

# Chez nous

MCH EMPLOYEE NEWSLETTER

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gift of all

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# The best gift of all

By Stephanie Tsirgiotis

Family hopes to celebrate the holidays at home with their twin daughters



► Craig and Joelle Hasilo hold their daughters Evelyne (left) and Chloe (right).

Joelle Hasilo always knew she wanted to be a mother. So when she found out she was having twins she was beyond excited. And then her water broke 28 days early. “It was exactly like the movies,” she says. “I got up off the couch and then it was ‘swoosh’. It all started to feel very real in that moment.” She was rushed to the Royal Victoria Hospital (RVH) of the MUHC where she underwent an emergency c-section because both babies were breeched. Evelyne and Chloe were born two minutes apart on September 24, 2017.

## **BREAKING THE BAD NEWS**

Since Joelle had just undergone surgery, her husband, Craig, was brought in to meet the twins first. Doctors informed him that they were having a hard time suctioning Chloe’s nose and the twins were rushed to the Neonatal Intensive Care Unit at the Montreal Children’s Hospital.

As Joelle recovered in post-partum, she was unaware that something seemed critically wrong with her daughter. The

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doctors were soon troubled by a second discovery: besides the suctioning problem, they were also having difficulty opening her eye. "They weren't sure if the eye was too small or if she was missing an eye," says Craig. "I then had to walk down the hallway to tell my wife that something was wrong with our daughter. It was the longest, hardest walk of my life because I just kept thinking of how I was going to break the news to her."

The next day, Chloe was sent for a CT scan which confirmed that she was in fact missing an eye. Because her left eye never developed, her septum curved too much to the left causing the blockage of both nasal passages. "It was a critical and urgent issue, because she couldn't breathe out of her nose and therefore couldn't eat," explains Craig. Doctors introduced an oral airway to help her breathe through her mouth while they waited for her to grow. She needed to weigh close to five pounds in order to have her first surgery.

Joelle and Craig then met with the Medical Genetics team to rule out any genetic disorders, and had consultations with Otorhinolaryngology (ENT) and Ophthalmology. "Eventually we'll look into fitting Chloe for a prosthetic eye, but the more pressing issue is her airway problem," explains Craig. Chloe was screened for various syndromes and underwent a series of genetic tests. "Doctors had never seen anything like this," he says. "Sometimes babies are born with one of these issues, but never both at the same time." All the genetic tests came back negative—Chloe was simply born with two major, unrelated anomalies. Her eye condition is known as Anophthalmia and her airway problem is called Bilateral Choanal Atresia.




### THREE SURGERIES IN TWO MONTHS

At three weeks old, Chloe underwent her first surgery. The ENT team at the Children's wanted to open up the right nasal passage to give her an airway. The surgery was successful and she started to bottle feed. Her sister, Evelyne, was



► Dr. Marc Tewfik (2<sup>nd</sup> from r) and Dr. Lily Nguyen (r) meet with the family in Chloe's room after safely removing her stent. *continued >>*

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*On the cover: Chloe Hasilo and her sister Evelyne.*

*Cover photo: Owen Egan*



## The best gift of all... (cont'd)

discharged from the NICU the next day. "Bringing Evelyne home was such a bittersweet moment. I was so happy, but at the same time so sad that Chloe couldn't go home with her," says Joelle.

Chloe started to struggle again with her breathing and stopped being able to feed. Her nasal passage began to block again. On October 24, she had her second surgery. This time the team decided to make a larger opening on her right side and explored doing the same thing on the left. "At first it looked like it worked, but her nasal passages started to block again," says Craig. "Alarm bells would go off every time she ate because her oxygen and heart rate would drop drastically as she struggled to breathe."

### ASKING FOR EXTRA HELP

Performing a third, similar surgery was not an option. At this point, Dr. Lily Nguyen, a pediatric head and neck surgeon in Otolaryngology at the Children's, got involved and decided to ask for help. She contacted Dr. Marc Tewfik, an ENT surgeon from the RVH. Last May, Dr. Tewfik became the first surgeon



► Dr. David Chan, a second year resident with the ENT team, examines Chloe's nasal cavity.



