

Chez nous

MCH EMPLOYEE NEWSLETTER

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Hôpital de Montréal
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Montreal Children's
Hospital
McGill University
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Making Team Canada

An inspirational young woman whose determination has everyone cheering for Team Raphaëlle

By Sandra Sciangula



► Raphaëlle (c.), poses with (l. to r.) Lyne Martinelli, mom Valérie, and younger siblings Daphné and Guillaume.

In her 33 years working in Housekeeping at the Montreal Children's Hospital (MCH), Lyne Martinelli has gotten to know many patients. There was one girl though, who Lyne already knew before she ever became a patient. Raphaëlle Tousignant is Lyne's step granddaughter, and when she was admitted to the Children's in 2012, she began a long journey that would demand strength and determination from her and her entire family.

At nine years old, Raphaëlle was active, athletic and passionate about the sport of ringette. After falling on the ice during a game, a bump formed on her right hip but she didn't think much of it. But the bump didn't get better so Raphaëlle's mom made an appointment with their pediatrician. "The doctor thought it was normal since I noticed the bump after falling on the ice, but to be cautious, I was sent for more tests," says Raphaëlle.

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A biopsy revealed something far more serious, and Raphaëlle was put under the care of Dr. Sharon Abish, a pediatric oncologist at the Montreal Children's Hospital. Raphaëlle soon began treatment for osteosarcoma, a cancer of the bone most commonly found in children and adolescents.

A long journey ahead

The diagnosis was followed by eight months of intensive chemotherapy. Raphaëlle and her family were in and out of the hospital dividing their time between the Hematology-Oncology day clinic and the ward where Raphaëlle would sometimes have to stay overnight. "The goal was to shrink the tumour with chemotherapy to make it more easily resectable," explains Dr. Abish. Unfortunately, Raphaëlle, her family and her care team would be dealt with a heart-wrenching blow: the chemotherapy hadn't shrunk the tumour and Raphaëlle would have to undergo a hemipelvectomy, a major surgery to remove her right leg, hip and part of her pelvis.

"It was not easy," says Raphaëlle's mom, Valérie. At the doctors' suggestion she and her husband broke the devastating news to Raphaëlle. "We sat with Raphaëlle and told her that she would have to give up her leg to save her life,"



► M'hamed Benmokhtar and Valérie Lamarche catch up with Raphaëlle as she shows them her official Team Canada photo.

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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: Raphaëlle Tousignant and Lyne Martinelli
Cover photo: Owen Egan

Making Team Canada... (cont'd)

says Valérie. "Her immediate concern was how she was going to play ringette without her leg."

Surgical oncologist Dr. Robert Turcotte performed the procedure. "We always try to remove the bone and maintain the limb, but we couldn't do it in Raphaëlle's case," he says.

The 12-hour surgery required ten blood transfusions, after which Raphaëlle spent a week in the intensive care unit followed by a month on the surgical ward and another round of chemotherapy. Drs. Abish and Turcotte agree that the strength and determination of Raphaëlle and her family got her through the treatment, surgery and healing process.



► Raphaëlle on the ice while at a tournament in Brampton, Ontario.



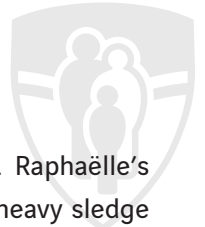
► Raphaëlle shows off her sledge.

An uncommon bravery

Valérie Lamarche, a nurse on the hematology-oncology unit, would often change the dressings on Raphaëlle's surgical wound, an incredibly painful but necessary procedure. "She was so tough. It was rough at first but together we developed a routine to change the dressings and she would bravely allow us to do our work." Valérie remembers one day asking who Raphaëlle's favourite Disney princess was, and she answered Merida from the movie *Brave*. "Merida was an unexpected answer yet so fitting since Merida is a go-getter and a strong character," she recalls.

Not long after her surgery, while still in hospital, Raphaëlle had to face the daunting task of getting out of bed to ensure her muscles didn't atrophy. After weeks in the hospital, Raphaëlle just wanted to go home. "It drove me to work hard to get better," she says. Eventually, her father had an idea to keep Raphaëlle active and to ensure that she'd still be able to enjoy playing an ice sport: he introduced her to sledge hockey. "When I got back on the ice, I gave sledge hockey a try and fell in love with it." *continued >>>*





► Raphaëlle's official Team Canada photo.

