

OUR ANGELS Shaw family spreading awareness for CdLS

Wednesday, June 19, 2013
By Brandon Hurley -- Staff Writer

Angela Shaw had a big heart.

She also had a playful personality and a strong will to live.

A rare genetic disease called Cornelia de Lange Syndrome (CdLS) robbed Angela of a full lifetime here on earth. She would've been 40 years old in 2013. Her parents, Bob and Kate have spent the last 35 years spreading awareness about the disease.

Angela's parents have created a weekend full of activities capped off with a concert benefiting those affected with CdLS. It's a way to connect families affected by the disease and allow them to share their experiences. Tickets are \$10 for "Our Angels Concert - A night to Remember Hud and Angela Shaw" at 8 p.m. Saturday, June 22 at the Sami Center in Spirit Lake.

LIVING WITH A DISEASE

CdLS affects mental and physical capabilities and also causes deformities. There were only 50 known cases of the disease in the entire world when Angela was diagnosed in 1973. Doctors told her parents to prepare for a funeral -- Angela's life expectancy was three to five years.

Multiple identifiable physical symptoms are present in those affected and often look very similar to one another. A protruding unified eyebrow or deformed extremities are common among most CdLS individuals. Angela was born missing a finger -- other children are born without legs or arms. Angela couldn't walk or talk. She was able to stand with help by the age of 5 and could take a few small steps. Crawling was Angela's preferred way of getting around. If she spotted a toy across the room and someone else desired it as well, she'd beat her playmate to it every time.

"Communication with her was very difficult," Bob said. Many of their conversations would consist of spitting and goofy noises.

She was also born with a very low birth weight. She only weighed eight pounds as a 1-year-old and 17 pounds when she died at the age of five.

For the first year of Angela's life, Kate and Bob lived in fear. The life expectancy for CdLS varies from person to person. They walked on eggshells not knowing if she would live to see another day. A normal sickness would send her into a coma. She got pneumonia with such regularity that it was as frequent as the common cold.

Angela had a bright personality and loved to goof around. She would let her parents know of her displeasure when they brought a new baby into the world by turning her back in pictures. She loved to eat and her favorite foods were spaghetti and chocolate.

Angela had many people impact her during her short life. Her teacher became a great family friend and was instrumental in her development. A doctor they met from Mason City that they call "Dr.

Justin" was the only professional they could find that truly understood her disease. Her bus driver to and from school quickly fell in love with her -- Angela touched many, many lives.

SUPPORT FROM THE COMMUNITY

On Angela's 30th birthday 10 years ago, the Shaw's held an event for CdLS families at Cutty's. They had 14 families come from all over the country.

These gatherings between CdLS families have not only been a way to spread awareness of the disease, but it also has been a coping mechanism. It was a powerful moment 10 years ago and the Shaws hope to recreate the scene once again this weekend.

"It's like getting our daughter back each time," said Bob Shaw. "The kids and families had a common bond when they met each other."

CdLS families show an unbelievable resilience. The disease creates a tremendous financial burden on families -- many parents work two jobs and would do anything to help their children live a longer and easier life. There is no cure for the disease and is very difficult to treat. Doctors have identified the gene that creates complications, but because there are so many different variations, it's tough to treat. Some victims can live into their 40s while others die as young children.

"Being a parent, we understand the need to connect," said Kate Shaw. "Angela was really an inspiration."

The Shaws have planned the weekend with many events to help the families take a break from daily stresses and to find a sense of normalcy. The weekend culminates with a benefit concert called "Our Angels Concert" -- the Shaw family lost two of their children at a very young age. Nine months after Angela was born, Hud, who was three years old, passed away from a viral infection.

"Hud was always a protector of Angela," Kate said. "He loved her from the moment he saw her."

The Shaws know that the people will come to show support on Saturday.

"We've had a tremendous response from this community," Kate said. "We couldn't live in a better place and all the businesses have been very supportive in our cause as well."

© Copyright 2013, Dickinson County News

Story URL: <http://www.dickinsoncountynews.com/story/1979118.html>