

Hunter is Knowles family 'miracle'

Second benefit for CdLS Foundation is scheduled for June 13 in Seabrook

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SEABROOK — Everybody loves Hunter.

At 3 years old, Hunter Knowles, with his curly blond hair and his gleeful smile, wins the hearts of everyone who meets him and hears his story.

Knowles was born with CdLS, a congenital syndrome named for Dr. Cornelia de Lange, the Dutch pediatrician who first recorded her observations of the disease in 1933. Her initial studies noted similarities in characteristics between several children, as well as common medical problems.

But while his parents, Jason and Marcia Knowles, suspected early on that Hunter might have developmental issues, it took an agonizing 21 months for a diagnosis to be made.

"He was developmentally behind and had a small stature," Marcia said.

With appropriate diagnosis from other medical professionals, the Knowles sought out a geneticist, Dr. John B. Moeschler, who told them Hunter had CdLS.

"It was a bittersweet diagnosis," Marcia said. "It was a blow as a parent to receive this news, but it finally had a name."

Marcia said she and her husband, along with the diagnosis, were immediately handed a packet. It gave them information about CdLS and how to contact the foundation that assisted parents in dealing with the disease.

"The CdLS Foundation was God to us," Marcia said. "We were devastated, and to call them and have them empathize — I don't know where we'd be without the foundation."

Marcia said she feels lucky that Hunter's most serious symptom associated with CdLS is his severe acid reflux. Others she has come to know through the CdLS Foundation often have more severe issues, including mental retardation. The condition also may include both internal and limb abnormalities.

With the diagnosis, Marcia said, came the next step. The family became proactive about dealing with the disease.

The diagnosis came in the fall of 2007 and by the following spring, the Knowles family — and the many, many friends who have supported Hunter since birth — organized a benefit walk called "Hoof-it 4 Hunter." The event raised more than \$6,000 for the Cornelia de Lange Syndrome Foundation.

In the year that has passed, and with another walk planned for June 13, the changes in Hunter's progress are nothing short of remarkable, his mother said. He goes to school as part of the Reverse Mainstream Pre-School at Seabrook School, where, for 2½ hours a day, four days a week, he receives speech therapy while socializing with other children.

He happily shares his thoughts with his family using sign language even as he begins to master speech.

"He has an unbelievable memory," his mother said. "He can now identify 17 countries and continents."

With that, Hunter ran to his room, climbing up on his brother, Jason's, bed to show off his geography skills on the map on the wall. That's an academic exercise that just started a couple of weeks ago, Marcia said.

Hunter is also a bit of a Matchbox Car addict, come to find out.

However, there are still social issues the Knowles family must work through.

"He doesn't transition easily," Marcia said. "He needs structure.

He often is fearful of strangers, she said.

Despite Hunter's progress, he still has a long list of medical specialists in his life, including gastroenterologists, audiologists and ophthalmologists, to name a few. The Knowles are also regulars at health food stores, choosing probiotics, flax, Vitamin C and special teas as a natural path to cope with Hunter's compromised immune system.

"During those first 21 months, the advice I kept getting was to feed him more," Marcia said. "For 21 months, I was forcing him to eat."

These days, Hunter loves all foods, his mother said. The avocados and coconut milk that she was giving him for their fat content are now just some of the many foods he has come to enjoy.

"Hunter has brought so much love into this family," Marcia said. "Miracles happen because of Hunter.

"He has wiped out all the dysfunctions that so often are present in families," she said. "I really truly believe that Hunter chose us."

Marcia said having an older brother, Jason Jr., 10; and sister, Tessa, 14; is a big advantage as well.

"I am thankful for him," she said. "I'm thankful for me."

On Saturday, June 13, at 10 a.m., the 2nd annual "Hoof-it 4 Hunter" 2-mile walk will kick off from Seabrook Elementary School, 256 Walton Road. All proceeds will benefit the Cornelia de Lange Syndrome Foundation.

For more information or to request a pledge form, contact Marcia Knowles at 603-474-1966. To learn more about CdLS, visit www.CdLSusa.org.