Getting back on the ice

For the last three years, Raphaëlle has been playing sledge hockey; her passion for it is evident, and she lights up when talking about it. "I have friends on the team who have amazing jobs, get to travel and spend time with their boyfriends. They are able to live normal lives despite their handicap."

Even on the ice, Raphaëlle's strength is on display: her game is physical and competitive and she never loses sight of the puck. She—and her style of play—did not go unnoticed this past August when she made the Canadian National Women's sledge hockey team. At 14, she is the youngest member on the team, and she has already travelled throughout Canada and to Europe, playing in tournaments and exhibition games.

Raphaëlle's dream does not end with making Team Canada, "I want women's sledge hockey to become popular enough to be a paralympic sport, and my goal is to compete in the 2022 games," she says.

Her family's pride is undeniable: on a recent visit to the hospital, Raphaëlle's mom gave personalized copies of Raphaëlle's official Team Canada photo to the many people

who were part of her daughter's care team. Raphaëlle's little brother did his part too by carrying the heavy sledge throughout the visit. Lyne regularly shares photos of Raphaëlle playing sledge hockey with her colleagues and friends at the Children's to keep them up-to-date on the teen's remarkable progress.

Raphaëlle is not a person who is easily forgotten. M'hamed Benmokhtar, another nurse who cared for her on the hematology-oncology ward says, "When days on the ward are a little bit more difficult, remembering Raphaëlle's strength inspires me to continue working hard and doing my best." ■



► Connie Richards and Raphaëlle share a heartfelt hug.

The Montreal Canadiens at the MCH



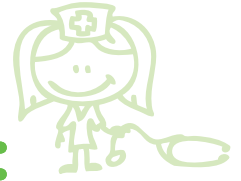
The much-anticipated visit from the Montreal Canadiens brings excitement and joy to the patients, families and staff of the Montreal Children's Hospital.

*On December 14, Habs players handed out presents to young fans on the wards and in the outpatient clinics, and like every year, put ear-to-ear smiles on little and big faces alike. Thank you to our beloved team for spending some time with us. **Go Habs Go!***





Including patients in the process:



Caring for the family as a whole

By Sandra Sciangula

Putting patients at the centre of care goes beyond the examination room. Alexandra Black, Patient and Family-Centered Care (PFCC) Coordinator at the Montreal Children's Hospital (MCH) is committed to recruiting families to take part in the hospital's decision-making processes. So far, Alexandra has recruited 14 Family Partners who, because of their experiences at the MCH with their children, are able to offer a unique expertise to the committees and projects that they are part of.

Jamie Fiset's son Ryder was born prematurely and spent three weeks in the Neonatal Intensive Care Unit (NICU) at the MCH. Jamie was asked to sit on the NICU Developmental Committee in May. She has a unique perspective since professionally, she is a nurse in the Intensive Care Unit at the Jewish General Hospital. She believes that including Family Partners on quality improvement committees completes the multidisciplinary team. "As a nurse, I have learned a lot by being the parent of

a patient." says Jamie. "We do our best to care for the family as a whole and including a family partner in the decision-making process brings to light issues that we would not have otherwise thought of simply because we haven't experienced them from the patient perspective."

In 2015, Accreditation Canada made important changes to the accreditation program to place greater focus on patient and family-centered care. One of the new requirements is to include patient and family representatives on advisory and planning groups. "The ultimate goal," says Alexandra, "is to have families involved at every level of decision-making in the organization, since they are our most important stakeholders."

