

Reaching Austin

He's been deaf and blind since shortly after birth. But with help, this little boy is learning to explore his world.

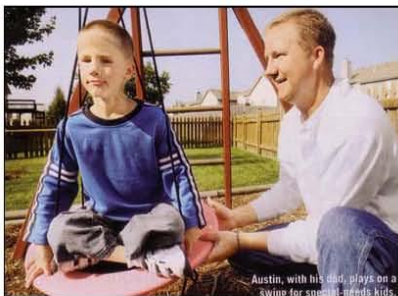
Reprinted with Permission of Good Housekeeping

By Elizabeth Gehrman

Published in Good Housekeeping Magazine, November, 2006

When seven-year old Austin Howell gets home after a long day at school, he might stretch out on the floor with his face pressed against an air vent, laughing as the cool breeze hits his cheek. Or he'll play in the water from a bathroom faucet, shrieking with delight as the liquid runs down his arm. Or lie in the sun on the backyard picnic table, stomping his feet to feel the table vibrate. "He can entertain himself for hours," says Austin's mother, Kari, 32, a ninth-grade English teacher. "I have no idea what's going on inside his head, but whatever it is, it must be pleasant and funny. He's such a happy kid."

Austin, who lives with his family in suburban Olathe, Kansas, is both deaf and blind. Many people know about deaf-blindness—or DB, as it's known in the community—because of Helen Keller, whose autobiography inspired the play and movie *The Miracle Worker*. Today, there are roughly 9,500 DB kids in the United States, most of whom have enough vision to make out some light, color, or even images, and sufficient hearing to recognize some sounds. But not Austin. He is one of very few children in America today who are both profoundly deaf and totally blind. He has no spoken or written



Austin, with his dad, plays on a swing for small, needs kids.

language to help him express his needs and navigate his dark and silent world. With just the tips of his fingers, the soles of his feet, and his lips, tongue, and nose, he explores texture and consistency, scent and flavor. Austin experiences life through only three senses: taste, touch, and smell.

When Kari and her husband, Thane, an accounts manager for a landscaping company, learned they were expecting their first child, they were thrilled. Kari felt fine—until her water broke 14 weeks early. "I was hysterical," she recalls. Her doctor tried to delay labor but couldn't; the baby was born two days later.

The first time the Howells saw Austin—who weighed under two pounds and measured less than 14 inches—he was hooked up to a ventilator with a tube down his throat. He stayed in the neonatal intensive care unit for nearly three months, fighting a series of problems common to premies. Several times the family wasn't sure Austin would live through the night, but he slowly recovered from each complication. Then, when he was nine weeks old, a routine exam showed severe damage to his eyesight from having been born too early. Three operations failed to help him, and Austin became one of the roughly 500 American children who lose their eyesight every year because of prematurity.

"Within a matter of weeks, it went from 'OK, he'll have tunnel vision' to 'OK, he'll be blind,'" says Kari. Then, at 11 weeks, he was given a standard newborn hearing test. He failed it and then failed two subsequent tests. No one could tell Kari and Thane what had gone wrong. Panicked, Kari brought her newborn to the hospital's neonatal intensive care unit, "I was



Austin and his mom, Kari, in the backyard of their Kansas home.

bawling," she remembers, "I said, 'You can have him back, I don't know what to do with him!' I had no idea how we were going to handle this."

On their own

Soon after Austin came home from the hospital, a social worker got the Howells involved with the Children's Center for the Visually Impaired (CCVI), a preschool in nearby Kansas City, Missouri, and specialists began coming to the house to get Austin going on what Kari describes as "every kind of therapy imaginable." At first the couple dealt primarily with the same kinds of problems—sleepless nights, endless diaper changes—that confront all new parents. But as Austin neared his first birthday, some of his unique needs became an issue. For instance, as soon as Austin sensed he was somewhere new (by smell, Kari thinks), he'd throw a raging fit, so the Howells were forced to spend much of their time at home. (Luckily, the pressure on them was partly relieved by Kari's mother, who lives nearby and could frequently babysit Austin.) ▶

When he turned three, Austin received a cochlear implant, which bypasses damaged structures in the ear and stimulates the auditory nerve directly. Tests now show that Austin's brain is responding to sound, though there's no way to know how clear the sound is or how much is getting through. Around the same time, he also started attending the CCVI preschool for a couple of hours every day, which was paid for by the school district.

