

Journeys of Inspiration



Rolf Benirschke was the placekicker for the San Diego Chargers for 10 seasons, but his career nearly ended because of a difficult battle with ulcerative colitis. He would require ileostomy surgery but returned to play in the NFL and has been educating and encouraging ostomy patients and WOC nurses ever since. His illness led him to start his patient engagement company, Legacy Health Strategies, and author three books, including his autobiography, *Alive & Kicking*. He is married and the father of four children, three with special needs. www.rolfbenirschke.com.

Better Than Fine

Seeing your stoma for the very first time causes a variety of reactions and may include some comments that are not fit to print! When Krista Deveau got her first look at her stoma, she exclaimed to her boyfriend, "It's not that bad!" Diagnosed with Crohn's disease at 9, Krista recalls how fragile she was, "I only weighed 56 pounds and my complexion was so pale I blended in with the walls in my house."

Instead of playing with her friends after school, she was forced to take a nap because she was always so exhausted. Like many young Crohn's patients, Krista says sadly,

"Being from a small town, everyone knew about Krista's illness. She was surrounded by love and support."

"I didn't really recognize there was anything wrong. I thought everyone got that tired." A blood test revealed low iron levels, so a treatment plan was enacted. After not seeing any improvement, her mom sought a second opinion at a children's hospital. It was there that Krista remembers being diagnosed "on the spot" with Crohn's disease.

Just Two Options

In 2001, biologics were not readily available so Krista was given two options: steroids or tube feeding. Krista was adamant that she did not want to go on steroids because there was a boy in her school who was on steroids – he had big, chubby cheeks. She certainly did not want to end up like that!

So Krista headed off to fourth grade with a special backpack and equipment that delivered her nutrition through her nose continuously for 20 hours a day. She only had four hours a day without it. She remembers with a smile, "It was the most freeing feeling not having to wear that backpack so I could actually play with a friend or go to dance class."

Being from small town, Yarmouth, Nova Scotia, everyone knew about Krista's

illness. She was surrounded by love and support. When arriving at her best friend's pool party she recalls being swarmed by all her concerned friends who proceeded to hug her and then all cry together. Krista fondly remembers, "My classmates were extremely protective – especially the boys!" And those sweet girl friends who cried with her at the birthday party taped pieces of yarn to the faces of their dolls, so it looked like they had feeding tubes too.

As Krista began to gain weight, she was able to gradually decrease the time on the feeding tube so that when she got to junior high school, she only needed it during the night. When Krista was in eighth grade, her doctors decided to put her on Remicade infusions which continued until her high school graduation.

She still experienced flares from time to time that required steroid therapy causing her to develop that dreaded facial swelling she so desperately hoped to avoid. She also underwent her first bowel resection when she was a senior in high school, but was able to recover in time to go to the prom and even enjoy a trip to Europe with her graduating class.

Leaving Home

In 2013, Krista decided to attend university in Calgary. Unfortunately, the stress of moving to an unfamiliar city, starting a degree program and a job caused an increase in her symptoms. By this time, she had tried all the available biologics and watched her blood marker numbers (inflammation, iron, vitamin deficiencies) bounce up and down for several years. She also began experiencing increasingly severe abdominal pain and developed a mass on her right side due to an obstruction.

Determined to finish her degree, she begged her surgeon to let her walk the stage



at graduation before her second bowel resection. Unfortunately, she developed complications from the surgery that included an infection and a bout of pneumonia. When Krista finally returned home from the hospital, she remembers, "I knew something was not right. I just didn't feel normal."

In High Demand

Within a week of graduation, Krista found herself surrounded by a group of energetic kindergartners in her first job. She was a bit overwhelmed at first. Her symptoms began to return even stronger and it became critical that she was near a



bathroom all the time. As things got worse, she had accidents driving to work as well as during the school day and sometimes had to finish the day in dirty pants.

Krista tried eating less, but it didn't help. She soon had a hard time just walking up stairs and one day at work, she physically could not stand up after reading a story to her students.

Her doctor advised her to go to the hospital immediately. So off she went, weighing less than 100 lbs., with just the clothes on her back. She was hospitalized for two-and-a-half weeks. Krista returned to work with a modified schedule and things seemed a little bit better for a short time.

Then, her symptoms worsened to the point where she had to wear adult underwear to work and she never left her house unless it was absolutely necessary. She sadly recalls a one-hour road trip with Jason, her former boyfriend, now husband, to the Rocky Mountains for her birthday, "I can't even count the number of times I had to stop on the side of the road to go to the bathroom and when we arrived at the restaurant, I spent more time in the bathroom than at our table."

Very Dark Place

That was really the "beginning of the end" as far as Krista was concerned. She describes being in a "very dark place" as she battled anger and bitterness and the haunting question, "Why me? I've been a nice person

and always tried to do the right thing. Why me?" After disappointing results from a scope that revealed strictures, ulcers, and active disease, Krista felt like she had exhausted every conventional and unconventional therapy available. It was time to move on in life and face a decision she had always been too scared to address.

Since her wedding was scheduled for July, this should have been one of the happiest times of her life — and Krista was determined to make it so. With the vision of a pristine white wedding dress dancing before her, she resolutely told her doctor, "I don't want to live this way. I'm ready to have ostomy surgery." Making that decision was incredibly freeing for Krista, who was so relaxed the day of her surgery that she even took a bubble bath.

She says now with a grin, "I hopped up on that operating table and said, 'I'm at peace and I'll be fine. I'll actually be better than fine, I'm happy.'" Like many new ostomates, Krista said she didn't realize how sick she had been and how much she had compromised her life trying to manage her illness. Suddenly she was free of pain and the fear that she might have an accident at any moment and was excited for her new marriage and to get on with her life.



Without Fear

In July of 2018 Krista was thrilled to wear that beautiful wedding dress

with no fear of having an accident. And she recently found out that she is pregnant! Her GI doctor was "over the moon" at the news, yet a bit surprised that she'd been able to conceive so easily and readily attributed that to divine intervention. "God wanted you to be a mom, so he made you a mom!" he triumphantly declared.

After a bout with morning sickness that caused some dehydration, Krista has been feeling great and said her appliance fits better on her growing belly and her output has changed to become thicker and easier to manage, nice bonuses of her ostomy. Krista and her physician are planning on a vaginal delivery and a smooth recovery when her sweet daughter enters the world in a couple of months. A fitting ending...or beginning...to a courageous young lady! 🌈