► Karen Verrillo, a transport/night nurse in the NICU, loves looking after Chloe.

in North America to use a new augmented-reality technology, called Target Guided Surgery. There are a lot of danger zones when performing ENT surgeries due to the close proximity of the brain and eyes. This new technology allows surgeons to develop a surgical roadmap that helps guide their instruments during surgery and alerts them if they veer off course.

Dr. Nguyen and Dr. Tewfik discussed the possibility of using it to help Chloe, making her the youngest patient to ever undergo such a surgery at the MUHC. "It took us several days to come up with a plan, because we had never worked with such a young patient," says Dr. Tewfik. "I reached out to some of my colleagues for advice. Chloe is so small so I had to go through all my equipment to pick out the smallest instruments because everything I have is adult-sized. Her nostrils were barely big enough to get the scope in." On November 12, eight OR personnel from the Children's and three from the RVH performed the surgery. "It was a real success," says Dr. Nguyen.

As an extra precaution and because of her size, the ENT team also decided to insert a stent to help hold her septum in place as she healed. "Because of the stent, we had to suction every three hours to make sure her airways were clear enough to feed," says Joelle. *continued >>*

### SO CLOSE, YET SO FAR

Two weeks later, Dr. Nguyen and Dr. Tewfik removed Chloe's stent and were happy with the healing process. The Hasilos were set to head home, but a new narrowing in Chloe's nose, separate from the place that was operated on, was discovered a few days later. "Craig and I were completely devastated," says Joelle. "We were so looking forward to going home."

In the meantime, Joelle makes sure to visit the hospital every single day, with Evelyne in tow. "Evelyne and Chloe love co-sleeping in Chloe's crib," she says. "They are better together. Chloe's best medicine is having her sister by her side." If all goes well, Chloe will be able to make it home for Christmas, but only time will tell. "She will come home when she's ready. Hopefully, it'll be in time for the holidays. Having her home is all we want for Christmas." ■



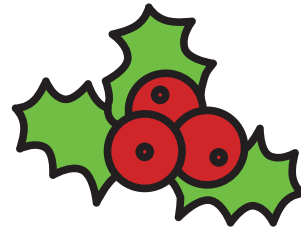
► Craig shares a special moment with Chloe.

## Little Hercules and the Inuksuit are back at the Children's

Originally displayed at the MCH Legacy site, Little Hercules and the Inuksuit were re-installed outside the P.K. Subban Atrium on December 7. Dr. Harry Rosen, creator of Little Hercules, was on site overseeing the installation of his sculpture which he created in the early 2000s. A prosthodontist at the Montreal General Hospital and professor at McGill University for over 60 years, Dr. Rosen sees many parallels between his profession and his art, "In dentistry and sculpture, we are working with hard, unforgiving material that require accuracy. In both cases, if we cut the tooth or stone too much, we cannot go back and fix it," he says. As for the sculpture's new location, Dr. Rosen says, "It's just right". The two pieces are on permanent display by *Je suis là*, more commonly known as the Giant Bear. ■



# The Habs bring Christmas cheer!



On December 12, patients at the Children's received one of the most anticipated visits of the year from the Montreal Canadiens. Like previous years, their visit created a buzz and excitement that permeated the entire hospital. Patients and families were thrilled to receive gifts, and have their photos taken with the players. Here are some pictures from the very special visit. ■





# A day (and night) in the life of a ...respiratory therapist in the Sleep Lab!



*Chez nous continues its series highlighting some of the less familiar professions in the healthcare industry. Sure, we've heard about them, but what do they actually do?*

*By Stephanie Tsirgiotis*



► Respiratory therapist Angie Penta places a respiratory band across six-year-old Samuel's chest.

The Montreal Children's Hospital's Sleep Laboratory (Sleep Lab) first opened its doors in 1990. They were initially set up in an office space that was converted into a sleep laboratory and only saw one overnight patient a month. Fast-forward 27 years and the Sleep Lab has grown tremendously, both in patient volume and physical space. And, respiratory therapist Sylvia Ladan has been there to see it all.

