



Davenport boy is beating the odds

Deirdre Cox Baker | Posted: Thursday, October 2, 2008 12:00 am

Kelly Hunt's newborn child had a curved pinky finger, a weak cry and extremely flexible limbs.

All of the signs worried those attending the birth. "The pediatrician immediately called genetics," said Hunt, the mother of Kevin Pilgrim, who is now 7 years old.

Hunt was told by the geneticist that Kevin had three extra X chromosomes and would be severely retarded, and unable to walk, talk or feed himself. "I was so shocked," she said, adding that the baby looked just perfect and beautiful to her. "I started to cry and cry."

Happily, the doctor's prognosis was wrong.

Instead, Kevin has a rare disorder that occurs in about 1 of every 100,000 births, said Dr. Carole Samango-Sprouse, a neurodevelopmental specialist at George Washington University in Washington, D.C.

Samango-Sprouse has helped identify the "49ers," children born with three more chromosomes than the normal number of 46. While the condition might mean a youngster will have learning and developmental disabilities, they may not have mental retardation.

The doctor has founded the Focus Foundation in an effort to help 49ers and those with other types of sex chromosome disorders, dyslexia and developmental dyspraxia.

From Alabama to Iowa

Kevin was born in Alabama, but Hunt moved her family back to Davenport in 2005, two weeks before Hurricane Katrina hit the Gulf Coast. She was able to see Samango-Sprouse in July to help with Kevin's evaluation.

Kevin does not speak normally, but he can read and recognize what the doctor calls "a remarkable number of words." He is in the Exceptional Education Program at Jackson Elementary School in Davenport and is being treated by a speech pathologist.

"He's super-smart," Hunt said with pride. It took her son some extra time to learn to walk, but Kevin keeps up with three younger siblings these days.

Hunt works at a Davenport restaurant and attends college full-time. The four children in the family include a 7-month-old daughter, Melina, whose father is Hunt's partner, Cory Reinhardt.

Kevin loves to cook

"Kevin is a wonderful, energetic worker. He wants to dig in, to figure out what you are trying to teach him," said Beth Bair, his teacher at Jackson.

"His willingness to learn is key to his development, and I attribute a lot of that to Kelly."

He's also a typical big brother to Christopher, 6, and Zachary, 4, and he loves to cook and serve food, Hunt said. Kevin also likes to put items together to make a new potion, especially in the kitchen. This habit has given him the title "mad scientist," a term used by both his mother and teacher.

Road trip required

When Kevin was diagnosed with three extra X chromosomes, his mother got on the Internet to try to find more information. There was nothing available seven years ago.

Hunt eventually joined an e-mail list that connects families who have children with similar disabilities. That led her to some

specific help through the Focus Foundation, based in Maryland.

Hunt, Reinhardt and the children took a break in late July to drive out east and meet with Samango-Sprouse. They received \$2,000 in grants and aid to help with expenses and multi-disciplinary testing.

Samango-Sprouse, who organized a 49ers Conference through the Focus Foundation, has treated a number of “49” boys, focusing on early intervention and targeted treatment methods to help the children.

It was the first time the family had seen others with the same disorder as Kevin. “There were 18 kids there and they all looked like brothers,” Hunt said.

Samango-Sprouse’s analysis showed Hunt that her child was reading and understanding much more than previously thought.

“You need to be around him to understand what he’s saying,” Reinhardt said.

“He says ‘No, Mommy!’ really well,” Hunt added with a laugh.

Many successes

“He speaks very softly, and it’s hard for him to get words out,” said Bair, who has been Kevin’s teacher for two years. But the boy makes many more initial letter sounds than he did last year and is able to communicate with less frustration, she added.

Kevin is a classroom helper and loves to assist other children — with sign language, for instance. “I let him help the kids; it’s good mentoring for the children, and it’s good for him to practice with others,” Bair said.

“Instead of seeing a disability, we identify the unique ability,” Samango-Sprouse said. “In Kevin’s case, he can’t speak well, but he does have very good word recognition.”

Kevin is able to do much more than what some anticipated he could achieve, Bair said. “Kids like him are just amazing,” she added.

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ON THE WEB: The Focus Foundation Web site is thefocusfoundation.org.