Journeys of Inspiration

Rolf Benirschke is an NFL Man of the Year who played ten seasons with the San Diego Chargers. Following his ileostomy surgery for Crohn's disease he returned to play seven more seasons in the NFL! He has spent the past 40+ years educating, encouraging, and supporting patients facing ostomy surgery, their caregivers, WOC nurses, and the colorectal surgeons. He is currently developing "Embracing Ostomy Life" (Grateful Patient Foundation 501c3) — an ostomy recovery program designed to virtually hold the hand of patients going through ostomy surgery to assure them that they are not alone and that there is a great life ahead. www.embracingostomylife.org

While it's not unusual to give your stoma a name, Nashville therapist, Dr. Rachel Christian Gulley takes it one step further and encourages her clients to think of their ostomy almost like getting to know another person — what do they like, what don't they like, when do they work best, what strategies can you use to keep them calm? With her sweet smile and gentle southern drawl Rachel explains, "After ostomy surgery, you have a chance to get to know yourself in a whole new way."

In her private practice, Rachel focuses on clients with chronic conditions, especially those with IBD and, like any good therapist, she wants to empathize with what her clients are experiencing which comes quite easy, because Rachel has an ileostomy too.

Rachel started experiencing her first IBD symptoms when she was in middle school and realized that she was low on energy when playing soccer…and then the bleeding began. She remembers, "Almost every time I went to the bathroom there was a lot of blood, and like any 12-year-old, I panicked and told myself that if I just ignored it, it was going to go away." But after fainting in science class due to blood loss, she ended up in the ER and was whisked away for a colonoscopy.

Trying Everything

Then, through what Rachel describes as a "God thing," the general surgeon that was evaluating her reached out to his son, who was studying IBD in med school, and helped reach the diagnosis of ulcerative colitis. She was referred to the Vanderbilt Pediatric GI Clinic where Rachel was "terrified" by the large hospital until she was put under the care of Catherine Arthur who treated her for the next ten years.

During that period, she tried every medication available. "I can't think of one medication that I wasn't on. We tried so many," Rachel recalls. Being on steroids for 18 years wreaked havoc on her body and her emotions, "Every time we would start to wean me off steroids, which was our goal, my disease would flare right back up again. So, prednisone was both my best friend and my worst enemy."

When Rachel was 20, Dr. Arthur performed a routine colonoscopy and biopsy to determine disease progression and called Rachel with some surprising news, "I know you've had a UC diagnosis for all these years, but this actually looks more like Crohn's than UC." With this new information, Dr. Arthur introduced biologics but, unfortunately, due to allergies, Rachel couldn't keep taking them. While Rachel wasn't in remission, she says her symptoms were "handled" when she got married in 2013. But right after celebrating her one-year anniversary she came down with a virus that set off her immune system and she developed the worst flare of her life. That became the defining moment in her ostomy journey.

Difficult Transition

Making the transition from the pediatric hospital to the main hospital at Vanderbilt was quite a shock for Rachel, "When you walk into the peds section there is a flower garden, and you get to order dinosaur chicken nuggets and happy face fries but when I moved over to the adult section the walls were beige and brown and felt very cold. I was so overwhelmed." With a new physician now treating her, she was referred to a surgeon who rocked her world when he walked in and the first thing he said was, "Okay, so when are we taking out your colon?" Rachel and her father, who are self-described "talkers" were absolutely stunned, and left the office in silence, not saying a word for 30 minutes, "We felt like we had been hit by a truck. It was the first time ever a physician had recommended an ostomy."

After being "blindsided" with something as serious as a total colectomy, Rachel quickly took it upon herself to move to another doctor for a second opinion. She soon found herself in the care of Dr.

Tommy Lewis at Centennial Hospital in Nashville and describes him as "the sweetest and smartest person on the face of the earth." Unfortunately, Rachel's Crohn's became so severe that she was in the hospital for two months. She remembers clearly looking in the mirror and not even being able to recognize herself due to the swelling in her face and the tremendous hair loss from the high dose of steroids she was taking.

Not sure what else to do, Dr. Lewis presented Rachel's complicated case to the board who ultimately recommended she visit the Mayo Clinic in Rochester, Minnesota, hoping there might be a new treatment or medication available. The care at the Mayo Clinic was wonderful and the ability to have all your appointments with specialists in one place was refreshing and comforting. They began by running all the scans and tests again within their facility by their staff and doing a complete review of her complex history. After the extensive analysis, Rachel received a phone call that each one of us dreads, "I was in the lobby of the hotel, in a wheelchair since I had gotten so weak, I could not walk, when my phone rang, and the doctor told me that they had found precancerous and cancerous cells in my colon."

