

Chez nous

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Learning how to eat

Toddler on his way to
overcoming tube dependency
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Hôpital de Montréal
pour enfants
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Montreal Children's
Hospital
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One bite at a time

Toddler learns how to eat by mouth after years of being tube fed

By Stephanie Tsirgiotis

Dante spent the first 292 days of his life in a hospital. He came into the world a lot sooner than expected; his mother, Mariarosa, was less than six months pregnant when he was born — and against all odds, he survived.

Overcoming many obstacles

At six weeks old, Dante developed necrotizing enterocolitis (NEC), a common condition in premature babies where the tissue in the intestine becomes injured or dies off, causing inflammation. As a result, he was transferred from the

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► Above: (l. to r.) Mariarosa, Michael, and Dante.

Jewish General Hospital to the Montreal Children's Hospital's Neonatal Intensive Care Unit (NICU).

After a month and a half, doctors could see a stricture in Dante's intestines. They decided to operate to remove the damaged tissue, but two days later, it necrotized again so he underwent two more surgeries to repair and reattach his large and small intestines. "This left Dante with a smaller gut," explains Mariarosa. "At this point, he was being fed almost exclusively through an IV tube and he was monitored closely to make sure his stomach was fine and that he could digest food properly."

Eventually, a nasogastric tube (NG tube) was inserted in his nose and down into his stomach. He began gavage feeding 21 hours a day, but he could only tolerate 21 millilitres of formula an hour. "Doctors weren't sure why he couldn't tolerate more liquid, so we decided to perform another surgery. The surgeons made a revision to his intestine and at the same time we decided to remove the NG tube and insert a gastrostomy tube (G tube)," says Mariarosa. "My husband Michael, and I, were hesitant about inserting a G tube, because it



► (l. to r.) Dr. Maria Ramsay, Dante, Dr. Ana Sant'Anna, and Marie-Josée Trempe.

sounded more permanent, but in the end it was the right decision."

The main difference between the two tubes is that the G tube delivers food directly into the stomach. It also meant that Mariarosa and Michael were one step closer to bringing Dante home. Then on June 21, 2016, their dream finally came true. "It was a very emotionally overwhelming day for us. We didn't think our son was going to survive

and now we were bringing him home," recalls his mother. But Dante still had many more hurdles to overcome.

Learning how to eat

Shortly after being discharged, Dante began being followed by the MCH's Neonatal Follow-up Clinic and met weekly with pediatric gastroenterologist, Dr. Ana Sant'Anna, and nutritionist, Marie-Josée Trempe. Because he

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On the cover: Dante

Cover photo: Owen Egan

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Then on May 31, 2017, Dante made a huge breakthrough. Occupational therapist, Christine Labelle, had been working on developing his eating skills and managed to get him to swallow a piece of food. “She ran into my office with the biggest smile,” recalls Dr. Ramsay. “We were both so happy, because we knew he was ready.”

Trial and error

In an effort to continue to expose Dante to more food, he first had to stop his continuous feeding. “We started to give him three set meals of bolus feed throughout the day,” explains Mariarosa. Bolus feeding is a method of delivering formula from a syringe or pump into a feeding tube. “We needed him to get used to eating three meals a day like the rest of us,” she continues.

Their son was then prescribed an appetite-stimulating medication. “For maximum effectiveness, it’s important to cycle the medication. For Dante that

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► Shortly after being discharged, Dante began being followed by the MCH’s Neonatal Follow-up Clinic and met weekly with pediatric gastroenterologist, Dr. Ana Sant’Anna.

had been gavage fed his entire life, he hadn’t developed the skills to eat, and was dependent on his G tube. “We didn’t want this to be a permanent solution, so we were eager to have it removed,” says Mariarosa.

In order to help with the transition, the family was referred to Dr. Maria Ramsay, Director of the Children’s Pediatric Feeding Program. The program, whose patient population has doubled in size in the last five years, offers a multidisciplinary approach to evaluating and treating children with a variety of feeding problems, especially those who are dependent on a feeding tube.

“After meeting with Dr. Ramsay, she explained that it was too early to remove his G tube and there were many steps we had to take before beginning that process,” says Mariarosa. One of those steps was being able to eat some pureed food and drink liquid safely. “Before beginning to wean off a child from gavage feedings, I assess whether or not they are physiologically and medically ready,” explains Dr. Ramsay. “Based on the guidelines I developed for home-assisted tube feeding removal for medically fragile infants, it was clear that Dante wasn’t ready yet.”

meant five days on it and two days off, because you don't want the body to get used to it," says Dr. Ramsay.

