

Hearing Health

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GLOBAL SOLUTIONS:

Hearing Health Pediatrics

RESEARCH

Trust Your Instincts

By *Haleh Rabizadeh Resnick*

I was thrust into the world of hearing issues after the birth of one of my children. And, like many, I was forced to learn the ins and outs quickly to help my son. But first, let me jump to the end and say, "Trust your gut and always question."

When our son Alex was born they told us that he failed his newborn hearing test in one ear, but we weren't concerned. We figured that he probably, as the nurse suggested, had fluid in his ears. Six weeks later when I went to have his ear rechecked, I was surprised to find that he failed again. The diagnosis was unilateral hearing loss. He had normal hearing in one ear and wouldn't need hearing aids or any other kind of therapy. He just needed an auditory brainstem response (ABR) test to confirm the results.

A few weeks later we went for the sedated ABR. This time we were shocked. The results now indicated that he had severe hearing loss in both ears. Our doctor told us Alex would need hearing aids by the time he was 6 months old or he would not be able to speak normally. The trouble was I just didn't buy it. It made absolutely no sense to me.

Alex was highly aware of his surroundings, responded to sounds, and woke at the slightest disturbance—you'd figure with a baby with severe hearing loss at least we'd get a little more sleep. I asked questions nonstop for the 30 minutes remaining during our appointment, about the diagnosis and about my doubts. We scheduled another ABR since results can change from test to test. Six weeks later, the ABR once again confirmed severe hearing loss in both ears.

I was at a loss. I simply didn't accept the diagnosis. My son could hear. I was sure of that. By now I spent my days testing his hearing every way I could. The doctor thought I was in denial. The audiologist thought I was in denial. And every other professional I contacted deferred to my doctors because Alex was tested at one of the top hospitals in the country.

So, what were we to do? I enrolled him in speech therapy. I signed up for support groups. I got him hearing aids. Struggling with a 5 month old who clearly did not want hearing aids and with my own feelings that this just wasn't right, we continued searching.

Two weeks after Alex got hearing aids, we found a doctor who believed us. In retrospect we now know that the absent ABR was simply misread as an irrefutable sign of deafness, without including the assessment of otoacoustic emissions and middle ear muscle reflexes. The absent reflexes and present emissions showed that he did not in fact have a severe hearing loss, just a de-synchronized ABR and normal or nearly normal hearing sensitivity.

At this point Alex was properly diagnosed with auditory neuropathy. He was not a candidate for hearing aids. As a matter of fact, had he been wearing the hearing aids any longer, his normal hearing would have been damaged permanently—requiring him to have hearing aids. The truth he was hearing everything, and I wasn't in denial.

Today Alex is 4. He speaks beautifully with normal hearing yet continues to be monitored because of his diagnosis. It's true that professionals can help guide and inform us. But as parents we bring something to the table as well. We know our children best and we are our children's greatest advocates.

Haleh Rabizadeh Resnick, who lives in New Jersey with her family, is a speaker, educator, and author of the book "Little Patient Big Doctor: One Mother's Journey." To learn more, see www.littlepatientbigdoctor.com.

