

# Cochlear implants give boy with Down syndrome new lease on life

March 9 2015, by Stacy Finz

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Joshua Copen, who is deaf and has Down syndrome, with his mother, Iara Peng. Copen received cochlear implants to help him hear and learn to speak. Credit: Iara Peng

There was something wrong with Joshua Copen's hearing. No matter

how many times doctors told Iara Peng, Joshua's mother, that her baby with Down syndrome had normal hearing, she knew they were wrong.

"I was saying things to him and he wouldn't respond," said Peng, who lives in San Carlos. "Noises that should have made him react weren't. Sometimes children with Down syndrome respond differently to sounds. But Down syndrome or not, this wasn't right."

That was in 2009. Now, Joshua can hear. And talk. And take part in birthday parties. "He can participate in our family," Peng said. "He can participate in school. He can go to the doctor or the dentist and understand what's happening."

Peng said she owes Joshua's new lease on life to Kay Chang, MD, a pediatric otolaryngologist and otologic surgeon at Lucile Packard Children's Hospital Stanford and Stanford Children's Health, who passionately advocated for [cochlear implants](#) for Joshua. For many doctors, cochlear implants would have been an unconventional approach for a child with Down syndrome.

## **Profoundly deaf**

"Traditionally, developmentally delayed patients haven't been seen as ideal candidates for cochlear implants," said Chang, associate professor of otolaryngology-head and neck surgery at the School of Medicine.

"The electrical stimuli delivered by the implants have no resemblance to regular hearing. The brain has to adapt itself to learn the electrical patterns. Someone who is developmentally delayed isn't going to progress as fast as a child who is developing normally. However, just because it's a lot tougher to rehabilitate a child with developmental delay doesn't mean they won't benefit from it."

Chang didn't believe that hearing aids were enough to help Joshua hear

or learn speech; he thought the cochlear implants were the child's best shot for interacting with the world. Peng, who had looked at all her son's options, including sign language, agreed.

"Like my husband and I, Dr. Chang believed that Joshua can be anything—and that cochlear implants were critical to giving him the opportunities he deserves," Peng said.

The journey began when Joshua was 16 months old. An auditory brain stem response test—an examination of the nervous system that controls hearing—revealed that he was profoundly deaf. Hearing loss is not unusual for children with Down syndrome, who have a higher incidence than other groups. When Peng conferred with physicians across the country about what to do, they told her that the premier expert, Chang, was right in her backyard at Stanford.

## **A physician's dedication**

Although Chang and Peng were convinced that implants were the best option for significantly improving Joshua's quality of life, they had to prove it to insurance companies.

"It's a huge process to prove that a hearing aid won't work instead," Peng said. But Chang believed that with the right auditory rehabilitation and speech therapy program, Joshua could learn to take full advantage of the cochlear implants, and that's why Peng said she appreciated the physician's dedication to her son.

"Here was this world-class surgeon telling me he believed my son's quality of life mattered," she said, adding that that hadn't always been the case.

"You don't get the same reception treating a Down syndrome child that

you would get with a typical child," said Peng, whose two other children are developmentally normal. "What you get is a lot of pity and low expectations. Doctors will say, 'You're doing too much for him.' It's like they're giving up. Never once did I get the feeling that Dr. Chang was giving up on him."

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Chang performed the implant surgery in 2011, just before Joshua turned 2. There was a caveat to ensuring the implants' success. Joshua would have to attend a special school to learn how to train his brain to hear and speak. The family's insurance providers came through, convinced by Chang that the implants were Joshua's best course of treatment. Peng and her husband, Brent Copen, then enrolled Joshua in the Weingarten Children's Center, a nonprofit school in Redwood City that teaches language skills to kids with hearing loss. Joshua did so well after the first cochlear implant that six months later, he had the other ear implanted as well.

Joshua's life began to drastically change. Now 5 years old, he's in the 50th percentile for learning comprehension of all children his age.

## **Measuring benefits of implants**

John Oghalai, MD, is completing a study funded by the National Institutes of Health in which he is trying to measure the benefits of cochlear implants in developmentally delayed patients like Joshua. Oghalai is director of the Children's Hearing Center at Lucile Packard Children's Hospital Stanford and an associate professor of otolaryngology at the School of Medicine.

In a similar 2012 study, Oghalai found that the use of cochlear implants in deaf children with developmental delays can help them from falling

further behind their peers and shouldn't be readily dismissed. And the earlier the child gets the implants—12 months is the minimum age allowed by the FDA—the better, that study found.

Chang said the studies are significant, but he didn't need them to know that cochlear implants were the best choice for Joshua. "There is no question in my mind that without them, Joshua wouldn't have learned speech," Chang said. "Look at what a great success story he is. He's the best proof possible that we should never, ever write these kids off."

Provided by Stanford University Medical Center

Citation: Cochlear implants give boy with Down syndrome new lease on life (2015, March 9) retrieved 24 April 2024 from

<https://medicalxpress.com/news/2015-03-cochlear-implants-boy-syndrome-lease.html>

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