

# Chez nous

MCH EMPLOYEE NEWSLETTER

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## This is Heart Month

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Hôpital de Montréal  
pour enfants  
Centre universitaire  
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Montreal Children's  
Hospital  
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# Heart Month

An occasion to highlight patients cared for in the Cardiology clinic



By Pamela Toman



► Parents Sheryll and Brad with two-year-old Carmelo.

## **Carmelo, 2 years old** ***Congenital pulmonary lymphangiectasia***

Sheryll and Brad learned about Carmelo's heart condition at a routine ultrasound during Sheryll's pregnancy. "The doctors were concerned about the amount of fluid around Carmelo's little heart, so we were referred to the Cardiology department at the Children's for further evaluation," Sheryll explains. Dr. Adrian Dancea, pediatric cardiologist, met with the family to explain their son's diagnosis: congenital pulmonary lymphangiectasia. "Everyone has fluid called lymph in their bodies, and Carmelo just produces more than everyone else," explains Sheryll. In fact, there was so much fluid around his heart that Carmelo had to undergo a procedure called cardio-centesis, where doctors drained the fluid from around the heart with a needle. "He was hospitalized for a few days, but unfortunately the fluid came back," says Sheryll.



"In December, Dr. Pierre-Luc Bernier performed pericardial window surgery on him, creating a small window so that fluid from around Carmelo's heart could be drained into his lung cavity. He bounced right back and recovered quickly. Even when he was sick, he never showed it. He continues to be very energetic, loves hockey and all sports. He's wild about it all!" ●

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## Ferro, 4 months old *Hypoplastic right heart syndrome*

First-time parents Vincenzo and Hratchouhi were looking forward to their five-month ultrasound when they would find out if they were having a boy or a girl. But when the doctors looked at the images, they saw something that concerned them. “The right ventricle of Ferro’s heart was missing,” says Vincenzo. “We were referred to the Cardiology Department at the Children’s, and they explained that he had hypoplastic right heart syndrome. Basically, the oxygenated blood doesn’t flow into his heart like it should. This meant he would need open heart surgery as soon as possible.”

What seemed like a dire situation at first suddenly seemed more manageable, says Vincenzo, due to the Cardiology team’s optimism. “We got smiles and support as soon as we met them,” he says. “Suddenly we felt like we didn’t have anything to worry about.” At just six days old, Ferro underwent a five-hour open heart surgery with Dr. Christo Tchervenkov, pediatric cardiovascular surgeon, to install a shunt that would allow oxygenated blood to flow to his lungs. Though he will need another surgery in a few months and another between the ages of two and four, Vincenzo and Hratchouhi happily report that Ferro continues to thrive despite the challenges he’s faced in his young life. “Looking at him today, you’d never know anything was wrong at all!” ●



► Ferro with his dad Vincenzo and mom Hratchouhi.

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### **Did you know you're reading an award-winning magazine?**

*Chez nous* received second prize for best internal health care newsletter in Canada! The award was given by the Health Care Public Relations Association of Canada.

*On the cover: Carmelo Thomas  
Cover photo: Owen Egan*

# Heart Month... (cont'd)



► Mom Claudia and dad François with Léa.

## Léa, 12 years old *Narrowing of the aorta*

The day after she was born, Léa and her parents, Claudia and François, were transferred to the MCH because she was breathing rapidly. Dr. Luc Jutras, pediatric cardiologist, explained that their daughter was breathing abnormally because her aorta was blocked. She would need an aortic transplant and just a week into life, Léa underwent surgery with Dr. Christo Tchervenkov to replace part of her aorta using a chemically treated aortic transplant from a cadaver.

The family knew early on that Léa would need follow-up surgeries to further correct her aortic narrowing, and this past August, Léa had another surgery, which she was quite nervous about. However, with help from Child Life Services, she felt reassured and the experience was a lot less scary.

In fact, Léa had such a positive experience that she and her parents created a special scrapbook about what to expect during heart surgery: She presented the book to her classmates recently to explain what it's like to be followed for



a heart condition. "It was only supposed to be a 10-minute presentation, but my classmates had so many questions that it lasted an hour and a half!" says Léa. ●

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**Cesar, 12 years old**  
***Atrial septal defect***

“As soon as I heard it was a heart condition, I was worried,” says Nelsy, Cesar’s mother. “But Dr. Dancea really took the time to explain everything clearly to me, and I felt a lot calmer.” Cesar and his twin brother, Andres, share a lot in common: they both love video games, playing soccer and cheering for their favourite European teams (Cesar loves Barcelona, and Andres is a Real Madrid fan). But during a routine medical appointment, the twins’ doctor discovered that Cesar had a heart murmur. He was referred to Dr. Adrian Dancea, who confirmed that Cesar had not one, but two holes in his heart.

