

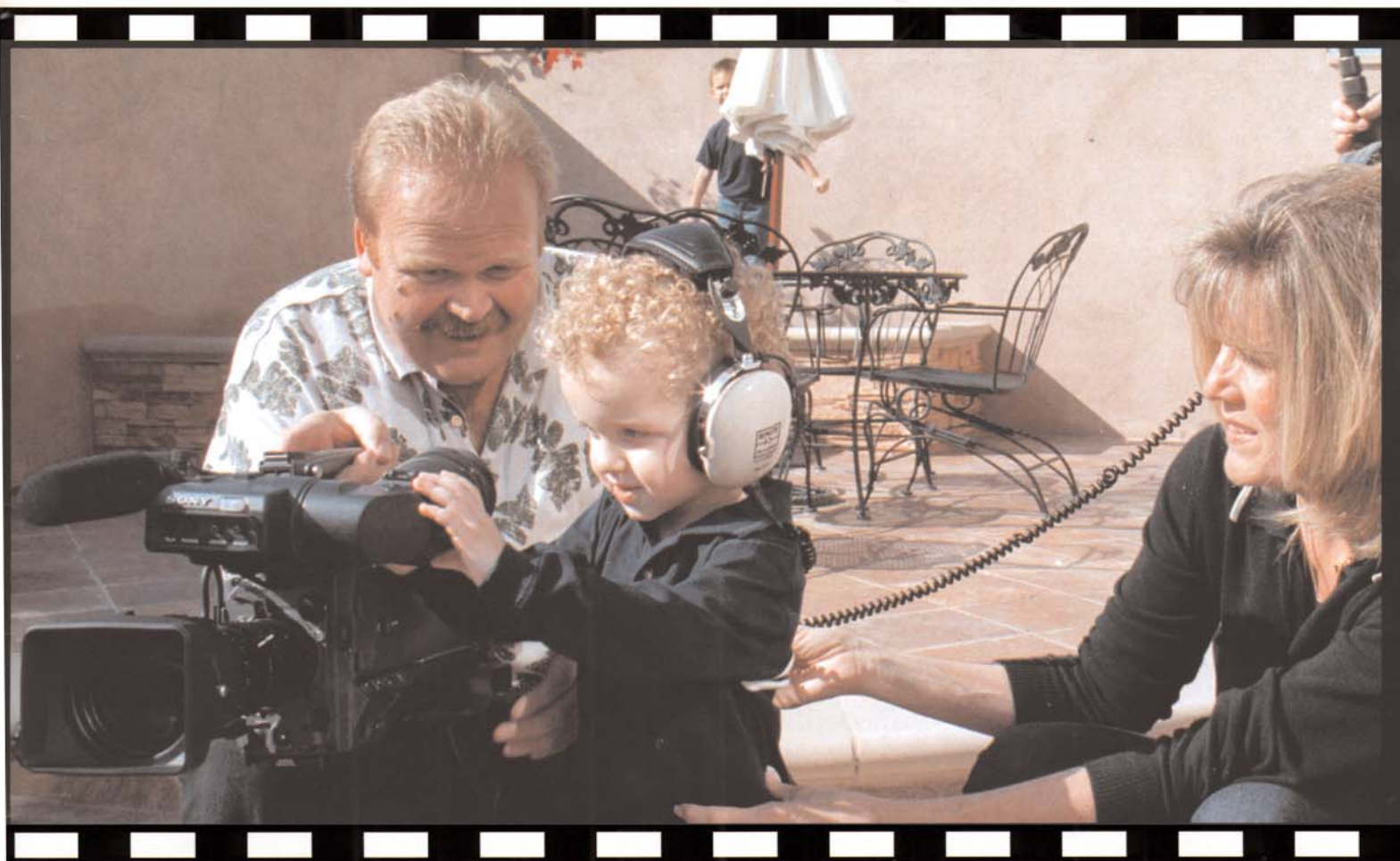
Documenting the Progress:



HEI's documentary team films Verscye with parents Ben, Jennifer and grandmother Debra.

