



# UNHS in Ohio



## Third Report to the Legislature



ORC 3701.509 (D), 3701.509 (A) (B), and 3701.504

**U**niversal Newborn Hearing Screening (UNHS) has been required in Ohio since July 2004. All 135 birthing hospitals, freestanding birthing centers and children's hospitals conduct hearing screenings and report results to parents, physicians and the Ohio Department of Health (ODH). Screening the hearing of newborns is critical. Permanent congenital hearing loss is substantially higher than the prevalence of PKU, hyperthyroidism, sickle cell anemia, or cystic fibrosis, averaging about three per 1,000 or about 450 infants per year in Ohio.

This report highlights activities and data in three categories: screening, diagnosis and early intervention. It also includes one family's story (on reverse). Their experience illustrates the importance of early ongoing monitoring for hearing loss.

According to the *Joint Committee on Infant Hearing, Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs*, all infants, regardless of newborn hearing screening outcome, should receive ongoing monitoring for the development of age-appropriate auditory behaviors and communications skills. Any infant who demonstrates delayed auditory and/or communication skills development, even if he or she passed newborn hearing screening, should receive an audiological evaluation to rule out hearing loss.

### National Standards for Early Hearing Detection and Intervention (EHDI)

#### Joint Committee on Infant Hearing EHDI 1–3–6 Goals

- 1—All newborns screened before 1 month of age
- 3—Diagnostic audiological evaluation performed by 3 months of age for babies not passing UNHS
- 6—Early Intervention services start before 6 months of age for babies with permanent hearing loss

### Screening

Ohio hospitals use automated otoacoustic emissions (OAE) and auditory brainstem response (ABR) hearing screening methods to test newborns before discharge.

	2007		2008	
	Number	Percent	Number	Percent
Total Babies Born	151,353	100	149,357	100
Reported Hearing Screenings	138,834	92	138,325	93
Screening Results not Reported	12,519	8	11,032	7

**Challenge:** Improve UNHS reporting.

**Action:** Educated hospitals about importance of complete, timely, and accurate screening results reporting.

### Diagnosis

Newborns not passing UNHS are referred to audiologists for follow-up hearing evaluations. ODH funds ten Regional Infant Hearing Programs (RIHPs) to help arrange for prompt follow-up appointments. Audiologists can perform tests to evaluate hearing while very young infants sleep. After 6 months of age, sedation (in a hospital) often is necessary in order to complete the testing.

	2007		2008	
	Number	Percent	Number	Percent
Total Non-pass Screening Results	5,304	100	4,865	100
<b>RIHP Follow Up and Tracking</b>				
Diagnostic Evaluations Completed	3,490	66	3,345	69
Evaluations in Process	629	12	290	6
Lost to Follow-up/Unable to Contact	1,122	21	1,151	24
Follow-up Evaluations Declined	63	1	79	1

**Challenge:** Reduce number of infants lost to follow-up and assure follow-up for diagnostic evaluation by 3 months of age.

**Action:** Improved transfer of referral data to RIHPs so families can be quickly contacted for assistance with audiology appointments.

### Early Intervention

Infants diagnosed with permanent childhood hearing loss (PCHL) are eligible for RIHP services, which provide language and auditory stimulation, information about communication options, family support and interaction with the deaf community. RIHP services are offered in all 88 Ohio counties at no cost to families. RIHP families also enroll in Help Me Grow (HMG), Ohio's birth to age 3 early intervention program, for help with needs in addition to the hearing loss. (Please visit [www.ohiohelpmegrow.org](http://www.ohiohelpmegrow.org) to learn more.)

	2007	2008
Number Diagnosed with Hearing Loss	163	242
Median Age at Diagnosis (months)	3.0	2.9
Infants and Toddlers (Birth to Age 3) served by the RIHPs Annually	500	552

**Challenge:** Continue to lower number of undiagnosed referral and subsequent entry into Early Intervention.

**Action:** Educated hospital and RIHP staff about the importance of prompt follow-up for diagnosis and revised the Parent brochure to emphasize the need for comprehensive diagnostic follow-up.

# How Brooke Hears

**B**rooke had her hearing checked soon after birth in mid-August 2005. The hospital personnel told her parents she passed the screening, but to be alert for hearing and speech development and have her checked if they had concerns. Brooke's father started to question her hearing when she was 2 months old because she did not respond to noisy toys clipped to the sides of her crib.

Brooke's parents talked to her pediatrician about their concerns when she was 4 months old. The doctor said in his 15 years of practice he never had a child who passed the hearing tests have a hearing problem. He advised waiting a couple of months. When Brooke was almost 6 months old, the pediatrician referred her for a hearing test. Due to an ear infection, it was two more weeks before the audiologist ran tests that showed Brooke had hearing loss in both ears.