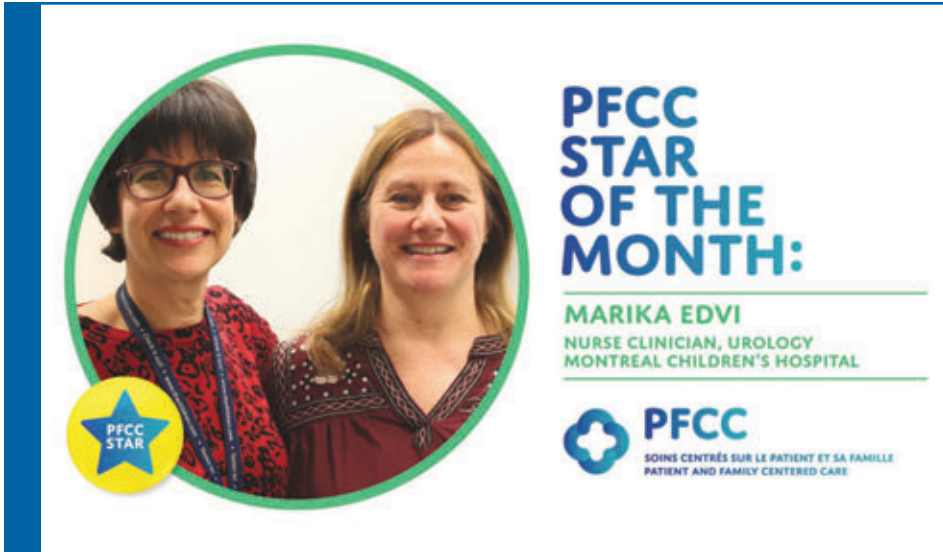
If you'd like to have a Family Partner join a committee or to recommend someone as a Family Partner, contact Alexandra Black at alexandra.black@muhc.mcgill.ca. ■



► Jamie Fiset and Alexandra Black



PFCC Star of the Month: Marika Edvi, Nurse Clinician, Urology



By Maureen McCarthy

► When Lina Di Re, last month's PFCC Star recipient was asked to nominate a colleague for the award, she didn't have to look far. "I chose Marika because she brings out the best in me as a nurse," says Lina. "I think she does that for families too, motivating them to do their best to improve their child's health. She's a real go-getter and she truly deserves this award."

Like Lina, Marika is a Nurse Clinician in the Children's Urology department, where she has worked for nine years in both the clinics and urodynamics lab. According to Marika, it's a superb team with "three great nurses and four wonderful physicians." In her time at the Children's, Marika has also worked in Allergy and Immunology, Ambulatory Services, Emergency, and Orthopedics.

She and her colleagues see patients ranging in age from newborns to 18 years old who have problems related to kidney or bladder function. Many of the children seen in Urology, some of whom are followed throughout their childhood and adolescence, live with chronic conditions that they learn to manage over time with the support of the department's team members.

"People don't always know the extent to which some children can be affected by these disorders," says Marika, "but it's really important to manage the condition so the child can stay healthy and have a regular lifestyle as much as possible."

What does patient and family-centered care mean to her? "I think it's about getting to know a family, and who is part of

the family and their support system," she says. "It's important to work with their strengths, give them help and support when they need it, and be available when they have questions or concerns. Part of our role is to accompany them through their journey."

Patrick's daughter is just one of the many children Marika sees regularly in clinic. "I'm very happy to hear that Marika received this award," he says. "We've known Marika since my daughter was just a few weeks old and she's always been there for us." Patrick feels that Marika's approach with children is great. "She's so devoted and I think she's like that with all the families she sees, plus she knows her work so well. People really appreciate her."

Marika has always been an advocate of patient and family-centered care, and she feels the focus on it shows how things have evolved in recent years. "Taking this approach enhances the whole relationship, and it helps a family help their child," she says. "Parents and family members are the experts on their child and they know what's best for their child. They help us give better care and ultimately become better at what we do." ■

Highlighting World AIDS Day

A pan-Canadian pediatric HIV study involving the Montreal Children's Hospital hopes to pave the way to finding a functional cure

By Pamela Toman



► Dr. Dorothy Moore and Dr. Christos Karatzios

Over the past 25 years, the development of powerful drug combinations has allowed patients born with HIV to live like any other patient managing a chronic illness. But one question that continues to baffle researchers is whether a remission from disease is possible, and how to achieve it.

The 'Mississippi Baby'

"What we've learned from years of studying HIV is that the virus lies dormant in some cells, creating a reservoir that can restart an active infection long after the active virus has been cleared from the blood by treatments," says Dr. Christos Karatzios, Pediatric Infectious Disease Specialist. "This is what happened a few years ago to a child from Mississippi who was thought to have been cured of the virus following antiviral treatments. This patient was given powerful drug combinations in the first hours of life and was kept on the regimen until 18 months of age, when she and her mother

were lost to care. When they returned after several months, the clinicians were amazed to find that, despite the child's having been off treatment for that period of time, she maintained an undetectable viral load—meaning the HIV virus wasn't traceable."