Dante also began being exposed to different types of food textures and smells. "We tried getting him to lick pieces of apples, pears, or taste things like apple sauce. At first, he didn't like anything, but then he tried bacon! It was the first time he licked something and smiled," she says. Dante's family was then advised to reduce his bolus feeds from three to two in an attempt to get him to eat real food. But after two days, he had lost too much weight, and returned to three bolus feeds. "This trial and error process is different for every child. What works for one patient might not work for another," explains Dr. Ramsay. "It's important to work closely with the family every step of the way."

During this time, Dante was being weighed regularly. He needed to gain weight before they could try weaning again. Then in November 2017, Dr. Ramsay and her team felt he was ready. On top of his two bolus feeds, Dante began eating pieces of food, like chunks of hamburger meat and of course, bacon. Over the next six months, Dante continued to eat food once a day, but he wasn't gaining or losing weight. "Eventually we had to stop again and return to the three bolus feeds, because he was getting taller, but not fatter. He was dropping off the growth curve again," says Mariarosa.

One step closer

Discouraged, Mariarosa and Michael began to lose hope that their son would ever have his G tube removed. "Dr. Ramsay helped us a lot during this



► Dante is no longer psychologically dependent on his tube and can now eat by mouth.

period. She said she was confident that Dante would eat normally one day and that gave us a lot of hope," says Mariarosa. "She told us that he was already a success, because he was no longer psychologically dependent on his tube. He now knows how to eat and that's a huge accomplishment."

Today, Dante is more open to trying new foods and he's eating more regularly by mouth. "Every morning, he wakes up and says 'Mommy, I'm hungry! I want breakfast'. Such beautiful words to hear," she smiles. He can now wolf down two high-calorie pieces of toast slathered in butter and Nutella. He still receives all of his main nutrients through his bolus

feeds, but now he adds breakfast and lunch to the mix. "We are fully concentrated on getting him to gain weight so we can begin the weaning process again," explains Dr. Ramsay. "We're getting there!"

"Initially, my husband and I were opposed to having the G tube inserted, but if that's what Dante needs, that's what he needs," says Mariarosa. "We wanted so badly for him to be a 'normal' kid, but this is his normal. When he doesn't need it anymore, he won't need it; but until then it's a big part of him and we don't want him to ever be ashamed of it." ●

Accreditation Canada

What to expect during the official visit from May 27-30, 2019

SURVEYORS WILL BE...

- Talking with staff, physicians, and volunteers about the care and health services they provide to patients
- Talking with patients and families about the care and health services they are receiving
- Listening to how staff communicates with each other
- Listening to the information that is provided to patients and families
- Talking with staff about organizational practices (policies and procedures, training, quality and risk management, etc.)

THEY WILL ALSO BE...

- Touring the facility and/or specific program areas
- Watching for hand-washing and two-step patient identification
- Looking at how medications are stored, obtained, and administered
- Observing the work environment for cleanliness to ensure infection control guidelines are being followed

HOW CAN YOU PREPARE?

- Review the key topics found on the Intranet/MyMUHC
- Speak to your manager if you are unclear about something or ask them about attending an information session
- Familiarize yourself with MUHC policies and procedures and know where to find them
- Take the quiz!

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Required Organizational Practices (ROP) Quiz

To help you prepare for the upcoming Accreditation Canada visit, we've put together a short quiz to test your ROP IQ! Answers can be found below.

1. Which of these events should you report by using the AH-223 (incident/accident) form?

- a. A nurse administers medication to the patient and realizes it is the wrong dose.
- b. An open needle is found on top of the patient's bed.
- c. Patient falls on the way to the bathroom because he tripped over vital sign machine cord.
- d. All of the above.

2. What type of medication should never be readily stored in patient care areas?

- a. Concentrated electrolytes (e.g. potassium chloride).
- b. Acetaminophen (Tylenol).
- c. High-dose formats of heparin.
- d. A and C.

3. What should be avoided when writing out prescriptions, order forms, or medication labels?

- a. Drawings.
- b. Abbreviations, like "QD" or "IU".
- c. Emojis.
- d. All of the above (but especially not b!)

4. What is done to improve infections rates at the MUHC?

- a. Hand hygiene compliance is assessed by audits and results are shared.
- b. Education/training on hand-hygiene is offered.
- c. The rates of nosocomial infections are monitored and shared.
- d. All of the above.

