

The Phoenix

Summer 2021

\$9.95

**Jonathan
Negretti**

**7 Marathons
7 Countries
7 Days**

WORLD MARATHON CHALLENGE 2020
NORTH AMERICA - Miami

27
Jonathan Negretti (USA)



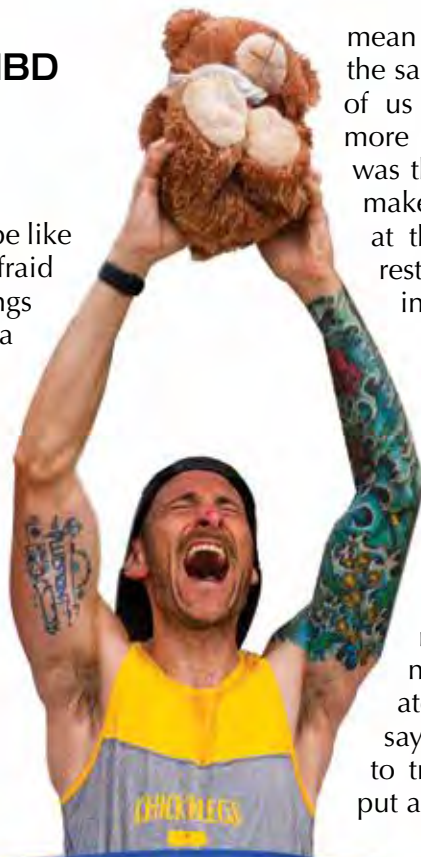
Jonathan Negretti

Going farther than ever imagined to find a cure for IBD

By Rolf Benirschke and Patti McCord

Did you wonder what your life would be like after your ostomy surgery? Most of us are afraid we might miss out on some of the things we enjoy the most —like sports, having a family and wearing stylish clothes. Yet very few of us dream of accomplishing something we would consider impossible once we have our ostomy.

Jonathan Negretti accomplished the “impossible” when he completed seven marathons in seven days on seven continents in early 2020 – after his ostomy surgery! While enduring temperatures in frigid Antarctica of minus 50 degrees and then blistering Brazil that topped out at 100 degrees with 100% humidity, Jonathan said when things got tough he held fast to the reason he was there: to bring awareness to the



mean for me.” And then he began to follow the same miserably predictable path so many of us have walked. At restaurants, he was more concerned about where the bathroom was than what was on the menu. He had to make the unimaginable choice when staring at the red “occupied” sign on the men’s restroom of whether to have an accident in the hallway or duck into the women’s restroom and pray he got out before being discovered. Like many of us, he endured all this shame and embarrassment alone, not willing to share his struggle with anyone outside of his immediate family.

Jonathan tried every treatment from Remicade infusions to Humira injections as well as a variety of alternative therapies. If he heard about a new clinical trial, he signed up immediately. Jonathan recalls his desperation by saying, “I was basically waving my hand to try every possible treatment that might put and keep this in remission...nothing was

1.7 million people in the U.S. who suffer from Crohn’s and ulcerative colitis.

With a determined set to his jaw and an intense flash in his warm chocolate-brown eyes he recalls, “Whenever I felt like I wanted to quit, I would literally look over my shoulder and think about all those people marching with me. I knew I simply could not come back and face myself if I had let them down.”

Predictable Path

Jonathan got sick in early 2000 and, like many of us who suffer from IBD, was totally stunned by his diagnosis. He remembers, “I had never heard of ulcerative colitis or Crohn’s disease and had no idea what it would

off the table.” Eventually, all the treatments began to fail and Jonathan was trapped on the prednisone roller coaster. He vacillated between 40 to 5 milligrams a day only to experience flare ups which forced him to revert back to the dangerously high dosage of 40 milligrams once again.

Silent and Detached

During an initial consultation with colorectal surgeon Dr. David Etzioni at the Mayo Clinic in Phoenix, Jonathan remembers his wife, Gianna, being fully engaged and asking questions about the possibility of ostomy surgery if there were no other treatment options. But Jonathan remained silent and detached throughout the conversation. He recalls, “The idea of being in my

mid 30s and having to wear an ostomy bag was simply incomprehensible to me.”

So, he continued to endure intense pain at night that forced him to get up and start his day early. When it was time for meals, he became a “champion” at moving food around his plate to look like he was eating so others wouldn’t become suspicious. He knew pain would surely come if he ate anything. While he might have been able to hide his illness from some, it was Gianna who would ultimately force him to face reality when she compassionately, but firmly said, “Look, this is no quality of life. You really need to consider how life could be on the other side of this.”

So, they set up another appointment with surgeon Dr. Etzioni who introduced the idea of j-pouch surgery that would only require a temporary ostomy for six months. Jonathan latched onto that idea like a drowning man grabs a life preserver. He reasoned, “It’s only six months. I can do anything for six months. It’s not like I’m going to be stuck with it for the rest of my life.”

Hitting Rock Bottom

Dr. Etzioni shared some very unwelcome news with Jonathan after the first surgical step in the j-pouch procedure, “I think you may have been misdiagnosed and don’t have ulcerative colitis but, instead, have Crohn’s disease. Unfortunately, the j-pouch is not a viable option for you. We’re going to have to perform a total colectomy and you will have your ostomy for the rest of your life.”

He tried to encourage Jonathan by quickly telling him that he would finally be pain free and be able to have a wonderful life like so many others who have gone ahead of him. But Jonathan hardly heard any of that. All that reverberated in his mind was ‘You’re going to have an ostomy for the rest of your life.’

