A mother’s gift: First parent-to-child transplant at the MUHC

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On September 16, Montreal Canadiens defenceman P.K. Subban and his foundation, the P.K. Subban Foundation, pledged a minimum of $10 million to the Montreal Children’s Hospital, the largest philanthropic commitment ever made by a professional athlete in Canada. As part of the agreement, Subban will also assist the Montreal Children’s Hospital Foundation as a spokesperson for select Foundation fundraising campaigns and flagship events. In recognition of this extraordinary support, the Children’s officially inaugurated the “P.K. Subban Atrium,” the 486-square-meter, three-story public space located at the heart of the hospital’s new facilities.

P.K. Subban says he got “goosebumps” when walking into the atrium and seeing his name on the wall.
Michel Lacroix, known as the voice of the Montreal Canadiens, hosted the press conference. Jean Béliveau’s widow, Élise Béliveau, as well as PK Subban’s family also attended. Young patients of the Children’s escorted the VIPs and got a chance to ask their role model some questions. Subban drew an impressive crowd of staff, patients and media for his big announcement.

“It is really an amazing feeling to be here,” said Subban. “I am proud to walk in the footsteps of my idol Jean Béliveau by giving back to the community and feel privileged to be able to help transform the lives of sick children and their families.” This new partnership will also see the creation of PK’s Helping Hand, a fund dedicated to assisting vulnerable families financially devastated by their child’s illness.

Six-year-old Jouri was all smiles during her visit with PK.

During the press conference, MCH patient Tristan asked PK what it felt like to win a gold medal for Canada in 2014.

PK also spent time visiting patients on the surgical inpatient unit. Parents, like Arville’s mom Lindy, were very touched by his donation.

(l. to r.) Marie-Josée Gariépy, Greg Rokos, PK Subban, Martine Alfonso, and PK’s sister Nastassia Subban.
A mother’s gift

A new era begins for adult to child transplants at the MUHC

By Stephanie Tsirgiotis

They say the fastest route between two points is a straight line, which proved to be very true for Noémie Bertrand and her mother, Martine. On July 20, 10-year-old Noémie became the first recipient of a living-donor, adult-to-child transplant at the Glen site. While Noémie was lying in the Operating Room (OR) at the Montreal Children’s Hospital (MCH), her mother was only 100 meters away in the OR at the Royal Victoria Hospital (RVH).

TRANSIT NO LONGER AN ISSUE

Before moving to the Glen site, when a kidney was removed from a patient at the RVH it was transported by car or taxi from one site to the other and was often delayed by traffic. In this case, the kidney was brought down a hallway from one OR to the other and transplanted in less than 20 minutes. “Just knowing that she was down the hall from me was very reassuring,” says Martine. “I was more nervous than she was for the operation. She was my strength during all of this.”

NOÉMIE’S KIDNEY

Noémie suffers from a chronic kidney disease and was born with only one kidney. The family was told that one day she might need a kidney transplant, but in April, her kidney started to fade quickly and was down to only eight per cent of its function. She began dialysis three times a week for four hours. Both her parents had already been assessed in 2010 to determine if one of their kidneys could be suitable for Noémie. “I happened to be a bit of a closer match. Since your kidney is the size of your fist, we decided that I’d be the donor because of how small Noémie is,” says Martine.

The Bertrand family spent a lot of time hanging out in the 7th floor playroom at the Children’s. continued >>>
AFTER THE SURGERY

Once the decision was made, the family prepared themselves for the big day. The close proximity of the Children’s and the RVH also turned out to be a major advantage for Martine’s husband, Charles, and their two other children, Maude and Cédric, who could easily visit their mother and sister under one roof. “It was so convenient having the whole family together,” says Charles. The day after the surgery, Charles wheeled Martine over in a wheelchair to visit Noémie in the Pediatric Intensive Care Unit (PICU) at the Children’s. “In any other hospital, I would have had to wait three to four days to visit my daughter,” says Martine. “That would have been very difficult for me. I couldn’t wait to see her.”

BACK TO A REGULAR ROUTINE

Noémie was discharged from the Children’s on August 6 and continues to be cared for at The Children’s Hospital of Eastern Ontario (CHEO), closer to her hometown of Hawkesbury. “It was hard for her to leave the Children’s. We all became very close to her nurse Angela Burns, as well as Drs. Beth Foster and Lorraine Bell,” says Martine. Since returning home, Noémie has regained her energy and colour. Her dialysis catheter and G-tube have both been removed, allowing her to take up dance classes and start swimming again. “There are no signs of rejection and her kidney is responding extremely well. I am so happy I was able to give this gift to my daughter,” says Martine. “But at the end of the day, she’s the real hero.”