5. How do we prevent falls at the MUHC?

- a. Universal interventions are used (e.g. putting the bed in the lowest position).
- b. An environmental scan of patient rooms is performed.
- c. Risk-assessment tool is completed for all adult patients (e.g. Morse scale).
- d. All of the above.

6. What are the most important things when identifying patients?

- a. It is done before you provide any service or procedure or administer medications.
- b. Two identifiers are used with each patient.
- c. You explain why it is important to the patient.
- d. All of the above.

Answers: Every answer is d.



A day in the life of a... **senior pharmacy technical assistant**

By Stephanie Tsirgiotis

Mélissa Despins spends most of her day on her feet. For the last 19 years, she has worked as a senior pharmacy technical assistant for the McGill University Health Centre (MUHC). She splits her time between the MUHC's central pharmacy and the satellite pharmacy that serves both the Montreal Children's Hospital's Pediatric Intensive Care Unit (PICU) and Neonatal Intensive Care Unit (NICU).

Playing a key role

Mélissa performs a wide range of tasks. She not only supports pharmacists by preparing medication and intravenous doses, but she also assists pharmacists with clinical research trials, and helps restock and manage inventory in the satellite pharmacy and automated dispensing cabinets (ADC) on B6.

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► Top: Mélissa Despins

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There are four pharmacists and three technical assistants in the NICU and PICU’s satellite pharmacy. Every morning, Méli ssa and her colleagues receive a list of medications, antibiotics, and intravenous doses needed for the next 24 hours. “We receive the list around 8:00 a.m., and then we get straight to work,” she says. “We prepare approximately 100 doses a day or more.”

One technical assistant identifies and arranges all the products and solutions needed in order of importance, while the other two work “under the hood.” The hood is a sphere-like structure that reduces the risk of airborne contamination during the preparation of sterile products. “We prepare the final products under the hood, but a pharmacist needs to verify everything before we begin mixing,” explains Méli ssa .

Méli ssa works solely on the pediatrics side, and says it’s very different than working with adults because the doses and types of medication prescribed are drastically different. “In the NICU, our patients are very small and fragile, so we need to dilute our doses,” she says. Once all the medications and doses are prepared, Méli ssa and her colleagues deliver them to the medication rooms on each unit. “And then we do it all over again later in the afternoon!”

Granting special access

When she’s not working “under the hood”, Méli ssa is supporting pharmacists and nurses by reviewing protocols and preparing medications for their clinical research trials in the central pharmacy or helping them navigate through Health Canada’s *Special Access Programme (SAP)*.

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The program provides access to drugs not sold or distributed in Canada. “Physicians have to prove that access to a particular drug is needed to treat a patient with a serious or life-threatening condition and that other conventional therapies have failed,” she says.

There are approximately 70 pediatric patients who currently fall into this category. Once special access is granted, Mélissa works at preparing the medication for the family. “If the patient is already at home, I prepare enough medication to cover 60 days, but it depends on the expiry date,” she continues. “A lot of these products don’t have a very long shelf life.”

Health Canada remains well-informed throughout the process to make sure the patient is responding well to the treatment and that the medication is still required. “I’m responsible for making sure both the government and



► Mélissa helps restock and manage inventory in the satellite pharmacy and automated dispensing cabinets on B6.

the drug company have all the information they need,” says Mélissa. “I also coordinate details like when and where the drug will be delivered.”

Best part of the job

“There are a lot of reasons why I love my job; especially when I get to work closely with patients and families — but as much as I enjoy helping them, I’m happiest when I get to see them go home.” ●

More clinics added to eRendez-vous

The deployment of the Montreal Children’s Hospital’s new appointment system, **eRendez-vous** (which is replacing MediVisit), is still underway. It began slowly last December with the nephrology clinics; and in March, cardiology clinics were also added (the diagnostic sector will be completed with Medical Imaging). The process has been slower than expected, primarily because the eRendez-vous deployment team is putting a lot of effort into ensuring there’s minimum impact on Oacis users.

During this deployment phase, please refer to Oacis when looking up past and future appointments, because once specialties are transferred to eRendez-vous they will no longer be visible in MediVisit.

In April, the team plans on deploying Audiology, followed by all the clinics under the Appointment Center (ARC). As the project moves forward, a more detailed deployment schedule will be made available. ●

Remembering those we have lost...

