



[This page prints out on 5 sheets]

## Meet Ricky

### Ricky, age 4 years, 1 month

- Identified with severe to profound hearing loss at 15 months
- Got a cochlear implant at 25 months
- Uses total communication
- Attends an early intervention program at a school for the deaf
- Parents are both hearing
- Has one older sister and one younger sister, both hearing

### Learning about Ricky's hearing loss

“  
**I was at the time 6 months pregnant, and she said, 'You should have a genetic consultation before you have any more children.' I looked at her and I said, 'That was an interesting thing to**

”  
**paranoid and 6 months pregnant.' It was like a nightmare.**

**Ricky's Mother**

When Ricky was 15 months old, his parents realized that he did not communicate as well as other babies his age. He did not seem to notice when people talked, or said his name, or laughed around him. Ricky's great-aunt commented, "Funny that Ricky doesn't respond to anything." But most other family members and friends told Ricky's parents not to worry. They said that Ricky was a 2nd child, and that it sometimes takes 2nd children longer to start talking.



Ricky's parents were worried enough to say something to his pediatrician, who told them to take Ricky to an audiologist at a local hospital. At the hospital, Ricky had ABR testing (auditory brainstem response), which showed that he had a severe-to-profound hearing loss.

It took a whole week for Ricky's parents to find out the test results. A secretary who looked at Ricky's medical papers was not allowed to read the diagnosis to his parents over the phone. She explained that an audiologist had to read it to them. The audiologist did not contact Ricky's parents for another week. Ricky's parents said that waiting and not knowing for this week was very hard.

### **We felt like our dreams for Ricky had died...**

“You have all these expectations and aspirations. Here we were a young married couple with our beautiful 2-year-old daughter, and Ricky was a baby, and he was a boy, and he was wonderful and marvelous and redheaded! He was darling. He was going to go on and be a star. Whatever goes through your mind.

And then somebody comes up to you and says, 'Wrong, this kid can't hear anything. He is deaf.' You go from thinking he is going to be a star to thinking this is a disaster. He is going to fail at everything. He is going to be awful. It is going to be a nightmare. It is awhile before you get your arms around it. You go into this deep dark hole.”

### **...but then we realized they would just take a little more work.**

“When I came out of it, my goal was to give him back his stardom and to say, 'You can do anything you want with your life. You can be anything you want to be.' And I am going to work really hard to make sure you get your opportunities and that this doesn't stay as a handicap. That he becomes, you know, just a redhead deaf kid. Who cares? And that is what drives us I think in a lot of this stuff.”

— **Ricky's Mother**

### **Thinking about different options**

Ricky's parents were frustrated by the bad experience with the audiologist, and also very upset about their son's hearing loss. They didn't know what their options were. They took Ricky to a new audiologist at a major hospital in New England. She did more testing on Ricky, including an MRI and a neurological exam, to make sure that he did not have other problems in addition to deafness.

She also fitted him with hearing aids. The hearing aids helped him a little bit, but not much. They allowed him to hear very low-pitched, loud noises like low-flying airplanes. But they did not allow him to hear normal conversations.

Ricky's parents talked to their new audiologist and several other audiologists about their options for Ricky. All of them gave very similar advice. They all said it was important to choose a communication method right away, and stick to it as a whole family, so that Ricky could start learning to communicate as soon as possible. But no audiologist would ever tell the family to choose one method over another. No one would say that total communication was better than oral, or that sign language alone was better than total communication.

### **We had stumbled into a huge political debate.**

“I think the most difficult thing was getting unbiased information because there wasn't any unbiased information there and you were in the middle of this huge political debate...It was really very difficult to get information...I became quite resentful of the fact that there was very little information around that was accessible to parents who have to make these decisions because no one can make them for you.”

— **Ricky's Mother**

## Deciding on Total Communication

In the end, Ricky's parents decided on total communication by getting rid of other options that they didn't like. First they decided not to use sign language alone, because Ricky's mother worried that Ricky would not be able to communicate with his extended family in sign language.

Ricky's parents wanted him to be able to communicate orally. But they decided against a strictly oral approach because they didn't like any of the oral schools they visited.

The total communication preschool they visited seemed like "a much more comfortable setting," according to Ricky's mother. It was "more established and organized. Which isn't how you make a decision, but it certainly helps you when you are looking around at a school to feel like your kid might survive in the fray."