## ACTIVITIES DURING THE DAY

The Pediatric Sleep Lab is divided into day and night activities. Sylvia works alongside Diana Zinno, Assistant Chief of the Sleep and Pulmonary Function Laboratory for Pediatric Respiratory

Services, as well as respiratory therapists Angie Penta, Isabelle Blanchette, Georgia Kotsirilos, and administrative agent Marisa Campellone. They triage referrals and work with pediatric sleep specialist Dr. Robert Brouillette, and Director of the Pediatric Sleep Laboratory, Dr. Evelyn Constantin. During the daytime, they assess patients who have been referred for suspected obstructive sleep apnea or other sleep disorders. Patients are sent home with an oximeter, a small portable medical device that measures the oxygen level in their blood and their heart rate while they sleep. It helps the team rule out obstructive sleep apnea or other breathing issues during sleep.

"We teach parents how to set up the machine at home by placing a probe on their child's toe," says Sylvia. "We use oximetry as a screening test to determine if the patient has abnormal oxygen levels and to see if the patient needs to come to the hospital's Sleep Lab for a more detailed overnight sleep study." The Sleep Lab can send out up to six machines a day, but the waiting list remains long as there is a high demand for this type of sleep assessment. In some instances, the team also sends patients home with an Actiwatch, an activity monitor similar to a Fitbit. The machine is worn on the wrist and measures light and activity to determine a child's sleep/wake pattern. "We see a variety of children with different sleep disorders, including obstructive and central sleep apnea, night terrors, sleep walking, restless leg syndrome and narcolepsy," explains Sylvia. "Our patients also range in age from newborns to teenagers."

## DIAGNOSING SLEEP DISORDERS OVERNIGHT

In more serious cases, a patient will be asked to come in for an overnight sleep study in the Sleep Lab. The overnight study is called a Polysomnography test, and is used to diagnose sleep disorders. It measures a child's brain waves and eye movements, oxygen and carbon dioxide levels, heart rate and

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breathing, as well as leg movements during sleep. Each study can last between eight to nine hours, and the Sleep Lab can run up to two overnight studies three nights a week. The child's parent sleeps alongside them in a cot, but the child is observed constantly by a night shift respiratory therapist close by in the monitoring room.

"Our patients usually arrive around 6:30 p.m. and then the respiratory therapist will begin putting the electrodes on," says Sylvia, who up until recently was working the overnight shift. Over 25 sensors are attached to the patient from head to toe. They attach two respiratory bands across the chest and abdomen to monitor breathing, 13 EEG sensors on the head and face, as well as a nasal flow sensor and a snore sensor on the neck to monitor vibrations.

While the patient sleeps, respiratory therapists analyze all the data in real time. They look at the child's sleep state, desaturation levels, respiratory patterns, carbon dioxide differences, and muscle activities. "We evaluate and analyze all of these channels every 30 seconds and then we come back the following day to look at the data more closely and score," explains Sylvia. Scoring is a quantitative analysis of the data to help evaluate the severity of the sleep disorder. A nine-hour recording contains over a thousand segments of data and all of it needs to be scored. This can take up to four hours of analysis per patient. Once the respiratory therapist scores the study, the sleep medicine doctor then interprets the polysomnography and provides a diagnosis and recommendations. "Infant scoring is different



► Sylvia Ladan met with Samuel and his mother during a recent visit to the Sleep Lab. She showed them how to use an oximeter at home.



► (l. to r.) Angie Penta, Marisa Campellone, Sylvia Ladan, Diana Zinno and Dr. Evelyn Constantin. Missing: Isabelle Blanchette, Georgia Kotsirilos, and Dr. Robert Brouillette.

than pediatric scoring and sometimes more difficult to interpret," says Sylvia. "The various sleep stages are very different in newborns compared to older children."

Sylvia says that respiratory therapists who work in the Sleep Lab develop a unique skill for setting up the patients so that they feel comfortable enough to actually fall asleep. "We put on the sensors while the child is awake, but it can be very difficult in certain situations, especially with younger patients who require more attention," she says. Some patients come in with existing equipment, like continuous positive airway pressure (CPAP) machines, and the settings of these machines have to be fine-tuned by the respiratory therapist during the night. "We have to be great multi-taskers and technically-savvy," says Sylvia, who in addition to her Respiratory Therapy degree also acquired extra certification as a Registered Polysomnography Technician. "It's definitely something you learn on the job and become very good at. We always have one eye on the patient and one eye on the data." And if the patient is struggling too much to breathe or requires immediate treatment, the physician on-call and the respiratory therapist will arrange for the patient to be sent to the Emergency department or admitted to the hospital for further observation and treatment.

