencer's voice has given me a voice and confidence I never knew I had. I am amazing at my job because it is his future that is in jeopardy if I'm not. I want the absolute best for my child and I am willing to make the sacrifices to get there.

### **Advocacy 101**

There are no Advocacy 101 courses available. There is no official rule book on how to be a parent to a child with special needs. This is a life that we are all thrown into, and we have to find our own inner advocate. However, I do have some advice.

**Remember you are awesome:** You really are. In spite of everything, your child is thriving! You have to remember how awesome you are because it gives you confidence. I give myself a little pep talk before every appointment so I go in feeling completely confident. When I have those days that I don't think I can do it anymore, I remember how awesome I am and it helps me make it to the next one.

**Be fierce:** I am fierce because I have to be. You have to be fairly assertive when dealing with some doctors' egos. I was fairly assertive before all of this, but I'm obnoxiously assertive now. I don't back down when I know I'm right, especially since it's my child we are talking about.

**Do your research:** Nothing drives me crazier than parents who know nothing about their children's medical conditions. It's your parental duty to become an expert on every single one of your child's conditions. How can you be an advocate and make informed decisions if you don't know anything?

**Be prepared:** I'm pretty sure our high risk clinic doctor hates me. I come to every

appointment with a giant list of questions and topics. It's an easy way to keep organized and there aren't any unanswered questions.

**Stay on top of things:** My son is one of hundreds of patients. It's my job to keep on top of things, since not one of his 24 different doctors can do it. If he has even the simplest test done I'm waiting for the results. If I had left it up to the doctor who ordered his echocardiogram, no one ever would have gotten the results, and I would have never known Spencer had a hole in his heart.

**Have an amazing pediatrician:** Your pediatrician is your ally in this whole mess. When I can't get something I want out of one of Spencer's other doctors, I know his pediatrician will do it. High risk clinic didn't want Spencer to be tested for food allergies when he was clearly having problems, so I had my doc order the testing for me. Low and behold, Spencer has food allergies. In addition, your pediatrician should see the potential in your child and focus on all the awesome things he is doing. If your pediatrician is focusing on the negative, it's time to switch doctors.

**Get a Nurse Debbie:** I love Nurse Debbie. Spencer is followed by a clinic with nurses on call and most of the time we get Nurse Debbie on the phone. After we took Spencer home, not only were we first time parents, but we were first time parents to a kid with a giant list of medical issues. I would call the high risk line in a panic if Spencer coughed twice in a row. Nurse Debbie would talk me down and tell me what to do. Nurse Debbie has gone above and beyond to get me what I need to make our lives easier. One time she even offered to drop off PediaSure samples to our house on her way home from the hospital. I also call Nurse Debbie when our orders run out for our medical supplies. It's so much easier than trying to call any of the 18 other departments that Spencer sees to try to get scripts filled.

**Ask and you shall receive:** Don't be afraid to ask for stuff. In addition to being my advice person, Nurse Debbie gets me pretty much anything I ask for, as long as insurance will cover it. We scored a suction machine to act as a glorified booger sucker for my constantly congested snot machine. The same suction unit has saved us from a few ambulance rides as well. I ask for anything that could help me in taking care of Spence, such as extra syringes and mepilex, and I usually get it.

**Go rogue:** We always felt like we had to go by the doctor's orders perfectly. You don't always have to. We started Spencer on a blended diet, which we tried before discussing it with our team. I felt so guilty when I started adding bananas to Spencer's bottles. Blenderized dieting has a small following, but quite a few GIs are against it. I constantly encourage my fellow moms to go rogue and try it because of how well my child has done. Just make sure you go rogue on the minor things and not the major ones.

**Find a support group:** Get a Facebook account. There are hundreds of parents out there who are just like you. They understand that you can't be a good friend sometimes--your fair-weather real life friends don't get it. Some of my closest friends are people I have never met. While their kids might not have the same diagnosis, many of us have

children with overlapping conditions. I have several Facebook groups that I go to for advice and ideas that help me be a better advocate. Facebook has also connected me with a few other families who have children with Ohdo syndrome, which allows me to pick their brains and talk to people who are in the same position I am.

**Educate others:** As Spencer's voice, it is my job to educate those around us to make his world more accepting. While I was student teaching, I taught an entire lesson on feeding tubes. While my students probably thought I was insane, it's my hope that one day those kids will see a child with a feeding tube and realize that it's merely a way to survive, not a reason to ridicule. Whenever you are approached by someone who asks you what's wrong with your kid, educate them instead of being defensive. Maybe what you say will change their perspective.

Spencer is thriving because of his strength and my hard work. He does something every day that amazes me. Every battle is worth it because it's for him. It helps him grow up. It's because I love my son that I gladly gave up those college degrees I worked so hard on and I'm just Spencer's Mom instead. While it's not the job I signed up for, it is the best job in the world.

*Rachel and Spencer Nichols reside in Ashland, Kentucky. You can follow them via their blog, [Joining the Club Foot Club](http://talipesbaby.blogspot.com/), at <http://talipesbaby.blogspot.com/>*