### Talking with other parents helped us decide.

“I met with a number of people who had deaf children from both sides of the road. And typically the kids who were totally oral had a horrible childhood because their parents couldn't communicate with them.”

**My larger family feels very uncomfortable with sign language because [where they are from] it is not done. People don't like signing. It is a very oral community for deafness. My mother used to refer to it as 'Oh, you are not doing that funny stuff with your hands with Ricky, are you?'**

**Ricky's Mother**

— Ricky's Mother

After a lot of research, Ricky's parents decided to start him in a total communication classroom that was part of an [early intervention program](http://www.raisingdeafkids.org/learning/ei/) (<http://www.raisingdeafkids.org/learning/ei/>) at a school for the deaf. The school was half an hour away from their house. After Ricky had been there for 2 years, his parents were very happy with the results and planned to keep Ricky there all the way through high school.

### Communication was key.

“The case that people [at Ricky's school] made to us, which I believe very strongly, is that language is language is language. You have to get language into these kids during the high language acquisition years, which are 0 to 5. And it doesn't really much matter what form of communication you use to get language in as long as you are getting it in.”

— Ricky's Mother

## Deciding on a cochlear implant

Ricky's audiologist was the first to tell the family about [cochlear implants](http://www.raisingdeafkids.org/help/tech/ci/) (<http://www.raisingdeafkids.org/help/tech/ci/>), when Ricky was 2 years old. She said Ricky might be a good candidate, especially because his hearing aids weren't helping him as much as everyone had hoped.

### Deciding whether or not to get a cochlear implant was tough.

“It is a horrible decision to have to make because you are deciding to implant your child, which is long surgery. There are a lot of risks in whether they get the electrodes actually into his ear properly, as to how much sound he will get. Whether or not he will ever figure out how to

use it. You know, there are a lot of variables in that. There was also the chance that he could break it any day.”

— **Ricky's Mother**

Ricky's mother finally decided that the worst that would happen was that Ricky would get no benefit from the implant. Since he had so little hearing left as it was, she figured he would not be any worse off if that happened.

**We didn't want people to hate him because of his implant.** “ Even the night before it was actually done I was still saying, 'Is this really and truly the right thing to be doing? Am I right, am I going to cause this child to be ostracized from everywhere forever?' Because the Deaf Community does not like people with implants. They don't like oral people either particularly. But they will deal with oral people before they will deal with [people with implants].”

— **Ricky's Mother**

Finally, Ricky's parents decided to go with the cochlear implant because they believed that it would help Ricky learn as much as possible. They planned to continue using total communication after the implant.

### **After the cochlear implant**

The surgery was very successful. After two years, Ricky's parents are still using total communication with Ricky, unlike a lot of families who drop sign language soon after their child gets a cochlear implant. His mother said she still thinks of him as a deaf person; the cochlear implant is just a tool to help him hear as much as possible and learn more quickly. His parents' biggest focus now is helping Ricky learn as much language as possible.

Ricky's parents are happy with Ricky's progress so far. He is learning a lot of language at school and at home with the implant.

### **Learning new words**

“ I mean we work, we do work. We do a lot of stuff with our kids related to language. We talk incessantly. In our house it is constant. My mother comes in and says, 'Why don't you be quiet?'

We have Ricky enrolled in a very good program, and the staff here and the program here are fabulous for Ricky. He loves it. He came home the other day with a pink flower that they made out of bits of tissue paper stuck all over it. I said to him, 'What's this?' 'Hyacinth,' he said. I nearly fell off my chair! Because, (a) he knows the name of the flower, but he actually said it, he didn't sign it. Because who knows what sign 'hyacinth' is. You probably spell it out. But, the point is that the program here is giving him a lot of rich language which is great...”

— **Ricky's Mother**

**We made the right choice.**

“For Ricky the implant has been great. Combining that with total communication has absolutely been the right thing for Ricky. Because he has learned the language. As soon as he feels comfortable that you will understand what he is saying, he drops the sign and moves on. So for us, it has been great. Because, pile new language into him and he will use it and use it and use it and then drop the signing, move on and use something else. He is funny. He is great!”

— **Ricky's Mother**

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*You can find this page online at:*

<http://www.raisingdeafkids.org/meet/families/ricky.jsp>