

First use of The Insides Neo at home

By Taylor Harrington

Introduction:

This case study follows Jaybie, a preterm infant born with gastroschisis who required multiple abdominal surgeries and experienced a complex postoperative course. She developed intestinal failure, became dependent on intravenous nutrition, and faced a long and challenging path to discharge. Jaybie's journey included successful use of chyme reinfusion therapy both in hospital and at home, making her the first paediatric patient in New Zealand to manage this therapy outside of a hospital setting.

Patient History:

Jaybie's parents were advised antenatally that their baby girl had a small gastroschisis, as well as a dilated intra-abdominal loop of bowel, likely representing an atresia. While they were prepared for surgery after birth, they were not expecting her to arrive early. Jaybie made a surprise entrance at 34+3 weeks gestation, weighing 2390g (68th centile).

She was born in good condition and breathing on her own. At a few minutes of age, Jaybie started to show some signs of respiratory distress secondary to her prematurity and needed some help with her breathing. Ideally, preterm babies are supported with continuous positive airway pressure (CPAP). However, CPAP can cause preterm infants to swallow excess air. Given Jaybie's gastroschisis and possible atresia, the team opted to electively intubate her to avoid inflating her bowel.

The surgical team reviewed her shortly after birth. They were reassured that her gastroschisis was very small, but more concerned about the potential atresia. It was decided that she would go to surgery soon after birth

Surgical HX:

On day 1, Jaybie was prepared by the NICU team for her first laparotomy.

Intraoperatively, it became apparent that her gastroschisis and suspected atresia were not as straightforward as initially thought. Internally, her anatomy was more complex. The surgeons found a short length of small bowel on a thin mesentery that was not in continuity with the rest of her bowel. She also had an ileal atresia with a markedly dilated proximal bowel.

The surgical team excised the atresia, removed the unhealthy and grossly dilated proximal small bowel, and formed a proximal ileostomy and a distal colostomy to allow the gut to rest and heal. They also resected the isolated short segment of small bowel that was not connected to the rest of the gut. In total, Jaybie lost 55 cm of small bowel, but retained a good length of proximal bowel. Distal to the resection, she had 15 cm of microcolon, which was confirmed to be patent.

Postoperatively, Jaybie recovered well. Given her prematurity, low birth weight, the extent of ileal resection, and the presence of a microcolon, the NICU and surgical teams agreed that early chyme reinfusion therapy would likely benefit her.

Starting The Insides® Neo:

Jaybie was started on enteral feeds and, unsurprisingly, had very high ileostomy outputs, up to 40–60 ml/kg/day on only a small volume of expressed breast milk. Given this, she was commenced on The Insides® Neo to begin chyme reinfusion therapy.

She had already been fitted with a Hollister Pouchkins Bag, so with her next bag change, the nursing team assembled and fitted the device. A size 6 Fr gastric tube was inserted into the distal fistula and secured at the 5 cm marking on the outside of the bag using the provided clip. Chyme from Jaybie's high-output ileostomy was withdrawn every 4–6 hours and reinfused over the next 4–6 hours via a syringe pump.

Once chyme reinfusion therapy began, her ileostomy output remained high, up to 120ml/kg/d, but the nursing team was able to refeed all of her stoma output through the distal limb without any distal reflux. This allowed her enteral feeds to be increased while gradually weaning off her TPN.

Three and a half weeks after her laparotomy, Jaybie was tolerating full enteral feeds via continuous infusion, as well as full chyme reinfusion via her distal colostomy. She was passing regular stools in her nappy and gaining weight. Four weeks after her initial surgery, she was transferred to the paediatric surgical ward to continue growing until her planned reanastomosis.

Shortly after her transfer, Jaybie's ileostomy outputs continued to climb, reaching 200 ml/kg/day. This required an increase in the rate of chyme reinfusion. As the rate increased, her distal fistula began to reflux chyme, and she was no longer able to tolerate full reinfusion. She became dehydrated and started to lose weight. In consultation with the surgical, gastroenterology, and paediatric teams, she was restarted on TPN and her enteral feeds were cut back. This was planned as a short-term measure, as her reanastomosis was scheduled for 10 days later.

Reanastomosis, Recovery and Revision:

Before her reanastomosis, Jaybie had a contrast study which showed a normal calibre colon with no strictures. This suggested that chyme reinfusion had helped get things moving distally.

On day 52, her reanastomosis went ahead as planned and she recovered well in the immediate postoperative period. She was graded back up to full enteral feeds, but on POD 5 she developed significant rectal output which then abruptly stopped. This was accompanied by abdominal distention. An X-ray revealed free air, and on day 58 Jaybie was taken back to theatre for her third laparotomy.

In theatre, the surgeons found copious yellow green serous fluid throughout her abdomen and fibrin in her pelvis. There was a kink at the anastomosis site in the right lower quadrant which was causing upstream bowel dilation. They also found a 2 mm perforation in the anastomosis wall, located between the mesenteric and antimesenteric sides.

The decision was made to remake her ileostomy and distal colostomy to allow the bowel time to rest. Given the issues she had experienced prior to her reanastomosis with her distal limb refluxing chyme during reinfusion therapy, the surgeons chose to site the ileostomy and colostomy on opposite sides of her abdomen. This allowed the team to more easily monitor distal limb reflux and replace extra losses with intravenous fluids as needed to prevent dehydration.

