

Boy offers hope to fellow "warriors"

By LINDSEY ADKISON The Brunswick News - Thursday, July 16, 2015



Carswell stands in the office where he processes requests from patients of various ages and conditions worldwide requesting his warrior beads. Bobby Haven/The Brunswick News

Chris Carswell took the bag and gently emptied its contents.

As he did, a seemingly endless strand of glass beads — of every shape, size and color — spilled across the table. All in all, the strand extended to more than 30 feet in length.

“This is the one when I died,” he said, holding a bead with an angel on it, turning it in his hand as he considered his near death experience. “I was nine and it happened at school.”

Chris, 16, has suffered from debilitating medical conditions all of his life. Enduring seizures as well as multiple brain surgeries, he was most recently diagnosed with Loeys-Dietz Syndrome, a rare

congenital condition that affects the formation of connective tissues. It can cause aneurysms in the arteries and can prove fatal if not properly treated.

But as always, Chris refuses to bend to the pressure of his ailments. Instead, he simply added more beads to the lengthy string of beads that has come to symbolize his medical journey.

“We spelled out Loeys-Dietz. Each bead represents something different. This one is for when I got Bronx (his service dog),” he said, pointing to a bead with a dog.

Some beads have come from friends and followers on social media.

“They send him a photography bead because he likes photography,” said his mother, Janet Carswell.

While his medical challenges are a real struggle, Chris has found a number of outlets for his energy and frustrations. He established a foundation, 1BoyForChange, and through it he spearheads many positive programs. Those include distributing K9 first aid kits, heat alarms for area law enforcement, as well as Cup of Joe for Joe, which benefits soldiers overseas.

Most recently, Chris began a program called Warrior Beads, which sends participants beads to string as a way of documenting their medical journeys. Similar to programs like Bravery Beads and Beads of Courage, Chris’ program was inspired when he was initially denied a chance to be involved in the latter program.

“We went to the children’s hospital in Florida for his brain surgery and I had applied to Beads of Courage for him,” said Janet Carswell. “I really wanted him to have those with him before his surgery, but they told me they were just for oncology patients. That’s when he was like, ‘We have to figure out a way to fix this.’”

Not to be deterred, Janet Carswell pressed the organization, eventually getting a few beads for Chris. But that’s when the two decided to offer their own program — Warrior Beads. Chris wanted to give all patients —

regardless of age or condition — a chance to string their own story, illustrating their medical journey through beads.

He set to work, taking on the task much like starting a new business.

Chris researched places to find donations, beads, string and ways of getting the message out to other patients. He also had to assign meanings to each bead. Chris also decided to change the materials — opting for plastic over glass for its durability.

Before long, he was finding his footing — and logging in up to 50 hours a week to get the program off the ground. It was worth every minute to Chris because he knows what stringing the beads did for him during some very dark days.

“It’s kind of stress relieving in a way, stringing these really long strands of different colored beads. And it’s a good way to tell your story to people who don’t understand,” he said.

To help tell those stories, Chris has come up with dozens of different types of beads, each with a different meaning.

“We have beads for injections, IVs, days spent in the hospital or in the ICU. The glow in the dark beads are for flash backs or nightmares,” he said. “Needle sticks, doctor visits and the one we run out of most, the clear yellow (represents) days away from work or school.”

Then Chris took his message to his friends and those who follow him on social media. The response was more than he ever anticipated. From every corner of the globe, patients of all ages with all kinds of conditions began flooding his inbox with applications for the program.

“They were coming from all over the country and then one day we got one from Dublin, Ireland,” Janet Carswell said.

That was just the tip of the iceberg. Applications continue to roll in from the United Kingdom, Canada, Finland, France and even New Zealand.

“We just got our first from Germany,” Janet Carswell said.

All told, Chris rounded up 400 patients who wanted beads, many of them taking photos of their strands to post on social media.

“There’s 380 posts on Instagram,” Janet said.

“It’s been awesome. It’s just amazing to hear all of these stories,” Chris said.

Of course, he’s also learned a lot along the way. Working out of a highly organized office, Chris receives applications, determines which beads to send, measures them out and mails them to their destinations. He’s written grants and secured donations — both of beads and funds.

Chris has even worked out a way to ship out the beads at a discount.

“The guy at Exit 29 Postal sends everything out for us at a discount which is great, but shipping is still very expensive. It’s one of our biggest expenses,” Janet Carswell said.

“That’s where we could use some help,” Chris conceded. “That’s the most expensive part, especially shipping overseas.”

Although it’s a lot of work the family has no plans of slowing down.

“Everyone has a story to tell, and they should be able to share that journey,” Chris said.