Though her physicians initially thought that she had been cured of HIV, it was found that after several more months off medication, the virus crept back up, and the patient's viral load increased. There was no "cure" in the purest

sense in this case, but researchers began to discuss the possibility of a "functional cure" instead.

The EPIC⁴ research study

Led by HIV researcher, Dr. Hugo Soudeyns at CHU Ste-Justine, the EPIC⁴ research study brings together a pan-Canadian team of researchers, including MCH physicians Dr. Christos Karatzios and Dr. Dorothy Moore, to answer this new and hope-filled question in light of the Mississippi baby findings: is HIV viral remission possible and what are the determinants for it?

Combining the expertise of nine pediatric centres across the country, the investigators hope to recruit 320 patients across Canada, all of whom were treated at different points after being infected with HIV at birth. Thus far, roughly 10 patients have already been recruited to participate at the Children's, and 150 Canada-wide.

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“Some of these patients were offered antiretroviral therapy within the first few hours or days of life, like the Mississippi case, while others were given these treatments within the first year, and some much later,” says Dr. Karatzios. “Our objective is to analyze these patients’ reservoir sites to uncover why one population might be faring better than the other so that we can uncover what approach will allow us to stop medication for a given—and hopefully prolonged—period of time without the risk of the virus triggering another active infection.”

“Today, managing HIV requires 100% adherence to medications—it’s all or nothing,” he explains. “But taking pills or syrups every day during childhood is hard. The ultimate goal of our research is to figure out whether a remission from HIV is possible and how. This could pave the way to prolonged ‘medication holidays’, which have been rightfully frowned upon by treatment guidelines for years now. But, if we can perhaps prevent a reservoir from forming, we can promote a remission that can allow us to indefinitely stop medications under strict supervision. The hope is that HIV could be rendered so ineffective that the patient is practically cured of it.” ■

PEDIATRIC HIV IN NUMBERS

Pediatric HIV

1985 **First infant** with perinatal HIV is seen at the Montreal Children’s Hospital

2016 **300 to 400 children** currently living with HIV
In Canada **320 children** to be recruited for the *EPIC4* research study
15 children currently treated in the MCH HIV Clinic

Adult HIV

1985 **First adult patient** with HIV is seen at the Royal Victoria Hospital

2016 **75,500 adults** currently living with HIV
In Canada **840 adults** recruited for the *Positive Health Brain Now* study
2,100 adults currently treated in the MUHC Chronic Viral Illness Service

EPIC⁴ website:
epic4.ca

United Nations target to end the Aids epidemic 2020: 90-90-90		
90 %	90 %	90 %
of all people living with HIV will know their HIV status	of all people with diagnosed HIV infection will receive sustained antiretroviral therapy	of all people receiving antiretroviral therapy will have viral suppression

Cree Board visit

On December 9, a delegation from the Cree Board of Health and Social Services of James Bay (CBHSSJB) paid a visit to Cree patients in the hospital. The Montreal Children’s Hospital works closely with the Cree population to provide care in the Northern communities, and when necessary, here in Montreal. Bella Petawabano, chairperson of the CBHSSJB, and artist Glenna Matoush presented the Montreal Children’s Hospital and the McGill University Health Centre a painting to acknowledge the longstanding relationship between the organizations. ■

► From l. to r.: Dr. Aisling O’Gorman, Glenna Matoush and Bella Petawabano



Modicana opens on RC



► From l. to r.: Shiva, Niloufar and Lucia

Modicana is the latest retailer to open their doors at the MUHC. Located near the Children’s main entrance in the Larry and Cookie Rossy Promenade, Modicana offers a whole range of health and beauty services for staff and visitors alike. Services include manicure, pedicure, facial care, massage therapy and much more.

MUHC employees receive a 20% discount on all services offered. You can make an appointment in person, or by phone or email (see the “Contact” tab on their website at modicana.ca). Modicana also offers gift certificates, a perfect idea if there’s still someone left on your gift list!

Opening hours: Mon-Wed: 9:00 a.m. – 7:00 p.m. • Thurs-Fri: 9:00 a.m. – 9:00 p.m. • Sat: 10:00 a.m. – 4:00 p.m.