This past fall, Cesar underwent a cardiac catheterization to close the holes. “They placed a long thin tube called a catheter through my vessels and to my heart,” he says. Using a prosthetic device, the team was able to almost completely block the holes. Dr. Dancea assured the family that Cesar could expect to live a completely normal life thanks to the intervention. “We are very grateful for the Montreal Children’s Hospital, Dr. Dancea and his team,” says Nelsy. ●

► Proud mom Nelsy poses with her twin sons Cesar (l.) and Andres (r.)



# An abnormality in utero

Waiting for baby's birth to treat a rare condition

By Sandra Sciangula



► Marina is a healthy baby thanks to the surgery she underwent the day after she was born.

Months before Marina was born, her parents Silvana and Peter already knew that the first few days of her life wouldn't be like most newborns. Silvana and Peter were scheduled for their first ultrasound at three months into the pregnancy. Excited about being pregnant with their first child, they were stunned to find out that their baby was showing an abnormality; her entire liver was growing outside of her abdomen.

The diagnosis was omphalocele, a condition in which a large part of the abdominal wall is missing, resulting in the baby's organs growing outside the abdomen during the gestation period. At six months, Silvana and Peter met with Dr. Sherif Emil, pediatric surgeon at the Montreal Children's Hospital (MCH). "We knew this case was going to be severe based on prenatal ultrasounds, but we never lost hope. Hope is not statistical," he says.

Omphalocele is often accompanied by other abnormalities including chromosomal problems but fortunately, Silvana's prenatal tests around her seventh month of pregnancy indicated there were no other issues. Silvana says that although she had months to prepare for Marina's birth, she didn't know what to expect. "Dr. Emil worked out a plan with us, and he explained the best and worst case scenarios," she says. Marina was delivered by C-section at the Royal Victoria Hospital (RVH) in October, 2015. Their expectations were confirmed: her entire liver was outside her body and was contained in a clear membrane.

The day after she was born, Marina was brought into the operating room where Dr. Emil performed surgery to place her liver inside her abdomen and reconstruct the abdominal wall. Silvana and Peter walked over to the MCH OR from their

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room at the RVH, and waited two hours while Marina was in surgery. “We had a lot of anxiety,” says Silvana. “After just giving birth to a baby who was now in surgery, and not knowing how many procedures she would have to go through—the whole thing was really difficult.”

Their worries were soon put to rest. “Considering that Marina’s case was severe and could have required multiple surgeries, it’s nothing short of a miracle that we were able to repair the abnormality in one operation,” says Dr. Emil. For three weeks after her surgery, Marina was in the care of staff in the Neonatal Intensive Care Unit and surgical ward. She is now 16 months old and, according to her mom, is a very happy and healthy baby, “Marina is our whole world,” adds the grateful mom. ■



► Marina just hours before surgery



► Marina and her mom, Silvana, visit Dr. Emil a year after her surgery.



► Marina is comforted by her father, Peter while she recovers in hospital.

# Schwartz Rounds in the PICU



## Compassion for colleagues translates into better care for patients and families

*By Sandra Sciangula*

Last March, the Pediatric Intensive Care Unit (PICU) at the Montreal Children's Hospital (MCH) adopted the Schwartz Rounds, a program developed by The Schwartz Centre for Compassionate Healthcare in Boston. The centre's mission is to promote compassionate care so that patients and caregivers can relate to one another in a way that provides hope to patients, support to caregivers and sustenance to the healing process.

The meetings, which are optional and open to anyone who works in the PICU, are held every six weeks and last 60 minutes. They are led by a facilitator and a panel usually made up of a doctor, nurse and an allied health professional. Moral distress is a recognized phenomenon that affects health care professionals in complex critical care medicine. The meetings are considered a safe space where staff can discuss how they experienced a situation. "Sometimes we're surprised by how a certain moment made someone feel. We might have thought they dealt with it very well, but in

truth it affected them more than we realized," says Matthew Park, a social worker on the unit. The meetings help build improved communication and make staff more sensitive to each other's needs. The literature supports that improved communication translates into better care for the patient and family. "Knowing that our colleagues have had similar experiences reduces isolation. It builds team cohesion and trust in that we can be honest about our feelings knowing they will not be shared outside rounds, and overall, the team functions better," he adds.

