

ADVOCATING FOR YOUR CHILD

by Rick Bowers

When Steffini Vandever's son, Jonah, was born in 1997, it brought back many painful memories. Steffini's first daughter, Ashley, had died more than 14 years earlier after just 11 months of life. Now, doctors were telling her that Jonah would probably not live more than six months.

Jonah was born prematurely with backward knees clubbed feet, and a missing baby toe on each foot; his hands were also malformed, and he had no forehead.

"The doctors didn't think that Jonah was going to make it so their plan was just for me to take him home and let him pass away," Steffini explains. This time, unlike 14 years earlier, however, Steffini was prepared to advocate for her child.

Because of what had happened with her daughter, she was able to realize when the system was failing and when she needed to be strong. "I knew whose toes to step on, when to back off, and when to push," she says. "Those are really important things that parents need to know so that they can get adequate care for their child. If you come on too strong, people don't want to work with you. If you come on too weak, they take over."

Steffini says that whenever doctors would tell her something about her daughter, she would just say, "OK," because they were medical professionals and she was "just a regular person."

"With my son, however, I could see other possibilities," she says. "That's why it's good to find somebody who has a child with a disability who has walked this path before you. They can help you see how to

do things differently." (See *ACA Parent Support Network*, page 9.)

Once the shock is over, she says, parents only have a short time to start advocating for their child or risk losing control. "If you don't, medical professionals start making decisions for you," she says. "After Jonah's birth, the medical staff made me feel like I didn't know anything. I was being pushed out of the scene, and they were giving me a lot of misinformation."

At one point, she decided not to take it anymore. "I said, 'Look, this is the way it's going to go. If you don't like it, that's fine; let's move him to a different hospital.' And I started running the show. I really had to fight to get him out of that hospital and into another hospital that I felt could adequately take care of his needs."

You have to make it clear to them that you are going to be a team member in any decisions made for your child, she explains.

Educating Yourself

Steffini strongly encourages parents to educate themselves on what their child has, to learn what options are available, and to learn what his or her rights are.



Nick is now a freshman at Eckerd College and plays on a quad rugby team. The sport is featured in the new acclaimed documentary "Murderball." Photograph by Charles Reeves (Reeves Consulting)

"Go on the Internet and read literature," she says. "The doctors won't like it, but who cares? It's your child, not theirs."

Steffini also learned a lot from other parents once she found other families of children with disabilities. "I found out about LifeLine Pilots, for example, a nonprofit organization of pilots who offer free flights to and from hospitals for those with certain healthcare needs." (www.lifelinepilots.org)

Being Politely Pushy

Nancy Ford Springer and Gary Springer faced the same kind of issues when their son, Nick, contracted meningococcal meningitis when he was 14.

One of Nick's doctors was wrong, Gary says. "He said that there was fresh skin growing under Nick's black infected skin so we became a little complacent."

It turned out, however, that Nick's condition was much worse than the doctor realized. So when another doctor told the Springers that Nick needed more amputations than they expected, the family insisted on getting another doctor and the president of the hospital involved to make sure.

The Springers realized early on that "the squeaky wheel gets the grease." "I always explain to people that you have to be politely pushy," Nancy says. "You need to support these people who are doing what they believe is best for your child, but you also need to question them."

Though she says you need to be as polite as possible, she also admits that she can get upset at times. "If I get to the point of steaming, however," she says, "then the system isn't working right, and I need to get another doctor, teacher, prosthetist or physical therapist to work with who will be part of my team." That's a better solution than just yelling, she says. "You don't want to get a reputation as a hothead because then people won't listen to you when you need them."

"No!"

Sometimes, however, you need to be more forceful, Gary argues. He recalls an incident when an intern was changing an IV (intravenous line) in Nick's neck. He was practicing on Nick, Gary says, and he was messing up. "Nancy went ballistic," he says, "and we said, 'No more interns.' In that type of situation, you just have to make a point of saying, 'No!'"

You don't, however, want to get into a conflict about everything, Nancy says. "You need to pick your battles and focus on the things that are integral to your child's well-being."

Proactive Advocacy

You also need to be proactive (for example, letting your child's new principal and teachers know about your child's needs), Nancy says. Don't wait until there's a problem.



After consulting 43 doctors, Steffini Vandever had her son Jonah's crooked legs amputated when he was 18 months old. Jonah now walks independently with prostheses and goes skiing every year.

Advocating in a more global way is especially important, Nancy says, because it can help your child and other children. For example, when the Springers had to sign papers allowing doctors to amputate Nick's legs, it was devastating, partly because of a lack of information. "That's why I became a co-founding board member of the National Meningitis Association," Nancy says. "I felt that other parents needed to have access to information as quickly as possible." (National Meningitis Association: www.nmaus.org)

You should also be proactive about finding out what services and benefits are available for your child, Gary says. "Nick can have a note-taker in his classes and extra time for tests, etc., but parents have to advocate such things for their child. They're not automatic."

The Ultimate Goal

"The ultimate goal is for children to advocate for themselves," Nancy says. "And we as parents need to model for them how to do it correctly. If you are

hotheaded, that's what your child is learning, and that's not what you want them to learn. Being hotheaded would only teach others that people with disabilities have short tempers. We want our children to become educated and to educate others."

Steffini has done that with Jonah. "When people used to stare at Jonah," she says, "I was right there going, 'You want to meet him. His name is Jonah.' Now, if we're out in public and someone is looking at him, Jonah does that. He'll say, 'Hi, I'm Jonah. Wanna be my friend?'"

Nick is also very comfortable speaking up for himself or asking for help, Nancy says. "If Nick was 20 years old and I was still advocating for him, I wouldn't feel that I was totally successful in achieving my goals for him."

As parents, Nancy says, she and Gary could have been a tremendous asset to Nick or they could have been his biggest handicap. It's all in how a parent chooses to deal with the situation, she says.

In Steffini's case, her strong advocacy for her son certainly paid off. The child who was only expected to live six months is now 7 years old, is attending a regular school, can ski upright, has been featured in numerous publications, and is an inspiration even to the soldiers who lost limbs in Iraq and Afghanistan and who participate in the same ski program he participates in. In fact, they call him "The Ambassador of Hope."

Was it worth stepping on a few toes to get him to this point? You bet it was! Just ask his mom. ❖

For more information about specific techniques for advocating for your child, see [Taking Charge: How To Become Your Child's Best Advocate \(www.amputee-coalition.org/inMotion/may_jun_01/childs.html\)](http://TakingCharge:HowToBecomeYourChildsBestAdvocate(www.amputee-coalition.org/inMotion/may_jun_01/childs.html)).