A Young

In November 2002, the House Ear Institute's film crew visited little Verscye Jackson and his family to begin documenting his journey through the process of early hearing loss and rehabilitation with a cochlear implant. The House Ear Institute and MED-EL Corporation, the manufacturer of Verscye's cochlear implant device, collaborated on this project, with MED-EL serving as the corporate underwriter. Both organizations felt that a video documentary of the Jackson family's experience would be a valuable tool for educating other families facing the tough decisions and challenges involved in raising a deaf or hard-of-hearing child. The Jackson family, in turn, felt that by sharing their experiences with the camera, they might be able to help other concerned parents avoid some of the fears and confusion they had faced.



Verscye takes a camera lesson from videographer, Ron Martinsen.

Cochlear Implant Patient

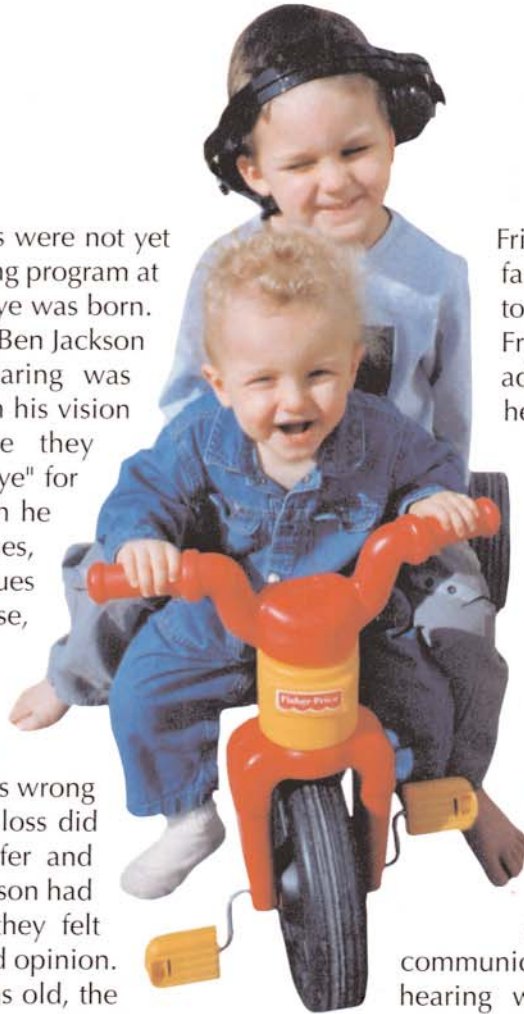
What follows is the Jackson family's compelling story – from discovery of their younger son's hearing loss to their first visit to the House Ear Institute's Children's CARE Center, where they received an orientation into the world of treatments and interventions for childhood hearing loss and early language development.

Hearing tests for newborns were not yet part of the initial screening program at the hospital where Verscye was born. Like many parents, Jennifer and Ben Jackson assumed that their baby's hearing was tested at the hospital, along with his vision and other vital signs. Once they returned home with Verscye ("Cye" for short) they noticed that although he was very responsive to visual cues, he did not respond to aural cues the way their older son, Adrease, had done as an infant.

Throughout Cye's infancy, Jennifer and Ben consulted with his pediatrician, who continued to reassure them that nothing was wrong with his hearing. Since hearing loss did not run in their families, Jennifer and Ben had no reason to think their son had congenital deafness, however they felt their suspicions merited a second opinion. When Cye was nearly 14 months old, the Jacksons were referred to a local audiologist, who performed comprehensive hearing tests on him and confirmed their fears. Cye had a profound hearing loss and it was likely he had not been hearing since birth.

The audiology center where Cye was first diagnosed did not provide any information about hearing aids or devices as possible treatments for his degree of hearing loss. The Jackson family, reeling from the news, weren't sure if hearing aids would ever be an option, and were not yet aware of an implantable hearing device called a cochlear implant. They purchased books and tapes on Signing Exact English (SEE) for the entire family and set about the task of learning a new mode of communication. Several days later, when the Jackson's pediatrician received Cye's hearing test results, he immediately referred them to the Children's CARE Center at the House Ear Institute (HEI) for further testing and appropriate intervention.