With financial help from the Andy Collins for Kids fund, the PICU was able to initiate the rounds. So far, they have been successful with about a third of the unit's staff from a variety of disciplines participating in the meetings. "The evaluations given at the end of each meeting have also been positive," says Maggie Ruddy, Nurse Manager of the unit. The goal is to get more people involved and introduce the Schwartz Rounds to as many units as possible at the MCH. ■





# PFCC Star of the Month: Lynn McCauley, Nutritionist, Nephrology



By Maureen McCarthy



“Our patients with chronic kidney disease often have feeding issues and their parents have a huge task as they learn about food restrictions or different devices to help with feeding,” says Paule Comtois, January’s PFCC Star, who nominated Lynn McCauley for this month’s award. “Every day, Lynn makes a difference to these families by teaching them how to manage their child’s diet. She acknowledges their anxiety, and simply works through things step by step, showing them what to do. Her approach helps families settle into a very difficult part of their life, which is really important.”

Lynn has worked in the Children’s Nephrology department for most of her career, caring for children with all types of kidney problems. Children with

chronic kidney disease often need diet restrictions, which may limit foods rich in phosphorous, potassium, sodium, fluids, or combinations of these. “I give parents the information and the tools they need but back at home, they are the ones who do all the work, feeding their child several times a day and following what is sometimes a complex diet.” Lynn believes that her communication with families is really important, and supporting and guiding them on an ongoing basis helps them succeed in managing their child’s care. “They have to think about it all the time, so I want to make sure they feel supported throughout the process.” Working with a great team is also something that Lynn values, and she often sees patients and families together with her nursing colleagues.

*continued >>>*

Our PFCC Stars are featured on the Children's Facebook page each month. Here's what people had to say about Paule.

**f Mély Ducharme**  
Without a shadow of a doubt, you are the star of the month... People who cross your path are really lucky – and your patients too! A considerate, dedicated and inspiring nurse!!  
**Congratulations Paule 🥳**

**f France Heroux**  
Paule is a star in our life ... she has been like a member of our family for at least 10 years at the Children’s. Sarah Anne was comforted, cared for, and grew to understand her illness with Paule’s help. A kind, caring and loving ❤️ person to the patients in nephrology. Irreplaceable along with the team. Without them the light wouldn’t shine through again. **Thank you Paule for everything. Xxxx**


**f Marie-eve Lussier**  
Wow congratulations!!! For me, you weren’t just a nurse, but a confidante. Continue to do your good work. I see that even after 20 years you are still an amazing person xx


👍 Like    💬 Comment    ➦ Share

Three-year-old Jayce and his parents got to know Lynn when Jayce was diagnosed with nephrogenic diabetes insipidus. Jayce was admitted to the Children's when he was 10 months old. "We were there for two weeks and we saw Lynn daily," says his mom, Crystal. "She often checked on him, and with the nephrologist, looked at his blood work to adjust the amount of formula and water he was taking in. I really

think her dedication got him through it." A couple of days before Jayce's first birthday, they were back at the Children's learning how to tube feed him, which they did at home for a year. "Lynn is amazing," says Crystal. "She really goes above and beyond. We've just transitioned from monthly appointments to every three months, and we kind of miss her!" ■

## Facebook (cont'd)...

 **Carina Mazloumian**  
Amazing nurse, teacher and colleague! ♥

 **Diane Desmarais**  
Paule! An exceptional nurse! I spent many years with her at Camp Papillon. Besides her wealth of experience and her love of children, she is truly a warm and caring person. **Bravo Paule** ♥

 Like  Comment  Share

## Upcoming events



### Jazz performance

On **March 15 from noon to 1 pm**, Daniel Bevan-Baker and Marie-Fatima Rudolf from the Concordia Masters of Music Therapy program will be performing jazz favourites in the MCH Family Resource Centre (BRC.0078).



### Teddy Bear Clinic

Child Life Services is hosting a Teddy Bear Clinic for inpatients and outpatients on **March 23 from 10:00 a.m. to 12:00 p.m.** in the P.K. Subban Atrium. There will be various kiosks and children who attend will receive a teddy bear, gown and bracelet and can learn about and prepare for procedures through medical play.

## The Cue to Action

As part of the We Should Talk campaign, stickers or magnets with "I am concerned about" have been installed in each patient room. The Cue to Action initiative encourages families and patients to write down their concerns in an effort to better communicate them to their health care team. If you'd like to

encourage families to express what's on their mind, bring their attention to the Cue to Action sticker or magnet. ■