Jaybie had a difficult recovery from her second laparotomy and remained in hospital struggling to wean off intravenous nutrition. On day 91 she was transferred from the surgical ward to the long-term medical specialities ward. At this time, she was still only tolerating 6 ml of continuous enteral feeds via NGT, with very high stoma outputs, and the remainder of her nutritional needs were met with intravenous nutrition. She was still having ml:ml chyme reinfusion through her distal limb, but reflux continued to be a problem.

During her time in hospital, Jaybie struggled with weight gain and tolerating enteral feeds. Her distal reflux was an ongoing issue, but eventually the team determined that she could tolerate a maximum distal reinfusion rate of 13 ml per hour, which was approximately 90 ml/kg/d.

After her transfer to the medical specialities ward, Jaybie's parents became the primary users of The Insides® Neo. By this stage, they were experts. They had been managing the device for weeks in hospital and could confidently set it up, troubleshoot, and adapt it to Jaybie's needs. This ward had never performed chyme reinfusion before, so The Insides Company provided training sessions for the staff. The nurses attended these sessions and made use of the company's online resources and teaching videos as needed.

However, many quickly found that Jaybie's parents were their best resource, as they could demonstrate the practical application of the device in real time. They showed the team step-by-step how to assemble, secure, and operate the system. The Insides Company's accessible training material, combined with the intuitive design of the device, had enabled the parents to become confident and capable operators and educators on how to use the device. Their knowledge and skill not only supported the nursing team's learning but also gave everyone confidence that Jaybie could safely continue chyme reinfusion therapy at home.

Discharged Home Using The Insides® Neo:

At 162 days old, or 5 months of age, Jaybie was finally discharged home with her family. She was on intravenous nutrition for 19 hours per day, continuous gastric feeds for 19 hours per day, and allowed 5 ml of milk via a bottle three times a day to meet

her developmental needs. She also went home on continuous chyme reinfusion therapy using The Insides® Neo, making her the first paediatric patient in New Zealand to manage this at home.

With home intravenous nutrition, nasogastric feeds, and chyme reinfusion therapy, Jaybie's parents had their hands full. Although they no longer had the constant support of the hospital team, they were overjoyed to be home. The freedom to wake up in their own beds and set their own routine was a welcome change after months in hospital. With strong family support, Jaybie could spend time with her cousins, play, and explore the world around her. That support was just as important for her parents, who had spent months isolated in hospital. Only one parent was allowed to sleep at the bedside throughout this whole journey, and the parent who stayed was unable to leave the room without leaving Jaybie unattended. Having family pop into their house to watch Jaybie for even 15 minutes so they could step outside for a quick break was a game changer. Jaybie's world quickly grew beyond the four walls of her hospital room, and the impact on her social and developmental growth was huge.

Managing her complex medical needs at home was not without challenges, but her parents approached it with organisation, planning, and a determination to make the best of their situation. Outings required plenty of preparation and equipment, but they still managed to get out and about, giving Jaybie experiences she never could have had if she remained an inpatient.

At home, her parents found refeeding with The Insides® Neo easy and intuitive. They were completely independent with the process and required no support from the community homecare nurse other than ordering supplies. There were no adverse effects from chyme reinfusion therapy at home and no hospital admissions related to it.

Their biggest frustration was the limited surface area of Jaybie's abdomen, which meant her ileostomy and colostomy bags overlapped slightly. Whenever the ileostomy bag leaked, the colostomy bag and refeeding set-up had to be changed as well. As Jaybie became older and more active, bag changes became a two-person job because she had little interest in staying still when there were more exciting things to do.

Final Reanastomosis and life today:

At almost 11 months of age, 326 days old, Jaybie underwent her final reanastomosis. Finally, after 300+ days of using the Insides® Neo, her refeeding journey would be over. The surgery went smoothly, and the surgeons noted there was no size discrepancy between the proximal and distal bowel, a result they attributed to the benefits of chyme reinfusion therapy. Her recovery was remarkably quick, likely aided by the conditioning of her bowel from months of refeeding. 10 days before her first birthday, she was discharged home without a stoma for the first time in her life.

Today at 20 months old, Jaybie continues to require intravenous nutrition and nasogastric feeds at home, but has recently been reduced to only 12 hours of TPN each day. She now receives continuous gastric enteral feeds overnight, with bolus nasogastric feeds during the day, and has begun trialling solid foods. This is a huge milestone for both Jaybie and her parents, giving them more flexibility, freedom, and hope for continued progress. Her journey is a testament to her resilience, the dedication of her family, and the role of chyme reinfusion therapy in optimising outcomes for complex surgical infants.

Conclusion:

Jaybie's journey has been anything but straightforward. After being born preterm with gastroschisis, she required multiple abdominal surgeries, over 20 months of intravenous nutrition, and long periods in hospital. She became the first paediatric patient in New Zealand to use chyme reinfusion therapy at home, which played a key role in her discharge from hospital and aided in preparing her bowel for her final reanastomosis. Along the way she overcame high stoma outputs, feeding challenges, and the complexities of living with intestinal failure.

Today, Jaybie is happy and thriving out in the community and her little world has grown for beyond the hospital walls. She continues to make steady progress with her feeding and development, and her bright personality is shining through. None of this would have been possible without her parents, whose dedication, resilience, and love carried her through every stage. They are the true superheroes of Jaybie's success story, and she is one lucky girl to call them Mom and Dad.