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Jax Batty

"It's No Big Deal"

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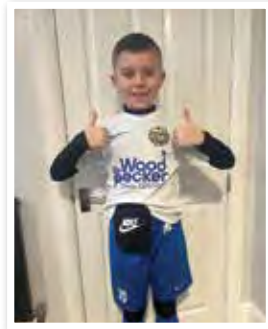
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Really No Big D

Inspirational boy stays positive, active and raises thousands for charity

By Rolf Benirschke

When Morris and Rose Michtom created the first teddy bear in 1902, they could not have imagined that those bears would become beloved by children around the world. And they certainly would have been astounded that 120 years later a bear named "Buttony" would change the life of a boy named Jax in the UK who needed ileostomy surgery when he was only nine years old.

Jax's medical odyssey began with his first hospital admission due to constipation at four weeks of age when he was diagnosed with lactose intolerance. Initial treatment with suppositories helped for a short time, but soon Jax could not keep any food down and his little belly began to swell. His mum, Mel, remembers her frustration when the doctors shrugged it off and family members told her that the "doctors know best."

Powerful Force

A mother's intuition is a powerful force, however, and Mel soon grew tired of hearing her sweet baby cry in pain that was next attributed to a bad bout of colic. When blood appeared in Jax's diaper, she decided, "Enough is enough! I'm not leaving this office until a referral has been made to someone a bit higher up." She got that referral, but things didn't go much better at the second hospital when she was simply given a bottle of Lactulose, a laxative used to treat chronic constipation. So now, loaded up with more laxatives, given several enemas, Jax was sent home to see if that would help.

Unfortunately, the relief was short lived and Jax was then referred to Dr. Richard Lindley, a pediatric surgeon at Sheffield Children's Hospital, who recommended Botox treatments, which have been shown to be helpful in relieving constipation. Jax was three years old at this time and when asked what he can remember about those treatments, he thinks a bit and replies, "I was put in a little room and given a ham sandwich." The Botox helped for about four months, but made Jax's stool very watery, which kept him from attending preschool. He

would undergo two more treatments of Botox over the next year, but again, with limited success.

Now, after three years of seemingly endless doctors, hospitals, endoscopies, and colonoscopies, there still had not been a definitive diagnosis. Mel was told that Jax was too young to have Crohn's disease and was likely suffering from severe chronic idiopathic constipation. Mel put her foot down again and told the doctors, "We can't go on like this, my son is now five years old. What is the plan or do you even have one?"

The doctors next suggested a Peristeen Irrigation System which introduces water into the bowel through a rectal catheter. This procedure is done while sitting on the toilet for 40-60 minutes every night. Remember, Jax is now an active five-year-old boy, and this is miserable for him, as it took away his nighttime play/family time. When Jax was asked how he endured this nightly treatment his answer was quick and matter of fact, "I just dealt with it." After a year and a half of Peristeen, problems for Jax started again, and it became clear that irrigation was not going to be a long-term answer.

The team at Sheffield's Children's Hospital next suggested an Antegrade Colonic Enema (ACE) where a small passageway is created from the appendix or a small piece of bowel. A conduit is made from a small section of the small intestine and brought to the surface of the skin via a stoma. While we traditionally think of a stoma as the place stool leaves the body, this stoma is used to flush a saline solution into the colon and produce a bowel movement.

Heartbreaking Sight

Jax got off to a rough start in the hospital when he collapsed on the floor during his first "washout." Mum described it as "heartbreaking" to see her son struggle yet again. After an ACE procedure, patients are typically discharged in 2-3 days, but Jax was there for more than a week getting used to his new stoma.

Upon finally returning home from Sheffield's, a nearly two-hour drive, Jax and his mum were pretty much on their own. There were not any continence professionals

"Now, after three years of seemingly endless doctors, hospitals, endoscopies, and colonoscopies, there still had not been a definitive diagnosis."

Deal



in Grimsby, his hometown, who had dealt with an ACE. Two weeks after his surgery, Jax got an infection in his stoma and Mel remembers having to educate the local doctors with a bit of a chuckle, “I knew more about this than the doctors did. I had to Google the procedure and show the surgeon. Nobody had a clue!”



A Brighter Future

Although the ACE procedure didn't go smoothly, there were two very good things that came into Jax and Mel's life that would change his future. The first was an introduction of Jax to his new friend, “Buttony Bear,” who also has a stoma. Buttony was created by Jenny Gow in Scotland to help her daughter cope with the multiple surgeries she would have to endure. Buttony and Jax bonded immediately and have been inseparable ever since – Buttony even accompanied Jax to the operating room!

