

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.

Don't you wish life was a smorgasbord where you could pile your plate sky high with just the things you love to eat, like a big slab of dark chocolate cake and a side of mint chip ice cream? The reality is that life *is* a smorgasbord but often we don't get to choose what ends up on our plate. And for those of us who have had ostomy surgery, we understand that reality all too well. As a culinary arts teacher for 350 high school students, Jeff Stanhill knows a lot about how to put together a plate of delicious food. He will also tell you that life put some things on his plate that were tough to swallow.

"I became angry with everything and everyone but, somehow, Melanie saw past all of that and still hung in there with me. It was then I knew that this was a true love that would last."

Patient Zero

During Jeff's last semester of culinary school, he started experiencing bowel issues. "I wasn't feeling well and started having painful abdominal cramping accompanied by diarrhea," he recalls. After living with it for a few weeks, he finally decided he needed professional help and reached out to Norman Panitch, a gastroenterologist in Southern California who was a friend of his parents.

Jeff was surprised to learn that he was about to become Dr. Panitch's first patient. While you might think that would be cause for concern, Jeff said he was in so much pain at that point that Dr. Panitch's lack of experience never really crossed his mind. At the time, Jeff was working in the banquet kitchen for Marriott Hotels and recalls how challenging that job was. "The hours were brutal: six days a week, 12 to 13 hour days. With my new diagnosis of ulcerative colitis, I realized my disease was progressing."

Jeff became anemic and actually collapsed one day on the job. This led to multiple hospital stays and a new reality for which Jeff wasn't prepared. "I remember it like it was yesterday," he

admits. The absolute confusion and fear about what was going on with his health and what the future might hold was so difficult. He was soon taking 13 different medications three times a day, including 50 mg of prednisone, which wreaked havoc on his body. He started to gain weight. He watched his toenails curl up like the Grinch's shoes and he developed the "moon face" so typical of people on high doses of prednisone.

During one of his hospitalizations it was determined that, like many patients with IBD, he was lactose intolerant. It was another crushing blow as he loved milk. As the days wore on and Jeff wasn't

getting any better, he turned to comfort food, not really caring if he ate something that made him sick. He confesses, "I got so desperate I would sneak down at night for a pb&j sandwich and a glass of cold chocolate milk even though I knew I was going to suffer. I simply didn't care anymore at that point."

True Love

Over the next two years, Jeff's condition continued to deteriorate as the continual diarrhea and severe abdominal cramps often left him doubled over in pain. He was in and out of the hospital six to seven times a year. There was, however, one very bright spot in the midst of all his challenges. He started dating his sweet Melanie who would one day become his wife. She turned out to be an angel, sent at just the right time. She would give him cortisone enemas when he was too sick to do it himself.

Jeff remembers that period as one of the worst of his whole illness because he was physically and emotionally done. "I was at a point where I would do anything to feel better. Unfortunately, we had limited

medications back then and nothing was working. I became angry with everything and everyone but, somehow, Melanie saw past all of that and still hung in there with me. It was then I knew that this was a true love that would last," he says fondly.

Even though Jeff was incredibly thankful for Melanie, he still struggled with those familiar questions we all wrestle with at some point in our ostomy journey. "Why me? Why did God pick me to go through this? Why is life so unfair?" He finally reached a breaking point and decided to reconsider the option of ostomy surgery that Dr. Panitch had suggested as a "last resort."

Jeff recognized that the disease had slowly but relentlessly taken away his quality of life and he now viewed the possibility of ostomy surgery differently. He remembers thinking, "If this is what it's going to take for me to finally feel better, let's get on with it." His surgery was scheduled for April of 1978.

Frustrating Challenges

Unfortunately, the operation was a difficult one, lasting eight hours and leaving Jeff with an incision from his sternum to his pubic bone. He also had an infection at the incision site and long, painful days in the hospital. He said he has little memory of what happened in the first few days after his operation, except that he relied on morphine a lot to manage his pain. He remembers joking with the nurses at one point saying, "I've had so many shots in my butt that if you put a garden hose in my mouth, I would be a sprinkler!"

As Jeff slowly started to feel better, he knew he needed to learn how to take care of himself, irrigate his wound with hydrogen peroxide and change his own dressings. Initially, Jeff needed 30-40 minutes to change his appliance which often left him frustrated and angry. He would often yell and scream angry words he quickly regretted, because they were often directed at Melanie, now his wife, who was only trying to help.

