

THE GREAT SELF-ADVOCACY WAVE!

mom teaches most important lesson: “explain!”

By Joey Lynn Resciniti



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Right: Julia and her surfing instructor communicate face to face while out on the water.

My first lesson on childhood hearing loss was a speech banana printed on glossy paper with bright red X's and O's. My daughter Julia was almost 3 years old. The speech banana showed that she had not been hearing most of the conversation in our house. She had not heard the birds singing outside or the whoosh of traffic along the busy road. The clinical term that described this was *moderate sensorineural hearing loss*.

Soon after she got hearing aids, Julia stood transfixed as a neighbor scraped garbage cans across asphalt. Soon, however, she turned her attention to speech and by her fourth birthday had caught up with her hearing peers.

Ever a proud parent, I was there for almost every moment of her earliest years. I followed wherever she went, carrying fresh batteries and a safe dry case in which to stow the hearing aids in case of rain or trips to the swimming pool. Julia patiently tolerated me, and I remember our first triumph of understanding and self-advocacy came with her pronouncement, “My magic ears can't get wet.”

Lots of other self-advocacy pieces came together quite easily. Julia is a front row character by nature. She automatically seeks the first pew in church, dragging us along with her, even in the face of our discomfort at being so close to the preacher—only to abandon us 10 minutes later for the children's program.

Kindergarten found her proud to explain hearing loss to her classmates. She had a trained teacher of the deaf and embraced the information and strategies she learned from her. She mastered drawing a remarkably clear picture of a cochlea and informed adults and children that “those little hair cells that transmit sound to my brain are not

Photos courtesy of Joey Lynn Resciniti



working or missing.”

For all Julia knew about her hearing loss and assistive technology, there was much she was content to let Mommy handle. She lost more hearing in late 2010 and started having a tougher time communicating when the hearing aids couldn't be worn. As she was an avid swimmer, the no-hearing-aid-possible occasions occurred frequently during the summer.

I took on the role of interpreter, repeating loudly in her ear what anyone might be trying to say to her. The next summer, she became reliant on me to announce, “Julia can't hear very well. Can you try to talk louder? Don't be afraid to get right in her ear.” We learned a few signs together as a family and got on fairly well when it was just the three of us in the pool. It was those other people in the world that caused the problems. A group swim lesson became a near complete waste of time when even I couldn't get the instructor to make himself heard. I ended up sitting in the hot sun at the side of the pool taking direct splashes to the face so I could repeat instructions into Julia's ear. It was then that I realized I

could not protect my daughter forever. Yes, she was still a child, but already she was going places I could not be, dealing with adults and other children as the individual she would become. I knew I had to step back, and I adopted a new mantra: Tell people what they need to do for you to hear them.

From then on, I would help her, but not without reminding her that she could do it herself. Instead of explaining to others, I told Julia to explain herself.

“Tell your cousin you need her to talk louder if you can't hear her.”

“It might help if you teach her some signs.”

“They probably don't realize your hearing aids are out. You might have to remind them.”

Julia learned—and she learned quickly and well. This past summer swim class went much better. Now a mature first grade graduate, Julia would at least give a hearty, “What!?” if she didn't catch what was said. “Don't go with the instructor unless you know what you're supposed to do,” I advised. Julia would nod and stay on the steps until she understood, often forcing the



me laugh or just shake my head. “I can’t wear my hearing aids in the water,” said Julia. “So I’m going to have a hard time hearing you when we’re out in the ocean.” That began the conversation, and Carol and Julia proceeded to discuss communication needs. Tim and Julia taught Carol the signs for “yes” and “no.” Carol indicated she’d give Julia a big thumbs-up when she was doing it right.

That moment froze in my memory. I could have laughed, cried, and done a happy dance. That was it! It took years and happened 3,000 miles from home, but Julia, at 7-and-a-half years old, had finally told someone exactly what she needed. Unprompted.

The plan worked flawlessly. Julia stood up on the first wave and rode it all the way in before politely crouching back down on her board. Time and time again she surfed, talking to Carol in between. At one point she told Carol, “My mom told me I wouldn’t be able to do this.”

“I was wrong!” I told her when she finally came in from the water two hours later. “You did it!” Later Tim and I told Julia how special it was for us to see her explaining her hearing loss to her teacher—self-advocating during her surf lesson. Julia shrugged. Suddenly it was no big deal.

But it *is* a big deal. It is a tremendous accomplishment. Now I know Julia has the tools. She can do anything.

instructors to repeat the directions or demonstrate the required stroke. She passed her swim test with flying colors, possibly empowered by the knowledge that it’s always okay to ask for clarification. It was a little win, but instead of telling the story myself I just constantly reminded Julia to tell her own story. Still there was that part of me, always charged, ready to take up my daughter’s cause.

The last week of August presented an extraordinary opportunity for my family. My husband, Tim, had to travel to Honolulu. Julia and I were fortunate to have the chance to accompany him for the week before the start of second grade. Influenced by a certain Barbie movie, Julia had developed what she called a lifelong dream. She wanted to learn how to surf. Living as we do in Pittsburgh, I spent the better part of two years trying to talk her out of this. “Surfing is hard,” I counseled. “We don’t live near an ocean... You might not even be able to do it!”

Once in Hawaii, Julia talked about surfing so much that her dad and I rather brusquely informed her that if she so much as mentioned the ‘S’ word again, we would most certainly not be surfing. She settled down and we set up a time for Julia and her dad to have a semi-private lesson with the North Shore Surf Girls. The two of them sat on gigantic surf boards talking to the instructor, Carol. I was hanging back from the group, waiting for a break in conversation and wondering if I should give my spiel about Julia’s hearing loss. Midway through Carol’s long talk, Julia’s hand went up. I expected she might have some Barbie-related question that would possibly make