As important a gift as Buttony was to Jax, Mel received something equally precious at the same time – a new friendship with Kim, a mum in Liverpool (about 2.5 hours away) whose daughter, Jessica, had undergone colostomy surgery at four years old. Having a new friend in Kim was life changing for Mel, “It was like a weight lifted off my shoulders when I could finally speak to someone who understood the battle we had been fighting.” When their kids were introduced to one another, Jessica and Jax bonded immediately and thanks to FaceTime, Jessica now eight years old, was able to share her experience as a “seasoned ostomate” with Jax and even show him her ostomy! The two would have daily phone calls for almost a year until last summer when they finally had a chance to meet in person when Jax and his family traveled to Liverpool.

Six months after the ACE procedure, Jax was unable to eat again, and his belly was swollen like a watermelon. X-rays taken at the local hospital determined

that Jax was experiencing a complete blockage. Over the next year, Jax was in and out of the hospital and the gaps between admissions were getting shorter and shorter to where he was admitted every two months. Although Jax was missing out on some of his childhood, he found joy in playing FIFA Rocket League and Mine-craft on his Play Station, being a striker on his soccer team and helping his mum around the house.

Jax describes being in and out of the hospital repeatedly as just “part of his life” and said he went there each time trying to “mind his own business.” The most unsettling thing was not knowing how long he would be in the hospital each time.

Enough Is Enough

Pushed to her limit, Mel went back into her “enough-is-enough” mindset to find someone who was willing to go beyond just minimal interventions and really find out what underlying condition was driving Jax's problems. This time she called for a meeting with PALS (Patient Advice and Liaison Service) which helps resolve problems in the hospital. Nearly at the breaking point, she firmly said,

“Look, this has been going on far too long. Things aren't working and we need a plan for his future. I have another child to care for and continually being separated from our family is hurting all of us.”



It took a couple of months, but they finally received word that Jax had been assigned to another surgeon, Dr. Murthi. After reviewing Jax's history, Dr. Murthi concluded that Jax's body needed a break and suggested they take three months to learn about the possibility of having ileostomy surgery. Unfortunately, Jax would not have three months to wait when, a short time later, he had another blockage. After a very scary night in the hospital where Jax also had a seizure,

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As an ileostomate, DripDrop has been a gamechanger for me. Now I only get dehydrated when I forget to drink it!

Adam R. Katz



No Big Deal from page 45

he was immediately placed on the surgery waitlist. Six weeks later on November 1, 2022, Jax finally had his ileostomy surgery.

As he had been throughout his entire ordeal, Jax was brave and incredibly practical, even changing his bag by himself while he was still in the hospital. While they had been hoping for a smooth recovery, poor Jax was hit with an ileus due to the anesthesia. Along with vomiting for several days, his heart rate was erratic, the pain was intense, and Jax went back into surgery on November 5 to straighten out a twist in his bowel.

Finally, Jax was able to return home and like the resilient kid he has proven to be time and time again, Jax quickly recovered and was soon able to rejoin his soccer team, Discoveries Inventors, and resume cheering for his favorite professional soccer player, Luis Diaz.

Jax and Jessica have continued their friendship and their mutual love for Buttony, inspiring them to raise funds to provide bears to other kids like them who are facing ostomy surgery. To date, Jax has raised \$13,558.

“Keep pushing because there is a light at the end of the tunnel. There are people who want to help, and you just must keep going.”

(link to Jax page: <https://bit.ly/3YNX7Uc>) In October, Jax and Jessica were both honored at Westminster Palace with the British Citizen Youth Award for their extraordinary fundraising efforts. And in March of 2023, Jax was announced as the winner of the North East Lincolnshire Young Inspirational Child Award.

When I asked Jax what message he would share with other kids who might be afraid of having an ostomy, a smile stretched across his rosy cheeked little face revealing several gaps where he had recently lost some baby teeth, and he said, “It is going to fix the problems and you don’t need to be scared. It’s really no big deal.” And from mum, Mel, she’d like to encourage other parents to trust their intuition. “Keep pushing because there is a light at the end of the tunnel. There are people who want to help, you just must keep going.”

Rolf Benirschke was the placekicker for the San Diego Chargers for 10 seasons. He started the patient engagement company Legacy Health Strategies and has authored three books. He is married and the father of four children, three with special needs. www.rolfbenirschke.com. 🐻