A Cochlear Implant for Zayd—A Young Child with Unilateral Hearing Loss
Part One—Gaining Coverage

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Before his second birthday, Zayd’s mother, Saba Ashfaq of West Virginia, realized that her son was not responding to her voice as he had in the past. Knowing that he experienced a head injury at 19 months, she knew there was the potential for hearing loss. It took over a year to confirm that her son now had profound deafness in his right ear. Thus began an eight month journey to the surgery and the challenge of obtaining Medicaid coverage for Zayd’s unilateral hearing loss.

Listening with Two Ears
For decades, the assumption has been that as long as a person had one good ear (amplified or not), the deaf ear could be ignored. However, a growing body of research has demonstrated that unilateral hearing loss impacts communication and especially language and learning in children. Research on this topic was reviewed in the ACI Alliance White Paper: In Support of Insurance Coverage for Cochlear Implantation in Cases of Pediatric Unilateral Hearing Loss authored by Lisa R. Park and others at The University of North Carolina at Chapel Hill. Children with untreated or undertreated unilateral hearing loss face significant educational, social, cognitive, and behavioral challenges. They are more likely to experience difficulty in educational settings and experience particular difficulty in noisy environments such as classrooms, restaurants, and airports.

Zayd Struggled with Unilateral Hearing
Saba Ashfaq witnessed first-hand the impact of listening fatigue. She saw that her son became overwhelmed and exhausted in noisy places. At an airport, Zayd could not hear his family and would look for them even if they were seated next to him. In his own home, he would “lose” his mom and go searching for her because he often could not place her location based on the sound of her voice. He became confused when he heard a siren outside and thought it was an indoor fire alarm. When his family noticed a change in Zayd’s hearing, they had his hearing testing and learned then the extent of hearing loss on the side of his fall.

Building a Case for Coverage
Reviewing the research on unilateral hearing loss convinced Ms. Ashfaq that the effects of unilateral deafness in a child were significant. She recognized the life-long impact single-sided profound hearing loss would have on her son’s life. With this research in hand, she actively pursued a cochlear implant for Zayd through one of West Virginia’s Medicaid providers, though she knew she was seeking a decision that was not part of the current coverage policy. With
support from her son’s early intervention educators and his medical team at West Virginia University, cochlear implant surgery for Zayd was scheduled for February 2019.

**Denial by West Virginia Medicaid**

It was no surprise that the initial request was denied because West Virginia Medicaid does not currently cover cochlear implants for single-sided deafness. What was unexpected was the second denial. Ms. Ashfaq was utilizing all of her research skills to track down information and reach out to anyone who could assist. She began researching and reading medical journals to shore up the family’s case for securing coverage. She knew time was of the essence as her son was approaching two years of age and she knew that early implantation would provide the best outcome.

Over the next few months, she reached out to everyone she could think of—CI manufacturers, other hospitals in West Virginia, hearing loss associations, additional ENTs and audiologists, local and federal representatives, other medical research facilities across the country, and Facebook groups. She realized that gaining CI coverage for unilateral hearing loss, while not unheard of, is difficult. But she also learned that some private insurance companies and state Medicaid programs were approving unilateral hearing loss CI surgeries, giving her hope that West Virginia might approve her son’s case.

In the end, West Virginia Medicaid denied coverage three times which meant Ms. Ashfaq had one final possibility—an appeal to the Board of Medical Services. Pressure was mounting as the rescheduled surgery date was fast approaching.

**Never Give Up**

One of the news articles she read was on US Congressman David McKinley of her home state. As Co-Chair of the Congressional Hearing Health Caucus and a cochlear implant recipient, he seemed like someone who might help. She thought “Why not?” and contacted him about her son’s case. Soon thereafter she received a call from Christopher Buki, the Congressman’s Legislative Director who then contacted American Cochlear Implant Alliance and asked if we could help. ACI Alliance members have conducted research and presented on cochlear implants for unilateral hearing loss. ACI Alliance asked if the University of North Carolina CI program would develop a white paper on relevant research, which they followed through on and we published.

Congressman McKinley provided this West Virginia family with additional support for coverage. ACI Alliance interviewed the Congressman for this article and he noted: “It was wonderful to be able to help Zayd get the device he needs. Not all hearing devices are the same, and it is key that people like Zayd have access to the device that will help them most. As the only Member of Congress with a cochlear implant, I will continue to work to ensure people with hearing loss are able to receive the care and hearing device that they need.”

With assistance from a pro bono attorney from Legal Aid of West Virginia Legal; Disability Rights of West Virginia; letters from Zayd’s school, clinical team, early intervention specialists,
educators of children with hearing loss; and the ACI Alliance white paper authored by Park et al, the fourth and final appeal was submitted to the state medical review board. The medical appeal board overturned the Medicaid decision and granted approval for coverage—one week prior to Zayd’s rescheduled surgery date.

Zayd’s surgery moved forward and on May 6th, his “Spiderman” ear was activated. While their journey is not over, Saba Ashfaq hopes her family’s story will motivate others to seek insurance coverage children and adults with unilateral hearing loss who may benefit from a CI. She notes “not everyone with hearing loss is a candidate for CI. And I understand that not every individual needs the CI intervention to reach their best quality of life. But the outcome of our research informed us; we decided as a family that moving forward with a CI was the best decision for our son.”

In Arabic, Zayd’s name means “to prosper.” We have no doubt but that he will do just that.