A memorial service is being organized to remember the children who have died recently at the Montreal Children’s Hospital. All staff members are warmly invited to attend this service, which will be held on **Monday, May 13 at 2:30 p.m. in the MUHC Research Institute’s Auditorium (E51.1129)**. ●

Former volunteer brings siblings together at the Just for Kids Sibling Park

April 7 to 13 marks National Volunteer Week in Canada

By Pamela Toman



► Kaitlen Gattuso

Kaitlen Gattuso began volunteering at the Montreal Children's Hospital in 2013 in the Hematology-Oncology Department. From the moment she set foot on the unit, she says, it was an eye-opening experience. "I would come back from my visits recharged and energized from interacting with patients and their families. It gave me perspective and got me thinking about my future."

Her future, it turns out, would be linked with the Children's for years to come. Since July 2017, Kaitlen has embarked on a new role as one of four coordinators of the Just for Kids (JFK) Sibling Park at the Montreal Children's Hospital — a space available to siblings of patients hospitalized in the Neo-

natal or Pediatric Intensive Care Units. Children under the age of 13 are not allowed to visit these units, presenting a challenge to families who wish to spend the day with their sick child, but also want their other children nearby. The JFK Sibling Park is a unique space for these brothers and sisters. It allows them to visit the hospital with their parents, all while building happy memories in a safe and educational setting. "I like to call it an alternative day-care," says Kaitlen, "because we don't have the same structure per se, but we have a curriculum that is flexible to cater to siblings and their needs."

Supported by donors and volunteers alike

Supported by the Just for Kids Foundation, the JFK Sibling Park is open Friday evenings, as well

as Saturdays and Sundays to support families with a child needing long-term hospitalization. It's staffed by a team of 16 volunteers throughout the weekend to respond to ever-fluctuating needs. "Some days we can have one or two siblings, but other days, we can have an influx of up to 10 children," says Kaitlen. "I really rely on our team of volunteers to help conduct our activities, provide supervision and enjoy the day with these special groups. Each of them really enjoy coming back because often, the same siblings return week after week, forging really wonderful bonds between volunteers and siblings."

Facilitating expression and participation

In order to best meet the needs of this unique population, Kaitlen and her team of volunteers work diligently to find ways to help children express complicated emotions and to deal with the stress of what is happening around them in the hospital. "Many of these children arrive with different conceptions or ways of reacting to the early arrival of a sibling who is sick and requires intensive hospital care," says Kaitlen, "we follow the lead of the child and try to introduce activities to help them feel like they are contributing to the care of their sick brother or sister by making a baby banner, or recording a voice message for the baby.

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► Valerie Harvey and her children Logan (left) and Noah (right).

This makes it easier for them to feel like their sibling is part of the family and that they are helping in some way.”

Forming life-changing bonds

In Noah’s case, the three-and-a-half year-old’s experience with Kaitlen and countless volunteers at the JFK Sibling Park was truly life-changing for the whole family. His mother, Valerie Harvey, gave birth at 35 weeks in September 2017 to his brother Logan, who required a 16-month long hospitalization in the Neonatal Intensive Care Unit (NICU) due to a malformation

of his esophagus. While Noah attended daycare during the week, Valerie says she felt an additional stress when the weekend would come knowing she would need to arrange care for Noah if she wanted to visit her new baby in the hospital.

When staff members introduced her to the idea of the JFK Sibling Park, she decided to try it out immediately. “At first, it seemed like a lot to have him in daycare all week and bring him to the hospital to get cared for too,” says Valerie. “But it quickly became part of our routine and Noah

absolutely loved it. We were able to eat lunch together every day, and he was able to be with me in the same building, taking a huge weight off my shoulders. I knew he was in excellent hands.”

Over the 16 months his brother was hospitalized, Noah forged incredibly strong bonds with the volunteers and with Kaitlen. “Coming to the hospital every weekend and participating in the amazing activities they facilitated really allowed Noah to feel like he was part of the whole experience,” says Valerie,



► Noah enjoys a snack with a team of volunteers from the JFK Sibling Park.

who laughs that he loved the experience so much, he preferred going to the JFK Sibling Park to his regular daycare. What’s more, the Park allowed Noah and his parents to connect with other siblings and families going through a similar experience. The friendships they created were instrumental to their journey, says Valerie, and she still connects with other families today, almost three months after Logan was discharged home.

“I don’t have the words to express how grateful I am,” says Valerie about her experience. “For 16 months we couldn’t go on vacation, we couldn’t go on day trips, we couldn’t bring Noah on outings. He was only able to physically see his brother a total of six or seven times. It was really hard. And he really wanted to be with us. This program allowed us to keep our family together, and I can’t think of anything more valuable.” ●

► A team of 16 volunteers work throughout the weekend to respond to ever-fluctuating needs.

