

Hero Quest: In Search of a Star to Shine Light on Spina Bifida

Laura Tellado has a mission to make the condition she and more than 166,000 other Americans were born with a cause célèbre.

By Christina Hernandez



Laura Tellado didn't choose spina bifida. The condition chose her, striking before birth and leaving a signature lesion on her spine.

More than two decades later, Tellado hopes others will choose spina bifida—as a cause.

As the author of the blog “Holdin’ Out for a Hero,” (willyoubemyhero.wordpress.com) Tellado, 23, has devoted the last year to encouraging movie stars and other big-name public figures to serve as spokespeople for spina bifida, and to educating the public about the condition she lives with. As she works toward an August graduation from the University of Central Florida in Orlando, Tellado posts on her blog just about every day, profiling actors, political leaders,

corporations, and others in hopes that some will agree to advocate for the spina bifida cause.

“I always wanted to do something big to get spina bifida on the map,” Tellado said in an interview. “It’s about more than just giving money. It’s about creating awareness. It’s about making it a household name.”

A Blog Is Born

Seven out of every 10,000 children in the United States are born with a neural tube defect such as spina bifida, according to the Spina Bifida Association. It’s estimated that more than 166,000 Americans live with a form of the condition. And as a Latina—Tellado was born in Puerto Rico—she is among the population most at risk for spina bifida, according to the Centers for Disease Control and Prevention. “My greatest fear is that as the preventive measures become so mainstream,” Tellado said, “they’ll forget about those of us for whom it’s too late to prevent it.”

Despite staggering statistics, Tellado said she felt spina bifida hadn’t garnered the media attention it deserved. She has watched as celebrities championed other health causes, pushing those conditions into the national limelight. “They always choose something else,” Tellado said. “They never choose spina bifida.”

So on August 29, 2009, Tellado turned her frustration into action. She published the first post on “Holdin’ Out for a Hero,” writing, in part: “Everything I have done, lived, dreamed and experienced in my life has led me to this very point, this blog that I am starting today... The goal will be that, by the end of the year, I will have recruited someone to adopt the role of spokesperson for spina bifida.”

Posting almost every day since—even through a jam-packed New York vacation—Tellado has reached out to some 300 people and companies. When she posts profiles of her subjects, including President Obama, Shakira, McDonald’s, Scarlett Johansson, and more, Tellado typically explains her choice by touching on their philanthropic efforts or on a personal connection. She accompanies each post with a personal letter to her subject, asking them to be her “hero.”

Blog posts require a time commitment of up to four hours, Tellado said, depending on the amount of research and writing involved. An aspiring journalist, she prides herself on not making mistakes. Tellado’s mother, Myrna Calderon, serves as copy editor, alerting her daughter to spelling or grammar slip-ups.

As she charged through weeks

and months of posts, Tellado said her mission evolved. Not wanting to lose interest after securing a single celebrity spokesperson, she decided to aim higher. “What started out as a search for just one national spokesperson has turned into a search for maybe a team of heroes,” she said. “We need star power. Anybody who’s really, really high profile can spark interest in the cause in the public eye. I think spina bifida needs and deserves that attention.”

The Spina Bifida Association, a national health organization based in Washington, D.C., is educating the public that spina bifida doesn’t have just one face, said Amanda Darnley, director of communications and marketing. “We really want people to know that it’s something that can happen in any family,” she said. “We welcome friends of every walk of life, and certainly influential friends are an important part of the organization... It’s amazing to see people, like what Laura’s doing, really taking the ball and running with it.”

Fearless

“Holdin’ Out for a Hero” has grown significantly since its launch last summer. Page views leapt to about 800 to 1,000 daily, Tellado said. The blog’s Facebook page has more than 300 fans from around the world. Other blogs and media outlets have also taken notice. In February, Tellado wrote a guest post for Hispanosphere, a blog on the *Orlando Sentinel* website about Latinos in Central Florida. “She’s definitely getting the word out and I think people are more aware of the spina bifida cause now,” said Alsy Acevedo, an *Orlando Sentinel* and *El Sentinel* staff writer who wrote about

Tellado. “She’s fearless.”

Though she reveled in her successes, Tellado admitted the blogging life has not been without difficulties. At times of panic, when she faced “mini-meltdowns” over fear she’d run out of subjects or be unable to handle the daily grind of posting, Tellado considered giving up.

But it was publishing the blog’s FAQ page that took the most confidence, she said. The post was inspired by an e-mail she received from a reader whose child had spina bifida. Believing parents deserved to know the basics of life with the condition, Tellado drafted a lengthy—and very public—missive that bluntly describes everything from the 19 surgeries she’s endured to her struggles with catheterization and bowel incontinence. Though she worried anonymous commenters would label her “a freak” for her admissions, Tellado said she was motivated by the need for education. “There are some basic key points about living with spina bifida that I think everybody should know,” she said.

And when she does encounter negativity, Tellado turns her anger into dedication. “What really motivates me: it’s a chip on my shoulder that I’ve been carrying for 23 years,” she said. “The complete bitterness that I feel when somebody calls me crippled... If something makes you angry, you really shouldn’t just sit and take it.”

It’s not only inner strength that motivates Tellado. The blog, she said, “really helped strengthen a lot of the relationships that I didn’t even know where there.” And although she’s spent months waiting for responses from her profile subjects, Tellado has

garnered some big-name backing.

Among the celebrity responders was Tellado’s friend and journalism mentor, Bill Hemmer, the co-host of “America’s Newsroom” on FOX. The two have kept in touch regularly since they met in 2004 when Tellado chose to meet Hemmer through the New Hope for Kids Wish Program. “She has a spark and an energy that is quite uncommon,” Hemmer said. “Her enthusiasm to bring attention to not just her specific case, but to all people that live with spina bifida, that’s her cause and she’s brought a tremendous energy to that.” And when Tellado asked him to be her “hero,” Hemmer said, “I told her I was game.”

As the blog’s one-year anniversary approaches, Tellado said she’s been considering the next step. Though she originally committed to “Holdin’ Out for a Hero” for one year, she plans to keep the blog going—but without the pressure of daily posting. “It wouldn’t kill me to keep going,” Tellado said. And even if she wanted to quit the blog, Tellado said she’d miss the support network she developed through her posts. “I’ve become almost as dependent on it as they have,” she said of her hundreds of loyal followers.

Whatever her path, Tellado said she’ll continue to champion her cause. “Everybody should have a cause,” she said. “People that have some sort of physical challenge are no exception.”

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