

UCSC alum's nonprofit could be a winner

The Gwendolyn Strong Foundation is in the running to win \$1 million prize money

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SAN DIEGO — When Gwendolyn Strong was born just over two years ago she was the perfect baby: happy, healthy and like her name, strong.

Little did her parents know, all that was about to change.

When Gwendolyn was just 3 months old she seemed to be having trouble feeding, said Victoria Strong, her mother a UC Santa Cruz alumni who now lives in San Diego. A few days later, on the advice of her pediatrician, Strong took Gwendolyn to the local hospital.

"Thank goodness we did," Strong said. "Because by that night she was not breathing — her whole system had crashed."

Doctors diagnosed Gwendolyn with spinal muscular atrophy, a genetic disease that causes muscle wasting in the arms and legs of infants and children. Children with the disease are unable to make their own motor neurons and gradually lose the ability to move, eat or even breathe without assistance.

Strong and her husband, Bill Strong, were devastated.

"To watch your child degenerate and not be able to do anything is torture,"



MEG FISH/CONTRIBUTED PHOTO

Gwendolyn Strong at 2 years old is totally paralyzed by spinal muscular atrophy. Her mother, UC Santa Cruz alumni Victoria Strong, is raising money for a cure.

Victoria Strong said.

One in 40 parents carry the recessive gene for the disease, according to the Spinal Muscular Atrophy Association, so a significant number of infants are born with it. However, the outlook for sufferers is poor: Most children don't make it to their second birthday, according to the National Institutes of Health.

At 6 months old the outlook for Gwendolyn was bleak, Strong said.

"The neurologist said just take her home and love her, there is nothing that you can do," she said.

Gwendolyn has proved him wrong, however. With breathing and feeding assistance she has made it to her

second birthday and continues to thrive. Although she is now totally paralyzed, she is a feisty and happy baby, who loves to be spun around, Strong said.

Equally exciting is that a possible cure the disease, which was previously believed to be incurable, is in sight, Strong said. New stem cell technology, which uses a patient's cells, not embryonic stem cells, could reverse the symptoms, she said.

In 2008, Strong visited a research group of UC Irvine, run by neurologist Dr. Hans Kerstead, who was investigating a cure. She watched mice, whom had previously been paralyzed by the disease, walk again.

"I just crumbled at the knees," Strong said. "I didn't realize how much hope I still had in my heart."

From that moment on Strong's vision was crystallized, she said: to raise money to find a cure for spinal muscular atrophy. She and her husband founded the Gwendolyn Strong Foundation to raise awareness of the disease and raise money for research into a cure.

"How could we sit there as parents and hope that someone else will do it," Strong said. "If it is just money, then we can do that."

The foundation has raised \$200,000 including the \$25,000 for making it to the final 100 nonprofit winners of Chase Cos. innovative Facebook charity giving campaign.

"We beat out 500,000 nonprofits," Strong said. "For a disease that no one has ever heard of, it is incredible."

Now the foundation is in the running to win the grand prize, the \$1 million jackpot. The Chase Community Giving Facebook Campaign is an online competition where Facebook fan's vote for their favorite charity.

Voting for the \$1 million prize opened Jan. 15 and closes Friday. The Gwendolyn Strong Foundation is currently in seventh place.