Limited Options

At that second, Rachel's options became limited; either have a proctocolectomy or let the disease progress to the only one tragic outcome. It was only later that Rachel found out that there had been a mistake – the cancerous cells had been found in an area they had not intended to biopsy. In Rachel's mind that was a "divine" mistake that saved her life. Up until that point she told herself, "I'd rather die than have an ostomy." But now, when faced with that decision, she chose ostomy surgery and life!

Rachel's surgery was in February of 2016, during a Minnesota snowstorm. As she lay there in the hospital bed thinking about her new life, she remembered her friend Lacey. Rachel and Lacey had met at Camp Oasis, a program of the Crohn's & Colitis Foundation of America. This summer camp experience is designed to enrich the lives of children with Crohn's disease and ulcerative colitis. Several years before when Rachel was a counselor and Lacey was a young camper. Rachel had great admiration for Lacey's spirit about embracing her ostomy and clearly remembers Lacey spouting off during one of their "rest times" in the cabin about how she handled boys and her ostomy. She confidently said to the rest of the girls, "You know what? If they don't like it, they can just go on — it's fine!" They stayed in touch after camp and became good friends.

Lacey and her stoma, Fred, became instrumental in Rachel's recovery as they walked alongside her, and her soon-to-be-named stoma, Button. And it was a difficult recovery. Rachel recalls coming out of surgery and feeling awesome while enthusiastically telling her family and medical team, "Hey, let's go! This was the easiest thing I've ever done," …until her pain medication wore off.

> ***"Rachel's work as a therapist gives her a unique vantage point into the hearts and minds of hurting people who deal with chronic illnesses."***

With her long incision as well as the pain from having her rectum removed and her anus sewn up, the pain was nearly unbearable and there seemed to be no comfortable position that did not hurt something. After two and a half weeks in the hospital, she was released to stay a few more days in Rochester, then go back to Nashville to resume her 29-year-old life cancer free and in remission from IBD, but now with an ileostomy.

Mental Battle

Rachel vividly remembers her intense mental battle, "It's like you have a choice, but you don't like either option. This thing that I never wanted has now happened." She worried about how it would affect her relationship with her husband, if people would be able to see it, and how she was going to explain it if they did. She remembered back to her days at Camp Oasis and how the campers there had changed the way she viewed her IBD. For years she had been vigilant about keeping her IBD a secret.

But being around others who shared their disease so openly, she suddenly wondered, "Why is this 'a thing' and why have I not been more open about this? It's ridiculous!" After all, plenty of people already knew because they had been praying for her throughout her journey. From that moment on, she determined that she would take the same approach with her ostomy and be open about it. And she's found that the more she shares, the more people she meets who can relate. Breaking free from the self-imposed isolation of her IBD felt like being a "bird out of a cage" and she wanted that same feeling going forward with her ostomy.

Returning to her practice as a therapist, Rachel remembers having to remind herself of the same things she always shared with her patients, "Look for those positive validations outside of yourself, expect something to go right, and hang on to those." But it wasn't

always easy and there were plenty of days that involved an internal struggle where she had to admonish herself, “Just do what you tell your clients to do. Do what you know how to do today.”

Double Blessing

While Rachel eventually wanted to have a baby, she longed for some time to “live for a little bit” following her surgery. Feeling like she had spent years of her life battling this huge monster, she wanted to take some time to enjoy it. So, she went back to school to complete her PhD and, on her graduation day, shared the good news with her family of a double blessing — earning her degree and being pregnant!

Rachel remembers being a bit nervous about her “high risk pregnancy” because of her ostomy, but with an awesome medical team surrounding her, everything went relatively smoothly. Although, she did have to switch appliances when her ostomy went from an “inny” to a “very big outie”. After being in labor for 42 hours, the doctors performed a C-section, and her precious baby boy was stillborn. The agonizing minutes ticked by and felt like hours but thanks to the determination of her medical team, and the hand of God, her precious Coy was resuscitated and today is the “healthiest and happiest little nugget you have ever seen!”

Rachel’s work as a therapist gives her a unique vantage point into the hearts and minds of hurting people who deal with chronic illnesses. When asked, “What is the one thing that you think is most important for your IBD clients to remember?” she does not hesitate. “Allow yourself the space to grieve and realize that may look different on different days. Some days it might hit you from out of nowhere and that grief washes over you again. That’s totally normal. The challenge before each of us is to continue to grow and adjust to whatever life puts in front of us.”

Rachel specializes in adult and pediatric chronic illness, gastrointestinal (GI) disorders, betrayal trauma for partners and children of individuals struggling with compulsive sexual behavior and sexual dysfunction. Rachel is a board-certified sexual addiction therapist (CSAT), betrayal trauma specialist (CPTT), and sex therapist (CST). She works with individuals living with inflammatory bowel diseases, disorders of gut-brain interaction, ostomies and other GI concerns in he Nashville area.

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