Jeff remembers wondering, "Is this all really worth it and will it ever change? I can't imagine having to live the rest of my life like this!" He felt overwhelmed and worn out and shared later that he seriously contemplated giving up. When I asked Jeff what got him through that really rough patch he smiled and said, "That's easy. I can answer that question in one word – Melanie." It



Jeff Stanhill poses with a Rolf Benirschke jersey worn in an NFL game in 1981. Benirschke was a role model for Stanhill as he battled the effects of ulcerative colitis

has now been over 40 years that Jeff has lived with his ostomy. As he reflects on the happy and fulfilled life he has led with Melanie, it prompted him to want to share some encouragement with anyone facing ostomy surgery.

"You will get better," he promises. "It does take some time and you will likely go through some tough stuff to get to the good stuff, but I encourage you to let your family and friends support you. Don't try to go it alone" he advises.

Jeff is quick to add that his life became so much better after his ostomy that he wished he had considered it having the operation sooner. "When you aren't in constant pain and you don't need to know where every bathroom is before you go anywhere, your whole attitude changes. Your self-esteem returns and you don't have to live defensively," he says.

In the early days, when Jeff was first getting use to

continued on page 67

Journeys of Inspiration from page 23

his ostomy, he said he tried to remind himself, "It's not about what's happening to me now, but about what my life is going to be like in the future. My life is going to get better because I will have control again and the freedom to make it what I want it to be."

Overcome With Emotion

Jeff's story is powerful and encouraging and I'm grateful that our paths recently crossed when I met him while speaking to a Mayo Clinic ostomy support group. I've shared my story hundreds of times in the past, although this was the first time via Zoom. While I can typically anticipate many of the questions that will be asked when I finish speaking, on this particular occasion I was completely surprised by the response from

"My life is going to get better because I will have control again and the freedom to make it what I want it to be."

one of the audience members.

A man quickly raised his hand and started waving at me from his little Zoom box in the lower right section of my computer screen. He introduced himself as Jeff Stanhill and proceeded to tell me about one of the lowest points of his life (his ostomy surgery) and a gift from his mother that became a powerful symbol of hope. It turned out that Jeff's mom had worked in the athletic department at Cal Poly University and had discovered that one of my NFL game-worn jerseys was going to be auctioned off at a fund raiser. When she told the event organizers that her son had undergone the same surgery I had, they surprised her by giving her my old jersey so she could gift it to her son.

Jeff followed my career because of our illness connection and was thrilled to get the jersey...now almost 40 years ago...because it symbolized hope that he could not just survive but thrive after his own ostomy surgery. At that point on our Zoom call, Jeff momentarily disappeared from his box on my computer screen but then quickly returned wearing a big smile and holding up my tattered 40-year-old, #6 Benirschke game jersey! I was stunned and overcome with emotion hearing him share how much it had meant to him over the years. The feeling was both wonderful and incredibly humbling.

Meeting Jeff renewed my passion to continue to share my story and I hope it also serves as an encouragement to you to embrace your own story – the good, the bad and the ugly – and look for opportunities to share it because you never know whose life you may be able to impact because of your experience. ☂

**Celebration
Ostomy Support Belt**



- * *Removeable Soft Plastic Hernia Support Plate*
- * *Built-In pocket holds the weight of your pouch*
- * *Stoma Shield protects your Stoma*
- * *Leak proof support for the confidence to be active*

\$110.00 4" wide

Visit our web site to see all of the
Celebration Ostomy Belts and to order on line
www.celebrationostomysupportbelt.com
Customer Service 1-413-539-7704

Wondering what
to do with unused
ostomy supplies?




**FOW
USA** **FRIENDS OF
OSTOMATES
WORLDWIDE - USA**

Friends of Ostomates Worldwide-USA is a non-profit 501(c)(3) volunteer organization which collects new ostomy supplies from US individuals and groups. FOW-USA donates the supplies to needy ostomates in developing countries around the world.

Please send your new supplies to:

FOW-USA
4018 Bishop Lane
Louisville, KY 40218-4539

Shipping cost and value of supplies may be tax-deductible.



For more information visit us at www.fowusa.org, call us at 502-909-6669 or email us at info@fowusa.org.