Up to this point, no one could say what, if anything, Austin was capable of learning. He would spend most of his day lying on the carpet, never trying to move around the room. Soon though there were glimmers of hope that Austin could learn: By riding his hands on the back of his parents' and teachers' hands, he picked up a few basic words in sign language, such as *hug*, *more*, and *eat*. Through a one-on-one teaching assistant from CCVI, he also learned how to dress himself. Once Kari and Thane's burden eased slightly, Kari became pregnant with their second child, Karinne, now three. "To have her be born healthy and to get to hold her in the delivery room was amazing," Kari says. This September, she and Thane welcomed their third child, a girl named Kaylee.

A teacher takes a chance

At CCVI, Austin met Bob Taylor, one of only a handful of educators in the country who are specially trained in working with the deaf-blind. In Austin, Taylor saw a bright child who just needed the right guidance to bloom. Taylor thought he could help: On his consulting trips around Kansas, he'd notice that there were several DB kids living close to Kansas City. Taylor applied to the Kansas State School for the Blind (KSSB) to start a two-year program aimed specifically at them.

Since August 2005, when Austin started attending this specialized program, his improvement has been dramatic. "It astounds us what he can learn," says his grandmother Judy Howell. The boy who once sat alone on the floor "is all over the place," reports Taylor. Austin is also able to find his toys and keep himself busy. "Suddenly, he has the tools to explore his world, just like



Austin's sister Karinne helps him onto the deck. They often play together.

any other youngster." Taylor says.

Taylor and the other teachers at KSSB are documenting everything their special students do, hoping to learn which teaching meth-

ods work best. "You can't just use techniques for blind children and techniques for deaf children and put them together," he says. To help the kids know what to expect each day, the teachers have set up a strict routine: When Austin and his classmates walk into their room, one of the first things they do is to "square off," orienting themselves by leaning their backs against a table just inside the door. The students have learned where this table is in relation to other things in the room, and they're able to move without help to the play area, the toy shelves, and anywhere else. Objects on the table also cue the students to what is going to happen next: A rope signifies gym, a diaper means bathroom, and a spoon stands for lunch.

The dedication of Austin's teachers offers the best hope for his future, experts say. "The question is not 'What can Austin accomplish?'" insists Nancy O'Donnell, who has worked with DB people at the Helen Keller National Center for Deaf-Blind Youths and Adults for 25 years. "It's really 'What people will he be surrounded by who can unlock his potential?'" When Helen Keller was a child, people compared her behavior to that of an animal—and she went on to graduate from Radcliffe College and to learn to read five languages. Austin will have access to technology unthinkable when she was born in 1880, such as laser canes that vibrate when they approach an object, vibrating alarm clocks, and a refreshable display that translates words on a computer into Braille. "I expect Austin to become self-sufficient," says Sandra Davenport, M.D., a developmental pediatrician.

"The more he practices communicating the more—and faster—he'll learn."

A changed boy

At home, Austin now zooms up and down the stairs like any kid. To get to his play area in the backyard, he follows ropes that lead to a deluxe swing set, a large sandbox, and a trampoline. In Austin's bedroom, there's an inflatable ball pit and a smaller trampoline, a giant plastic barrel to roll in, and other toys designed for kids with special needs. Austin's sister Karinne enjoys the toys too, as do many of the neighborhood children, who often come by to play. The kids' parents have explained how to "say hello" to Austin—by tapping him on the shoulder and letting him feel their hands and wrists—and he loves jumping on the trampoline with the other children. "We're so glad we've found things he enjoys," says Thane. I can watch him play for hours.

Austin's increased independence has pretty much ended his tantrums. "Most of his outbursts were from frustration," says Kari. "Now he has more control. If he's bored, he'll come downstairs or he'll go to the door to go outside." Thane now describes Austin as an "adrenaline junkie with the soul of an athlete." About the only time Austin isn't laughing is when he falls—and even then, his scowl is short-lived. His grandmother Delores Fitzpatrick notes that he is very loving. "I'll be sitting with him on my lap and he'll give me the biggest hug and grin," she says. "He puts his arms around me so tight, and he's just so affectionate."

The Howells are comforted by the fact that Austin doesn't have any concept of all the typical childhood activities he's missing. "He doesn't go to sleepovers or birthday parties," says Kari. "But he's not hurt by it, so it's not as big a deal for us." She is optimistic that science will someday provide her son with sight or hearing and hopes that he will eventually learn Braille. For now, though, she describes her family as being "at a really good place. We're happier than we've ever been." ■