"Watching a child struggle to breathe while sleeping is a difficult thing to witness," she says. "Sleep has such an effect on a person's quality of life and behaviour and it's so rewarding when a patient's sleep disorder is resolved and they can finally have a good night's rest. It really changes their entire life." ■

# First time visit from Cirque du Soleil

On December 10, performers from Cirque du Soleil's *Corteo* visited the MCH and put on unforgettable performances for our patients. They went from room to room creating little fantasy worlds for the children to delight in. Thank you to our home-grown circus for visiting our patients and adding a little magic to their day. ■





# Dr. David Mitchell, PFCC Star of the Month

By Maureen McCarthy



Dr. David Mitchell is Talia's doctor but Joy is quick to point out that his role goes much beyond that. "When I think of everyone in Hematology-Oncology, the way the department is run, the care that children and their families receive — Dr. Mitchell sets the tone as a leader and the result is an amazing department," she says. Joy acknowledges that everyone on staff plays an important part in helping patients and families going through the experience. "As a parent, you always want to give your child the best, to do whatever you can," she says, "and this team, with Dr. Mitchell at the helm, does everything to make that happen."

For Dr. Mitchell, who is a pediatric hematologist-oncologist,

Ten-year-old Talia spent almost one year under the constant watch and care of the Hematology-Oncology team at the Children's, and she still returns regularly for follow-up appointments. Talia's mother Joy was asked if she'd like to nominate someone for the hospital's PFCC Star program which recognizes staff who embody the idea of working in partnership with families. Joy recalls, "Our family went through this together but I wanted this to come from Talia. When I asked her who she'd like to nominate, she said Dr. Mitchell."

one of the key principles of patient and family-centered care is treating families with respect, the same way you'd want to be treated yourself. Dr. Mitchell emphasizes that the many team members together make a big difference to the patient's and family's experience.

During his studies, he was drawn to hematology-oncology because he was interested in the group of illnesses in this area of medicine, but also because of the opportunity "to feel

*continued >>*

## PFCC Star of the Month... (cont'd)

like you're doing something for the patient and their family." He further says, "In hematology-oncology, there can be intense amounts of time and treatment for the child, but you have the opportunity to follow them for a long time and you get to know the family in the process. For someone like Talia and her mom, I think they really epitomize why we choose to go into this." ■



**Our PFCC Stars are featured on the Children's Facebook page. Here's what people had to say about our previous award recipient, Dr. Elizabeth Hailu.**

**Sandy Thibodeau**

*She is an extraordinary doctor who is part of a wonderful team of dedicated professionals. I am proud to be part of their volunteer team where I see miracles happen. ❤️*

**constantiiina**

*Dr. Hailu is a phenomenal doctor and human being. She went above and beyond for my son when we were in the NICU and we will be forever grateful. We just adore her.*

**James Hisco**

*Thank you for saving my grandson Milo's life.*

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# Émile Jutras moves on

## MCH patient was first in Canada to use a Berlin Heart



► Émile Jutras (middle) stands proudly with (l. to r.) his mother, Sherley Grondin, his nurse, Eloisa Binder, his primary physician, Dr. Hema Patel, and his father, Steeve Jutras.

The story of little Émile Jutras brings back a lot of memories. In 2002, two-and-a-half-year-old Émile suffered from heart failure and was placed on the Berlin Heart, making him the first child in Canada and the youngest child in North America to receive a mechanical heart as a bridge to a heart transplant.

On December 13, he turned 18 and officially transitioned to the Heart Failure and Transplant Clinic at the Royal Victoria Hospital of the MUHC. The Children's Complex Care team gathered together to say goodbye with a party and cake.

"We will miss him, but he's in very good hands," says Dr. Hema Patel, Director of Complex Care Service at the Montreal Children's Hospital. ■