(l. to r.) Maude, Cédric, Charles, Noémie, and Martine Bertrand.
What did you do on your summer holidays?

Inspired by the traditional back-to-school homework assignment, we caught up with some of our MCH colleagues to find out how they kept busy this summer. Here’s what they had to say.

FUN AND FRESH AIR FOR KIDS WITH JUVENILE ARTHRITIS

When Dr. Sarah Campillo was still a fellow in the Montreal Children’s Hospital pediatric rheumatology division, she put forward a proposal to help children with juvenile arthritis. “I got the idea to start a summer camp, and make it a place where they could have fun and feel like they weren’t held back by their disease.” The project became a reality, and 12 years later, Dr. Campillo is still very involved, acting as medical director for the week-long camp.

When Dr. Campillo first got the idea, she approached the Quebec division of the Arthritis Society to develop a partnership. Camp Articulation, as it came to be known, takes place at the end of July at Camp Papillon, which is operated by the Quebec Society for Disabled Children in Saint-Alphonse-Rodriguez. “It’s an ideal place because the ground is flat, and the buildings are already adapted to children with mobility needs,” says Dr. Campillo.

In the camp’s first year there were 17 campers; now there are 40 to 45 children who attend every summer. “Our campers come from all over Quebec. They’re children who are patients from the province’s four pediatric teaching hospitals,” says Dr. Campillo.

FINDING THE SUPER HERO IN EVERYONE

The campers range in age from eight to 16. Most have juvenile arthritis but some have lupus, scleroderma or juvenile dermatomyositis. Their needs vary from taking multiple medications to using splints or having physiotherapy, all of which is carefully managed by the camp’s medical team.

One of this year’s highlights was a presentation by a former camper who’s now 19 years old. His recent 1,200 kilometre bike tour around Quebec to raise awareness of juvenile arthritis impressed the kids and was a fitting addition to this year’s theme of “How to find the super hero in you”.

A TEAM EFFORT

Dr. Campillo was joined this year by several rheumatologists and nurses from other centres, as well as a number of her colleagues from the Children’s, some of whom volunteered on opening day to do the required medical screenings as camp begins.

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Jack, (front) a patient at the Children’s, is pictured here with several members of the medical team at Camp Articulation including MCH pediatric rheumatology fellow Dr. Julie Couture (back row, left).
FUN AND FRESH AIR (continued)
Among the staff was Gillian Taylor, a retired nurse from the Children’s rheumatology service who was instrumental in developing the camp with Dr. Campillo. Dr. Angela Migowa and Dr. Julie Couture, the two fellows in Pediatric Rheumatology at the Children’s, also worked at the camp this summer, and Julie Bergeron from Child Life Services led the “How to find the super hero in you” workshop which was a big hit with the campers.

Dr. Campillo feels the campers get something special from their week. “The thing about most of the kids at our camp is that they ‘look’ well but they’re still dealing with complex treatments or physical limitations. When they’re at camp, they feel more free,” she says. “What’s nice is they get to meet other kids dealing with the same things. It helps them see that they’re not alone.”

HELPING KIDS WITH DIABETES ENJOY THE GREAT OUTDOORS
Drs. Preetha Krishnamoorthy, Mylène Dandavino and John Mitchell are big fans of summer camp. The three physicians from the MCH are part of the medical team at Camp Carowanis, a camp for children and teens with diabetes. Located on Lac Didi in the Laurentians, Camp Carowanis first opened in 1958 and has been running every summer since. Dr. Krishnamoorthy became the camp’s medical director about seven years ago.

Why a camp for kids with diabetes? “When you think of what a typical day is like for a child living with diabetes, the thought of going to summer camp can seem really daunting, if not impossible,” says Dr. Dandavino. “But at Carowanis, everything is geared to their needs. There are three meals and three snacks a day, the bells ring when it’s time for glucose testing, and the kids are all in it together. A lot of them arrive at camp thinking they’re sick, but they come out with a new energy knowing there are other kids just like them.”

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HELPING KIDS (continued)
Dr. Mitchell and Dr. Dandavino each spent a week working as camp doctor this summer which involves leading the medical team. The team is composed of a head nurse, nurses and nursing students, as well as medical students, residents and endocrinology fellows from both McGill and Université de Montréal. They supervise hundreds of insulin injections and blood glucose tests every day. They also teach the campers how to recognize and treat hypoglycemia, and adjust their dosages accordingly.

HAPPY CAMPERS
The camp runs for six weeks, and every two weeks, a new group of 80 kids arrive, many of whom are patients at the Children’s. Activities at the camp are non-stop and the kids take part in everything from arts and crafts to kayaking, archery, basketball, swimming, and even yoga.