Jonathan remembers being absolutely shocked the first time he saw his stoma. While he had seen pictures, he simply wasn’t prepared for the reality and said he felt overwhelmed. He recalls, “The WOC Nurse came into the room and was changing the bag and talking to me as if this happens every day and I’m thinking, ‘Hello! Don’t you realize that part of my intestine is sticking out of my side?’”

Jonathan hit rock bottom just a few days later when he was rushed back to the hospital due to a blockage and

the reality of his situation set in. His ostomy was permanent and there was no going back. Jonathan believed his life was over. He was certain he was destined to work from home for the rest of his life with virtually no human interactions. And he was OK with that because he didn’t ever want to talk to anyone about his ostomy.

Prophetic Words

Every person who has ostomy surgery processes their initial grief differently and there’s no way to predict the event that will help them move forward in their recovery. For Jonathan, that event was three days post-surgery when he was instructed to walk around the rectangular nurse’s station in the middle of the hospital floor. Hunched over and shifting his weight onto his IV pole, he carefully shuffled his nonskid socks in the direction of the door only to find he could not make it more than 10 feet.

Gianna, not wanting to push him too hard, gently said, “You rest a bit and then you can get back up and try to make it to the nurse’s station.” It was at that moment Jonathan remembers making a conscious mental shift not to let his ostomy define him and resolutely announced, “Oh no, Gianna, I’m going to go so much farther than that.” And he had no way of knowing just how prophetic those words would be about his future.

It wasn’t just the physical recovery he was battling; Jonathan was also fighting to turn his emotions around and remembers sharing his fears with one of his WOC nurses. She made quite an impression on him when she looked him right in the eyes and promised, “You can do anything that you put your mind to!”

She went on to tell him stories of a kicker in the NFL, a bull rider, a martial arts specialist

On A Mission

Jonathan’s wife, Gianna, co-founded the nonprofit Heather’s Mission along with Heather Christiansen. Heather met Gianna and Jonathan at CCFA meetings. She offered Jonathan support, advice and a shoulder to lean on during his IBD treatment and ostomy surgery. Gianna and Heather want to start conversations and offer support for the issues and people in Arizona effected by ulcerative colitis and Crohn’s disease. Heather’s Mission offers three programs: providing Awesome Ollie teddy bears, hospital visits for patients and a support dog. Call 480-245-8036 or visit www.heathersmission.org



and a host of other individuals who were doing amazing things after their ostomy surgeries. It was like someone drawing back the curtains in a dark room on a bright sunny day as Jonathan began to entertain the hope that there could be an amazing life ahead for him.

Perfect Opportunity

Although Jonathan wasn't a runner, based on his first trip around that nursing station, he decided to do something that he considered impossible — to run a half marathon. His friend, Rick Steele, a world-class triathlete, agreed to be Jonathan's training partner and in the fall of 2018, less than four years after his surgery, Jonathan clocked an unbelievable 1:37:31, even beating his coach by three seconds!

About a year later, Rick approached Jonathan with another challenge, a bit more ambitious than that first half marathon: running seven marathons in seven days on seven continents!! As ridiculous as the idea sounded, Jonathan was inspired by Rick's belief in him when he enthusiastically implored, "Do it with me!"

As Jonathan thought about the idea, he decided this would be the perfect opportunity to share his story with the rest of the world and encourage other IBD patients in the process. So, he teamed up with Heather's Mission, an organization dedicated to improving the lives of those with IBD and set his sights on raising enough money through donations to purchase 1,000 "Ollie the Ostomy Bears" to give to children who have undergone ostomy surgery.

There is really no way to prepare for the challenge. Imagine running 183.4 miles in seven days while adjusting to multiple time zones and dealing with conditions where you can't feel your fingers or your feet to 100 degree temperatures that made the pavement so hot that it would literally melt the soles of your shoes.

Doing all of that with an ostomy compounded things a bit...well a lot! Jonathan worried that he might have to change out his pouching system or empty during the race. He wondered how many extra pouches he might have to bring with him. Since marathon runners can't carry a bunch of stuff, Jonathan had to coordinate leaving his supplies at designated aid stations throughout the course.

Unique Challenges to Overcome

Problems, or as Jonathan calls them, "challenges to overcome," continued to mount throughout the week.

From having to set an alarm on his phone to wake up every couple of hours on the plane to empty his ostomy pouch to skipping meals before each race to avoid output interfering with his ability to run to the wafer melting in the hot and humid conditions in Brazil, Jonathan experienced a full gamut of challenges. The skin around his stoma became so red and bumpy that it looked a raspberry. With a sigh and a shake of his head, Jonathan sums it, "Everything that could go wrong, did."

But through it all, he did not share his challenges with his fellow runners, the race organizers or even the medical team. Why not? For Jonathan it was all about keeping everything in perspective.

"What I was dealing with paled in comparison to what many people face on a daily basis. Everyone is dealing with some-

thing, whether it be a physical or mental limitation, and mine certainly wasn't anymore significant. I was incredibly fortunate to set foot on every continent in the world in one week and I wasn't going to let a little challenge here and there derail what I set out to do," Jonathan declares.

Be Proud

While Jonathan is quick to acknowledge that there aren't many who would be insane enough to embark on a marathon adventure like he did, he encourages each of us to set our own stretch goals and to start working towards something we might consider "impossible."

Because of his ostomy journey, Jonathan says he has had a unique opportunity to hit the "reset" button on his life, something most people never get to do. He would not want to change anything about his journey — not the pain, not the fear and especially not the struggle, because it has been transformative and has given him a purpose that he didn't have before.

He sums it up well by saying with a grin, "Your ostomy surgery is not the end. It's the beginning. You get to write the next chapter of your life. So, whatever you write, make it so impactful that one day you will look back and be incredibly proud of what you've done." 🐻



Top: Negretti completing a marathon in Antarctica. Running in Perth, Australia.