It was during their first consultation in the CARE Center and with House Ear Clinic physician Rick

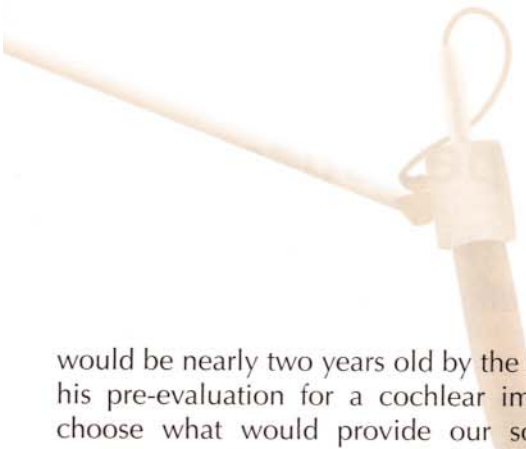


Friedman, M.D., Ph.D., that the Jackson family learned about the options available to treat Cye's profound hearing loss. Dr. Friedman advised that Cye undergo additional testing to verify the first diagnosis he'd received to determine if he might be a candidate for hearing aids. As a first step, he wore powerful hearing aids for a six-month trial period. During this trial period, Dr. Friedman and the CARE Center staff confirmed that Cye was profoundly deaf and was not receiving enough auditory benefit from hearing aid amplification. They considered him a candidate for a cochlear implant.

At this point, the Jacksons had to make a decision. Did they want Cye to grow up using oral modes of communication, or did they prefer to continue communicating with him in sign language and enroll him in a total communication class for the deaf and hard of hearing when he reached school age? If they decided that the cochlear implant was the best option, they needed to act quickly to ensure that Cye would receive the auditory access that the cochlear implant would provide during his crucial language-acquisition years. The Jacksons found these choices very difficult, and wished they could talk to other parents who'd been through this tough decision-making process on behalf of a child.

"Once we had a confirmed diagnosis from the House Ear Institute and Clinic, we did our homework on all of our options," said Ben Jackson. "I was lucky to have a wife who did her research, no holds barred. We learned about the deaf community and schools that teach sign language, but finally decided that for us, for our family, the cochlear implant was the best solution at this time."

"We learned that the cochlear implant would give Verscye sound so he could learn oral language and communicate verbally with his hearing brother," said Jennifer. "We felt pressure to make our decision on a tight timeline because we were advised that early implantation was optimal for language development. As it was, Verscye



would be nearly two years old by the time he completed his pre-evaluation for a cochlear implant. We had to choose what would provide our son with the most communication options in the long run, and then we moved forward."

After reviewing materials on the different cochlear implants available, the Jacksons felt that while all offered excellent products, MED-EL's miniature behind-the-ear processor with tamper-proof features would be best for their active child.

Once their decision was made, the Jacksons proceeded with Cye's cochlear implant surgery. The surgery was successfully performed by Dr. Friedman at St. Vincent Medical Center – located directly across the street from HEI. Eight weeks later, after Cye was fully healed from his surgery, the Jacksons returned to the CARE Center at the House Ear Institute, where the HEI film crew was ready to document Cye's initial stimulation or "hook-up" to sound.

The entire Jackson family gathered together in the cochlear implant mapping room for Cye's initial stimulation session. CARE Center audiologists worked with a MED-EL specialist to fit Cye with his external accessories – the microphone, transmitter coil and speech processor – and then test his hearing. Over a period of two hours, the audiologists programmed his speech processor using special software.

Cye responded well during his introduction to sound through his cochlear implant. His eyes registered surprise and curiosity as the beeps increased in volume. Over time, his audiologists predict that he'll gradually become more accustomed to receiving auditory stimulation, and begin to respond to environmental sounds, such as birds chirping and phones ringing. Later, perhaps six months down the road, Cye should begin to respond to his parent's voices and rudimentarily process spoken language. Follow-up

appointments will monitor his progress, and the HEI camera crew plans to be there to document each step in Cye's journey towards sound and oral communication.

When asked what their hopes were for Cye and his experience with the cochlear implant, Jennifer and Ben were very honest.

"We don't even know what to expect or how our child will react to sound," said Ben. "It's like bringing a newborn baby home for the first time – he may not be ready to respond to your voice, but you try talking to him anyway. We hope Cye will be speaking very soon, but we've learned from the experts that it doesn't work this way, so we'll try to be patient."

"One of our greatest hopes for Verscye is that



Jennifer and Cye work with HEI pediatric audiologist, Erin Manhke.

he'll eventually be able to verbalize his feelings and his needs," said Jennifer. "I especially want him to be able to respond to verbal warnings in dangerous situations. And of course, I hope to hear my son's voice when he communicates with me – that will be amazing. Now I may have the chance to hear my baby say, "I love you, Mommy." ❖