The audiologist gave Brooke's parents a lot of information about assistance for a child with hearing loss, but they felt lost. Dad said, "First we tried to deny it. We tried everything possible to prove the tests wrong. But, she could not hear us." There was no family history of deafness and Brooke's parents didn't know what life would be like for her. "We got on the Internet right away—to research jobs for people who are deaf—because we were so worried," said Dad. On the audiologist's list of resources was the Regional Infant Hearing Program (RIHP) telephone number.

"I still remember calling the RIHP," said Dad. "The person who answered was so nice and told me, 'You aren't the first parents to face this and you won't be the last, and we are going to set an appointment so we can start helping you.'" Two days later, Brooke's parents met with the RIHP parent advisor. Brooke's parents say, "This probably was one of the most important meetings in our lives. She talked to us for a long time and had a special folder with all kinds of information. She showed us how to bridge the hearing and deaf worlds." The parent advisor gave them confidence, they recall, which was very important.

Life for Brooke's family became extremely busy as they added appointments with various professionals. Brooke was 6 months old when the otolaryngologist wanted another Automated Brainstem Response (ABR) test. Due to a testing cancellation, Brooke was able to have the testing completed that day. Brooke fell deeply asleep,

from the long day and the testing was done while she slept in her mother's arms. Often by this age, sedation is required. The testing showed Brooke had severe hearing loss in both ears.

The audiologist made ear molds for Brooke's hearing aids and a CT scan was conducted that determined her hearing structures were normal. Wearing hearing aids was a big challenge and she did not seem to respond to sound, even when they were in place. The parent advisor encouraged Brooke's parents to keep putting on the hearing aids and trying sounds of different pitches to stimulate the auditory nerve. She coached them in ways to help Brooke be aware of sound and to look at people's lips. They used simple sign language for objects and activities to foster communication and reduce frustration.

During the months leading up to Brooke's first birthday, her parents researched information about cochlear implants and the track records of cochlear implant manufacturers. A DVD showed young children with cochlear implants talking and playing, but they wondered if these were just "prize examples" and if other children didn't benefit as much. One day at the hospital, they saw a boy about 4 years old with a cochlear implant. Dad asked the mother's permission to speak with her son. When the little boy clearly said "I don't want to talk with that man," he was convinced that a cochlear implant would benefit Brooke.

The doctor felt Brooke was an ideal candidate for bilateral cochlear implants. The insurance company, however, denied authorization for the joint procedure (24 hours before the scheduled surgery). So, Brooke received a single cochlear implant at almost 14 months of age. It was activated when she was nearly 15 months old. She received her second cochlear implant when she was 17 months old and it was activated a month later.

Brooke cried when the first cochlear implant was turned on. The device had to be turned way down and then adjusted upward in successive weekly visits. Soon the babysitter reported Brooke looking toward the door when she heard a wind chime and clutching the sitter tightly when an airplane flew low overhead, scared by the loud noise. Brooke responded to equipment being turned on or off as she heard for the first time e.g.—the TV, vacuum cleaner, sound system. Her parents realized she could hear now. Today they say she hears even whispers.



Brooke began imitating sounds and soon she mimicked "Mama." The parent advisor demonstrated games to reinforce making sounds as the speech language pathologist taught them.

Brooke's parents identified two things that were most helpful on their unexpected journey into the world of hearing loss. The first was the strong emotional support of their family. Secondly, the support from the RIHP parent advisor. "Right from the first meeting," said Dad, "she gave us confidence and that was what we needed most to help Brooke to have a good life."

Now that Brooke is approaching age 5, her parents reported that she is doing well. They are amazed about her hearing. "She is very close to her normal hearing peers in terms of hearing. Thanks to the cochlear implant, she can even pick up 15 db sounds. That is simply amazing." Her Dad said, "She has no problem picking up two languages; Chinese and English. For some subtle Chinese pronunciations, she won't get it the first time, but after we correct her two or three times, she will get it."

## Tips from Brooke's parents:

- Be convincing and even assertive in following up on hunches you have about your child ("Maybe" says Dad, "because of shared DNA you can tell when something is different, even before the medical people can.")
- Be diligent and don't delay. Schedule appointments right away and keep checking.
- Be persistent with insurance companies and organized in dealing with them.
- Accommodating employers will allow parents flexibility so they can schedule all the necessary appointments.
- Keep working with the parent advisor and the therapists, even though it may be hard to fit sessions in, because their teaching on how to apply the methods is valuable.



For more information about the Infant Hearing Program, please contact the Bureau of Early Intervention Services at the Ohio Department of Health at 614-644-8389 or see [www.ohiohelpmegrow.org/](http://www.ohiohelpmegrow.org/) (infant hearing link)