

## Child Who Needs Corrective Hearing Surgery Gets Wish

ABC News, 26 March 2013

*ABC News' Dan Harris, Julia Bain and Dr. Mark Abdelmalek report:*

You would have to look closely, but if you kept your eye on Carson Rubin, you would see he is consistently one step behind his preschool classmates.

Carson claps only after seeing everyone else doing it, sits for a few more seconds when all the other kids stand up, and stares off when teachers are talking to him.

"I think he's constantly trying to keep up," Shay Rubin, Carson's mother, told ABC News. "I think he wears himself out trying to keep up with everybody else, and trying to figure out what's going on all the time."

Carson is 5 years old and has a condition called auditory neuropathy, a hearing and nerve disorder where sound waves entering the ear can't reach the right parts of the brain.

For Carson, the world around him sounds like a radio station that's not quite tuned in.

"You hear a sound, but it's not very clear," Lauren Stott, Carson's audiologist said. "It's distorted or static. You feel like, ah, I can tell there's something there but it's not quite right."



Image Credit: ABC News

Carson's parents worry his condition is not only damaging his intellectual development, but also endangers his safety.

If there was a car coming fast down a street, he wouldn't hear it.

The good news is that there is a treatment that could dramatically improve Carson's hearing called cochlear implants.

Karen Munoz, associate professor of audiology at Utah State University, who is not involved with Carson's case, said: "Cochlear implants will open his world to sound and the ability to fully engage in the world around him."

Cochlear implants involve a surgery that has produced miraculous results for many children. But at a cost as high as \$132,000 per ear, individuals would either need to have \$264,000 on hand, or an insurance policy that covers the procedure.

The bad news is that when the Rubins first asked their insurance plan, Coventry Health Care of Georgia, they were told their policy didn't cover cochlear implants.

The exclusion for cochlear implants is listed on the Coventry Health Care of Georgia plan documents provided to the Rubins.

"Without appropriate access to hearing the skill to develop spoken language won't occur," said Munoz.

For Carson to get the surgery the Rubins were daunted by the idea they may have to set up a payment plan to get their son the treatment he needed to hear.

When ABC News first contacted Coventry Health Care of Georgia, Coventry issued the following statement:

"Coventry is committed to offering affordable coverage and access to high quality care to all of our members. While Coventry's policies provide coverage for a broad scope of benefits and services, no health insurance policy covers every procedure. Currently, states determine which benefits and services must be covered, and Coventry's policies always comply with state requirements. Consistent with the standards for Georgia's small group market and state regulations, Coventry's small group policies have not covered cochlear implants."

As many as 90 percent of private insurance companies and all Medicaid programs cover cochlear implants.

A 2008 Vanderbilt study estimated that 12,816 children would be considered for cochlear implants each year. And every year more than 1,000 kids who are candidates are likely to be denied cochlear implants by their private insurance companies.

In 2011, Coventry earned roughly half a billion dollars in profit. Allen Wise, Coventry's CEO, is number 53 on the Forbes list of richest executives, and in 2011 had a total compensation package of \$20.87 million, which could cover Carson's implants 80 times over.

"We're just an American family trying to raise children and have a family and this is the predicament we find ourselves in," Brian Rubin said.

Brian Rubin and Shay Rubin, a stay-at-home mom, live in suburban Atlanta, with their two children. At first, the parents turned to Facebook to raise money for their son's cochlear implants, raising nearly \$10,000, a drop in the bucket for a procedure.

Despite the setbacks, the Rubins remained determined.

"One way or another he's going to get what he needs," said Shay.

Coventry Health Care denied ABC News' repeated requests for an on-camera interview, but when ABC News made one last call to Coventry we learned they had changed their position on covering cochlear implants.

Coventry issued the following statement to ABC News on the matter:

"Until very recently, small group policies in Georgia have not covered cochlear implants, and Coventry's policies remained consistent with those standards. We understand policies have shifted, and as a result, we are making a similar change to our policies. Coventry Health Care of Georgia will cover cochlear implants for commercial members as of April 1."

Carson Rubin's cochlear implant surgery is scheduled on April 19.

This change in policy is only for members of Coventry Health Care in Georgia. But while Coventry Health Care operates plans in 25 states, cochlear implants are only covered for their members in Utah and now Georgia.

When asked if Coventry Health Care would change its cochlear implant coverage policy for its other 23 states, they told ABC News, "We are re-evaluating our policies in other states."

But coverage for hearing devices and specifically cochlear implants may improve with the Affordable Care Act, possibly as early as 2014.

Janet McCarty, the private health plans adviser at the American Speech-Language Hearing Association and a member of the organization's Government Relations and Public Policy Committee told ABC News, "Under the Affordable Care Act, as one of the essential benefits, there are rehabilitation and habilitation services that theoretically would cover health care services that would help a person keep, learn

or improve skills or functions of daily living.” McCarty hopes hearing aids and speech generating devices like cochlear implants would be covered under the Affordable Care Act.

The Rubins’ prayers were answered and when they heard Coventry had changed their policy to cover Carson’s cochlear implants, the shock was almost too much.

“I kind of couldn’t breathe for awhile,” Shay Rubin said.