

# 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](http://www.rolfbenirschke.com).

If you were to walk into a certain elementary school classroom in Churchville, PA, on Valentine's Day this year, you might have seen an energetic teacher wearing a bright pink blouse, humming "What doesn't kill you make you stronger," as she set red and pink crayons alongside a heart shaped white doily at each desk.

At first glance, you wouldn't notice anything unusual about her. In fact, as she sweeps her blond bangs off her forehead, she looks like the quintessential third-grade teacher that students will remember fondly for years after they have left her classroom. But if you look a bit deeper, past those sparkling green eyes, and infectious smile, you will see a woman who has suffered tremendously and recognizes that she has been given a second chance at life...all because of ostomy surgery.

## Dreaded News

I was first introduced to Maria by a business acquaintance in June of 2018. She was very frightened about her future, having just received the devastating news she had been dreading for 34 years – that she would need to have her colon removed. Growing up in a small town just outside Philadelphia, Maria was an athlete who played softball and basketball and wasn't sick a day in her life until her junior year in college when she began bleeding rectally and was diagnosed with Ulcerative Colitis. The fighter she was, she put on a happy face, insisting everything

was fine, despite losing 30 lbs. over the next couple of years.

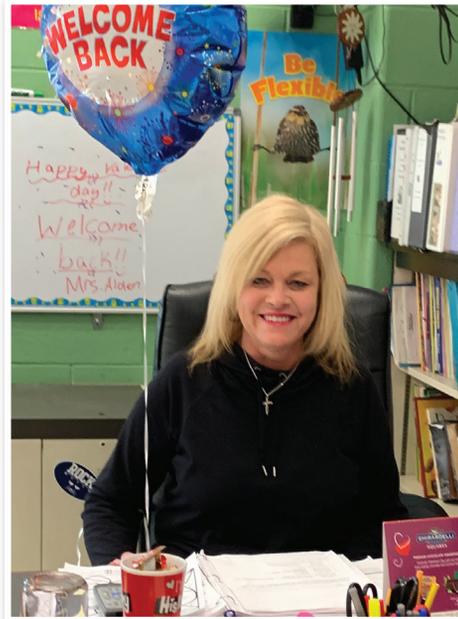
Finally, her physician, Dr. Geoffrey Braden stepped in and recommended she check into the hospital. But Maria had different ideas and responded to that suggestion with a definitive, "You can't put me in the hospital, I just got my teaching job." Anticipating this response, Dr. Braden looked her right in the eye and resolutely said, "Young lady, you have to set your priorities straight." Dr. Braden prevailed, and Maria was admitted to the hospital.

That was the first of three hospital stays that become all too familiar to UC patients. When she was discharged from that first visit, her 118 lbs. hung from her

5'8" frame and when she looked in the mirror she saw "a big moon face from the prednisone and two legs that looked like sticks." The illness cycle became horribly predictable and practically routine, until Maria almost forgot what it was like to live a life that was pain free and didn't include countless colonoscopies, medications, having to know where every bathroom was, and miserable side effects.

## Countless Drug Regimens

Eventually, after years of taking every available GI medication, Maria's immune system was weakened, and she was diagnosed with C-Diff twice in a six-month period. She had become terribly ill – weak, lethargic, and could just barely make it through the day. But no matter how bad it got, Maria believed that the alternative,



***"Maria recognizes that she has been given a second chance at life...all because of ostomy surgery."***

ostomy surgery, would be much, much worse. So, for 34 years Maria battled that option with every ounce of strength she had and underwent countless drug regimens that included prednisone, immunosuppressant drugs such as 6-MP and IV Remicade, Imodium, Paregoric and many others.

Maria's daily life was severely limited, especially when a flare-up would occur unexpectedly. Like all UC patients, when she left home, she carefully mapped out where every bathroom would be on her route, knowing she might need to find one—QUICK. She knew exactly what medications to take for spasms and carefully restricted her diet to eating very little, or even not eating at all if she needed to go somewhere. She stopped making commitments in advance to go places or do things with friends because she never knew how she was going to feel. UC took over her daily schedule and she became enslaved to the disease.

Married to a wonderful, understanding husband and having three children involved in sports should've created lots of opportunities to travel and enjoy time together as a family. While most parents choose their "favorite" sport based on the pace of the game or the fact that they played as a child, Maria had quite a different criterion.

### **Fear of Traveling**

She much preferred basketball because there was always a bathroom "inside" as opposed to softball which often only had outdoor port-a-potties – the nightmare of every UC patient. While Maria loved watching her kids compete, she said travelling was "quite a production" that entailed packing carefully with all the right medications "just in case." In fact, travelling was so difficult for Maria that her first plane flight wasn't until she was 40 years old! And only then because she could not bear the thought of missing her oldest daughter's national softball tournament.

After 32 years, Dr. Braden, her incredible GI doctor whom she had grown to love and trust decided to move to Utah. She was devastated as he had been by her side through her entire ordeal and helped her manage some very difficult flare-ups along the way. She was a little apprehensive when she was placed in the hands of a new physician, Dr. Gregory Schapiro, but soon discovered he was another excellent physician who also treated her with great care and respect. Unfortunately, it was after a routine scope Dr. Schapiro performed in September of 2018, when Maria heard the words she had been dreading most of her life, "You need to have your colon removed." She could hardly believe it but when she shared the news with Dr. Braden, and when he concurred, she knew the time had come to face her

biggest fear. Maria asked Dr. Schapiro if the surgery could be scheduled at the end of the school year, but he insisted this could not wait. It was time.

### **New Life**

After my first conversation with Maria in June, I had the privilege of speaking with her again on numerous occasions. I encouraged her that ostomy surgery was not the end of her life, but rather the beginning of a new life that would no longer be controlled by her illness. I knew she wanted to teach again, and I assured her that she could certainly go back to the classroom and now go out for dinners, to sporting events and concerts, and on trips, and do so many other things she had been avoiding for years. I told her about the thousands of patients I'd met over the years who came to view their ostomy as a gift because it gave them their lives back. And whether it was climbing Mt. Everest, flying a fighter jet, riding a bucking bronco or simply being a mom or a dad, they were all heroes to me and great inspirations for others.

Although Maria was discouraged that surgery had become the "final option" she began to research and learn all she could about living with an ostomy and what she could do to ensure a speedy recovery. She said that reading my story and the stories of so many others who had overcome tremendous obstacles left her with one thought, "If they can do it, I certainly can too." So, on December 11, 2018, Maria finally had her colon removed. And in the months following her surgery she shared with me on several occasions, "My only regret is not doing it much sooner."

When I asked Maria what her greatest fear had been before surgery, she answered, "having a hole in my side with part of my intestine exposed." She was also worried about changing the wafer/faceplate, getting an infection, pouch leaks, staying "clean" and a bulge sticking out from underneath clothing. She was also concerned about taking a bath, swimming and intimacy.

### **So Grateful**

Of course, my follow up question was, "Did any of those fears become a reality?" to which Maria smiled and answered, "Not a one. I can now go shopping, out to lunch or dinner, and take long drives with my family without worrying about colon spasms and living in fear of not being able to find a bathroom when I need one." She went on to say, "I am able to have a conversation with someone without having to excuse myself to run to the bathroom and I can make a commitment with a friend in advance without having to worry about how I will feel that day." Put quite simply she said, "My ostomy has given me my life back and for that I am just so grateful." 🌂