

INSPIRE: Barbara Huntress Tresness

By Lorna Oppedisano on May 2, 2016



CHATting Together

By Lorna Oppedisano | Photography by Gerard H. Gaskin

Barbara Huntress Tresness lived a storybook life. She didn't have birds braiding her hair and forest creatures doing her dishes, but her life had no major issues. She met her husband while studying psychology at the University of Vermont, and eventually moved to the Syracuse area. The couple was raising two boys, with a third on the way.

Then Barb's placenta abrupted. She had an emergency C-section. Her son Graham was born at 35 weeks with cerebral palsy. Doctors told Barb that he might not make it through the night. He did, and now he's one of Barb's greatest inspirations.

"As a person, when you're faced with a challenge, some people get stuck. And I just, as a person, said I'm not going to get stuck in the anger or the bitter," she reminisced. "I'm going to find a way through."

The first few years were tough. When Graham was born in 2000, he was silent. It consumed Barb. She remembers thinking, 'Why was he not crying?' When the tears came, it was loud, hard and continuous.

“You have a bad time with a sick child, and it’s a few days. This was unending,” she said, explaining that it lasted for years, and she didn’t know what to do for him. She followed the experts’ instructions, but nothing seemed to work; in some cases, medicines seemed to agitate her son even more.

When Graham was 4 years old, Barb heard about craniosacral therapy, a form of massage founded by Dr. John Upledger. She contacted a therapist, and he came to the house. When he began his work, it didn’t appear he was doing much, Barb admits, but then Graham stopped crying.

“And I’m staring,” she recalled. “And then all of the sudden, he smiled for the first time.”

Around the same time, the family took a trip to the Las Vegas, and stayed in a hotel with animals. Barb was surprised when a trainer asked her if Graham wanted to touch a dolphin. She hesitantly agreed, not even sure that her son could touch it. Much to her amazement, he did; and in return, the dolphin picked up her head and touched Graham. The crowd was in awe, Barb remembered.

“They had this connection, and it was immediate,” she said. “And I thought, ‘OK, there’s something to this dolphin thing. I’ve got to pursue this.’”

In August 2004, Barb followed the idea of dolphin therapy to the Upledger Institute in the Bahamas. She had no idea what to expect, but the animals seemed to intuitively know how to approach Graham, and had a positive effect on him. Moreover, shortly after the family returned home, Graham took his first unaided weight-bearing steps.

“And the only thing I’d done differently was the dolphin therapy with Upledger. So I knew then that there was something really magical about this,” she said. She continued on her journey with Graham, becoming a licensed massage therapist and learning craniosacral therapy.

Despite all of this growth, Graham still faced one major issue: communication. It’s not that people were intentionally dismissive; many simply didn’t know how to interact with someone like Graham, who Barb describes as a “nonverbal communicator.”

“I was telling our story, and I’m passionate about it. I realized that I’m just a mom in Manlius, NY. This is a global issue. This is misunderstanding disability and communication up here,” she said, raising her hand to a high “macro” level.

In the last few years, Barb and her husband have partnered with organizations like Syracuse University’s Burton Blatt Institute and AccessCNY to found CHAT Collective. The business started as a week-long summer camp, and then a club, but Barb wanted something less labor-intensive that could reach more people.

“How can we take what worked – the socialization, the communication and the awareness – and bring it to the community?” she pondered.

Now, CHAT Collective aims to help verbal people understand that communication is a universal concept, and doesn't always occur in an exchange of spoken words. She's written a guidebook and designed hand bands, communication cards, dog tags and T-shirts to help bridge the gap.

Barb remembers every piece of her 16-year tale in great detail. In sharing it, she's not looking for pity or sympathy for herself or Graham. She's not bragging about her strength. She's just straightforward and honest.

"The whole journey started with me as a mom, who was overwhelmed," Barb said simply.

They still have trying days. People still stare. While there are a lot of people who – thanks to CHAT Collective – know how to interact with nonverbal and limited communicators, there's still plenty who lack that knowledge.

At the end of last year, Barb shared her story in the memoir, "Beyond a Charmed Life: A Mother's Unconditional Love."

"I wanted people to know that they're not alone. And I wanted them to take the journey with me and see all that we went through," she explained. "And then you can appreciate whatever your next challenge is. You might come at it differently, because you've lived through someone else's journey."

If you want to learn more about Barb and Graham's story, visit barbarahuntresstresness.com. For more about CHAT Collective, visit chatcollective.com

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