

# 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).

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When people find out I played in the NFL with an ostomy they are astonished. In the forty years since my ostomy surgery, I've met hundreds of other ostomates with remarkable stories like Rob Hill who climbed Mt. Everest and Bob Cuyler who piloted a Black Hawk helicopter. They have taught me that you can enjoy virtually every activity after your ostomy surgery that you did before. But I must admit, even I was amazed to learn that Justin Mirigliani's goal after his ostomy surgery was to resume weight training (with very heavy weights), something all ostomy patients are cautioned against due to the risk of developing a hernia.

## Dreams and Heroes

Justin grew up in South Philadelphia. His heroes were the Philadelphia Flyers and his dream was to become a professional hockey player until, during a high school tryout, he was body checked and drilled into the ice.

It was then he realized that he wasn't big enough or strong enough to play the violent game he loved. After a humiliating experience in the high school weight room, he saved his money bought a set of weights and set up a gym in his basement. As his workouts intensified, and puberty started to kick in, he found himself getting stronger. And in addition to building his body, those workouts were also building his self-esteem. "Lifting gave me an identity and I began to feel good about myself," he remembers.

Following a wonderful college experience where his anxiety and depression were held mostly in check, Justin felt like he was "on top of the world." But Justin's world changed shortly after graduation, when he found blood in his stool and was diagnosed with ulcerative colitis. Justin

describes that day as "the exact moment when the first part of my life ended, and my new life began."

## Sick to Sicker

Over the next few months Justin would go from "sick" to "sicker" and remembers "watching my muscles shrink before my eyes." It was becoming nearly impossible to control his bowels and he was forced to wear what he referred to as "adult diapers" whenever he left the house. After a pancreatitis diagnosis and painful kidney stone,

he wondered, "How much worse can this get?" Fortunately, things did begin to get a little better and Justin dared to hope that he was finally turning the corner. But, like so many UC patients discover, all Justin found waiting for him around the corner...was another corner. He began to lose weight again, spend a lot of time in the bathroom, and his worries about the bloody diarrhea increased. Soon he was back in the hospital, having lost fifty pounds in just three months.

## Nagging Thoughts

Between his UC and psychiatric medications and lots of vitamins, Justin was now taking 30 pills a day! He says, "that didn't really bother me though, because I finally felt alive again!" He began to accept that his "new normal" would involve being in close proximity to a bathroom at all times and he would have to give up trips to the beach, skiing, and parties with his friends. Despite his best efforts to map out all bathroom locations wherever he went and time his meals carefully, he still endured some embarrassing accidents. He simply accepted that this was how his life was going to be with this disease.

He soon married his sweetheart, Amy,

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and become a proud dad to his first daughter, Alex, all while continuing to battle his UC and mental health issues. Unfortunately, his constant flareups wore on him and as things got worse, he wrestled with nagging thoughts of suicide.

### Regaining Control

To combat this downward slide, Justin returned to the place that had rescued him in the past – the gym. He loved being in the weight room and feeling like he was finally in control of at least one part of his life. The birth of Justin's second daughter, Rebecca, also reinvigorated him and he recalls, "I still had ups and downs and embarrassing accidents with my UC along with my ongoing challenges with depression and anxiety, but I just accepted that was my life and tried to make the best of it." And as every great hockey player knows, you will get knocked down...the important thing is to get back up and keep fighting.

Not content to fight just for himself, Justin founded a nonprofit association called "Checkmates" with the goal of "making the lives of those living with an ostomy as full as possible." Through their celebrity hockey events, Checkmates has raised over \$30,000 to increase awareness and find a cure for inflammatory bowel disease.

It was ultimately a challenging fistula that led Justin's physician to discuss the possibility of ostomy surgery. "Next to dying, having a bag would be the worst thing that could happen to me," Justin remembers saying. "I'm just not ready to do this yet."

### Thinking Long Term

That all changed, however, when during a routine colonoscopy a short time later, Justin's surgeon found pre-cancerous dysplasia in his colon – a day Justin describes as, "One of the lowest points of my life." He was now not just worried about wearing a pouch, but



*Justin with his daughters Alex (right) and Rebecca at a Checkmates Charity event he founded to benefit those with autoimmune diseases.*

about whether he would survive. After his surgeon, Dr. Michael Harris, outlined his surgical options, Justin asked just one final question, "What will give me the best chance of living long enough to be able to walk both my daughters down the aisle?" Dr. Harris answered decisively, "a total proctocolectomy with a permanent ileostomy."

That was all Justin needed to hear. He also remembers Dr. Harris encouraging him by saying, "If an NFL kicker can return to the game he loves after ostomy surgery, so can you return to the things you love." Justin could never have imagined that he would meet, share a Philly cheesesteak and become friends!

### You Will Be Better

Justin's days recovering in the hospital were difficult ones to be sure. Under the care of a wonderful WOC nurse named Trish McNamara, Justin learned how to navigate life with an ostomy even as he dealt with difficult post-surgery pain. A month later, Justin says he began to feel much better and, "Ready to get back to life." At his final post surgery appointment, Dr. Harris challenged Justin to start doing all the things he loved to do – even weightlifting – and encouraged him by saying, "Go live your life!"

Justin was thrilled when he realized that all of the things he had feared he would never be able to do after his ostomy did not materialize. In fact, the second chance at life he was given proved to be quite the opposite.

He sums up his experience by saying, "This bag that I once feared as a shackle, has been the most liberating thing that has ever happened to me." When asked what advice Justin would give to someone facing ostomy surgery, a wry grin slowly spreads across his face as he enthusiastically declares, "You won't be the same after a permanent ileostomy. *You will be better!*" 🍷