



THE POWER OF A

positive atmosphere

Jimmy Holmes' infectious smile and laugh say it all: He's a happy kid.

He smiles when his mother cuddles with him, laughs when his sister tickles him, and loves when his father sings to him. As long as he's around other people, that toothy grin and hearty giggle will make an appearance.

To some, Jimmy's happiness may seem surprising. He has faced numerous medical challenges in his short life. But to his mother, Sue Ellen, his enduring smile is proof that no parent should ever take no for an answer.

Before Jimmy was born, doctors in Syracuse, NY, told Sue Ellen he probably wouldn't live more than a day. He had hydrocephalus, or fluid on the brain, and agenesis of the corpus callosum, a rare disorder characterized by partial or complete absence of the corpus callosum that connects the brain's two cerebral hemispheres.

Sue Ellen refused to believe the doctors' prognosis. In what would become her standard practice, she searched for a more positive environment of care for her son. She eventually found one at the Kennedy Krieger Institute.

"If your child has any disability, Kennedy Krieger has an expert who can address any need you have," Sue Ellen says. "It's the 'go to' place."

The Holmeses' path to Kennedy Krieger began shortly after Jimmy was born, when doctors in Rochester, NY, treated Jimmy's hydrocephalus with a shunt to drain the excess fluid. The procedure was a success, but Jimmy still had ongoing health issues that needed attention.

In addition to agenesis of the corpus callosum, Jimmy had cerebral palsy, limited vision, nerve deafness in one ear, and Lennox-Gastaut syndrome—one of the most difficult-to-treat forms of childhood-onset epilepsy.

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Jimmy’s disabilities were caused by lymphocytic choriomeningitis (LCMV), a virus carried by wild mice that can infect pets, such as guinea pigs and hamsters, and cause severe birth defects in infants. Sue Ellen was exposed to the virus during her pregnancy.

At 18 months old, Jimmy was taking six different medications and still having more than 100 seizures a day. “I had lost my son,” Sue Ellen says. “He was in a drug-induced stupor.”

As she did before Jimmy was born, she started pursuing other treatment options, including the Ketogenic Diet—a calculated diet high in fat and low in carbohydrates that is used for difficult-to-control seizures in children. After his refractory seizure disorder was controlled at Johns Hopkins, Jimmy and his mother came to Kennedy Krieger seeking a comprehensive, coordinated management plan to optimize his function and potential.

Several specialists have treated or evaluated Jimmy at Kennedy Krieger, including Dr. Alec Hoon, director of the Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine, and Dr. Ewa Brandys, a physician with the pediatric rehabilitation program.

In 2003, Dr. Hoon performed a developmental assessment to determine the best treatments for Jimmy.

“Dr. Hoon is really the person who can tell you where to go or what the next step is,” Sue Ellen says. “He’s very preventative, and most doctors aren’t like that.”

Jimmy has spastic quadriplegia cerebral palsy, meaning he has muscles in parts of his body that cannot relax. Jimmy’s joints often become stiff and difficult to move, causing problems controlling movements, poor coordination and balance, and difficulty talking and eating.

After examining Jimmy’s muscles and bones, Dr. Hoon suggested aquatherapy and horseback riding to loosen his muscles and help him relax. Both suggestions worked remarkably well, Sue Ellen says.

Dr. Hoon also suggested Jimmy visit Dr. Joseph Pillion for guidance in finding an appropriate hearing device. Jimmy needed a device that could be used in a classroom, and in crowded situations. Dr. Pillion spent hours testing Jimmy, recommending the Phonak EduLink—a miniature wireless communication system. The system helps Jimmy filter speech from general environmental noise, which makes it easier for him to concentrate in the classroom.

“Dr. Pillion did not just mail a report to Jimmy’s pediatrician,” Sue Ellen says. “He explained everything to me in great detail on the spot—the ‘Kennedy Krieger’ way. He also showed me a sample of the Phonak listening device during our visit. Typically, we end up ordering out of catalogs for kids with special needs, and local doctors never have samples to show.”

Jimmy’s first appointment with Dr. Brandys lasted three hours. “Before the appointment, Jimmy was kicking his legs in a bicycle motion,” Sue Ellen recalls. “The first thing Dr. Brandys said when she walked into the room was, ‘Oh, this boy needs to be moving.’”

“I was surprised at how well he presented,” Dr. Brandys says of Jimmy. “He was smiling, very social, and attempting to use his hands. There was a lot of power coming from the inside.”

However, Jimmy still had neonatal stepping reflex, which most babies lose by four months of age, Dr. Brandys explains, “It’s rare that this reflex is active and working in a child his age,” she adds. “Without equipment, it’s impossible to use this reflex.”

After evaluating Jimmy, Dr. Brandys recommended the MKII Hart Walker—a customized orthotic walking frame that braces around the chest, pelvis, and lower

limbs with movable joints around the hips, knees, and ankles.

“The walker gives him a whole new perspective to feel sensation below his waist,” Dr. Brandys says. “It frees the hand of the child to explore his environment. Jimmy’s hands are his ears and eyes while walking. If he can move and use his hands to learn about the surrounding world, it’s a great benefit.”

Dr. Brandys completed all the necessary paperwork and spent hours on the phone with the family’s insurance company to ensure Jimmy’s new walker was covered.

Early in Jimmy’s life, doctors told Sue Ellen he would never walk. With the Hart Walker, Jimmy has initiated steps on his own.

Today, Jimmy is a thriving five-year-old. He does not yet speak, but his seizures are under control. He regularly attends aquatherapy at a nearby pool. He cheers for his sister at each and every one of her soccer games. He is even enrolled in school—and loving every minute.

“At the mere sound of the kids in his classroom he has a beaming smile,” Sue Ellen says. “Jimmy giggles out loud, and he laughs so hard that he has to catch his breath in between. I’ve watched him single-handedly make everyone around him burst into laughter—teachers, a classroom full of kids, and his family.” ■

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