

SANTA BARBARA

# LIFE & STYLE

MAGAZINE

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# Morton Capital Management Celebrates SANTA BARBARA WOMEN MAKING WAVES

## Victoria Strong

Never Give Up

Victoria Strong's Quest to Help Change the Future of Spinal Muscular Atrophy

Photographed by Carly Otness

Written by Madison Ludlow

### The Journey Matters

When two people received life-altering news about their firstborn baby girl, they never would have imagined the news would influence the world. Victoria Strong and her husband, Bill Strong, found out their six-month-old daughter, Gwendolyn, had a debilitating recessive gene called spinal muscular atrophy, also known as SMA. Blindsided by this discovery, the Strongs were told her disease was incurable and that the best thing for them to do was take Gwendolyn home and love her abundantly because her life would be short. At that moment they could not have predicted how Gwendolyn's life would influence the local and global community impacted by SMA.

With the mindset that Gwendolyn's life could help save others, Victoria and Bill altered their careers in order to start the Gwendolyn Strong Foundation (theGSF). Pouring every ounce of energy into educating themselves about SMA, it was clear to Victoria and Bill that information available to the public regarding this terminal disease was scarce and limited. The Gwendolyn Strong Foundation was created to serve as a touchstone in the community to provide much-needed information and resources about SMA.

### Innovation through Purposeful Change

TheGSF has raised over \$2 million for research and support programs and granted funds to 25 different research institutions in less than eight years. "Like all of our other programs, we've always focused on areas in the nonprofit world where gaps exist," says Victoria. Through their Project Mariposa initiative, they have granted 250 iPads to children and adults who have been severely disabled by SMA.

While running the foundation, the Strongs simultaneously developed the NEVER GIVE UP. nonprofit apparel brand that gives 100% of the proceeds from purchases to help fund programs and empower supporters of theGSF. "Gwendolyn's effect on others is what spawned the foundation. She was never able to say a word—but she made people listen," Victoria shares. Gwendolyn's story was shared on TED Talks and on the floor of Congress. Her picture is mounted in research labs worldwide, spreading awareness of this neuromuscular disease.

Their successes and innovation didn't stop there. The Strongs built a first-of-its-kind communication application for the iPad called Say Hi! AAC, designed to help the severely disabled communicate without having to touch the iPad screen. This application is not only relevant to those with SMA but its use extends to many other communication challenges in children and adults. With a download count of 150,000 people globally, this application brings people together like never before.

### Wave of the Future

The Strongs found that running the foundation grew out of their passion to create meaningful change and stemmed from their irrevocable love for their beautiful daughter, Gwendolyn. Gwendolyn passed away, just shy of eight years old, on July 25, 2015. The Gwendolyn Strong Foundation was created to educate the public and provide tangible support to the families and friends affected by SMA, but this "never give up" mentality was something that Victoria wished to strongly convey. Victoria urges those affected by SMA to not "let their diagnosis define their life. Listen to your child and help them live the life they want." Anyone who knew Gwendolyn would say she never gave up on life. Gwendolyn's legacy and the Strongs' efforts do not go unnoticed locally in Santa Barbara or globally by those affected by SMA. Their journey and accomplishments are not about them, but about the impact they are creating every day in thousands of families locally and nationwide. \*

For more information about the Gwendolyn Strong Foundation, go to [thegsf.org](http://thegsf.org).

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