Dr. Krishnamoorthy first went to the camp when she was a fellow in endocrinology at the Children’s. As medical director, her involvement is year round. She organizes certain aspects of the camp program, and prepares the trainee schedule. “By the end of the session, the campers often learn more about their diabetes and how to take better care of it,” she says, “so we’re not just helping them enjoy a great summer camp experience, we’re helping them better manage their diabetes.”

Dr. Dandavino first went to Camp Carowanis as a medical student, and this summer was her sixth time working there. Her family joins her for the trip too. “It’s a very hectic week for everyone on the medical team, but when I have free time, I can spend it with my husband and kids who really enjoy it,” she says. “Honestly, I love being there!”

The campers enjoy waterfront activities on Lac Didi.
A SURGICAL MISSION IN MEXICO

The setting might have been quite different from her day-to-day work at the Montreal Children’s Hospital, but OR Nurse Manager Karina Olivo felt completely at home in the surgical unit of Christus Muguerza Hospital Betania during a recent trip to Puebla, Mexico.

Karina went to Mexico as part of a humanitarian trip with Operation Smile, an international medical charity that treats children born with cleft lip, cleft palate and other facial deformities. The organization was founded in 1982 and since that time, medical volunteers from more than 80 countries have provided 220,000 surgeries to children all over the world. This was Karina’s eighth volunteer trip with Operation Smile; she was part of a 30-person team that included surgeons, nurses, administrators and even a child life educator, who worked with staff at the Puebla hospital to operate on 117 children and adolescents over the course of one week.

A few days after Karina returned, her voice was hoarse. “I talked a lot during the trip,” she says with a laugh. “We did pre-op care for the patients before they went into surgery and also worked in the post-op ward. Part of that work was teaching our local counterparts about standards of care. Teaching and transferring knowledge is an important part of the organization’s mission, so it’s important that we help them build a sustainable process.” They also helped teach the patients’ parents how to care for their children at home after surgery.

How Karina came to be involved with Operation Smile is a case of being in the right place at the right time: in this case, the dentist’s chair. “About five years ago, I was having my wisdom teeth removed and my dentist said he couldn’t do the entire procedure in one visit,” she says. “He asked me to schedule a follow-up appointment but said I’d have to wait a month because he was leaving for a mission to Guatemala to volunteer with an NGO. I spent the rest of my appointment asking him more about it.” The NGO, of course, was Operation Smile and Karina signed up with the organization that evening.

Of all the patients and families her team met on this trip, Karina says there was one person who touched everyone’s heart. “A young man of 20 years old with a cleft lip and palate came to the hospital for surgery. We help a lot of children who are babies and toddlers, but knowing that we just helped a 20-year-old who had lived with it all his life was very emotional. It really reminded us of how life-changing this work can be.”

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What did you do on your summer holidays? (continued)

MILES AND MILES FOR A GOOD CAUSE
Sophie Fournier and Véronique Courchesne spent their summer months preparing for a 42K run. Back in early spring, the two Montreal Children’s Hospital NICU nurses decided to make the Quebec City marathon on August 30 their summer goal. For Véronique, it was her fourth marathon; for Sophie it was her first. They both agree that running such a long race is a lot more fun with a friend, and keeps their motivation high. “I wanted to support Sophie in her first marathon,” says Véronique, “and of course, work on improving my own time.” Véronique crossed the finish line in 3 hours, 43 minutes and Sophie finished in 4 hours, 6 minutes—a great result for a first-time marathoner.

Next up for the two avid runners is the Relais de la Tribu, which takes place the weekend of October 10. Along with three other people, Véronique and Sophie will cover 250 kilometres in a relay run over the course of a 24-hour period. It will be the second time they take part in the relay. Their participation will help raise funds for an organization called DesÉquilibres. The not-for-profit group’s mission is to implement psychosocial sport programs for vulnerable youth in order to help them become engaged members of their communities.

Despite the distance they’ll cover at the run, Véronique says they don’t need to do any special training. “We’re already regular runners and the events we take part in throughout the year help us train. The relay is really about having fun, without any stress. We just give it our all and have a great time!”

NICU nurses Véronique Courchesne and Sophie Fournier at the finish line of the Quebec City marathon on August 30.
For many of us at the Montreal Children's Hospital, some of the recent negative news stories about the MUHC have been disheartening considering how far we’ve come over the last few months.

As we have learned in the past, it is not in our best interest to go up against the media every single time they print something we don’t like. With that being said, our media strategy is to push out as much positive news as possible, internally and externally. Every day, members of our hospital witness remarkable patient stories and I know that our staff goes above and beyond for our patients and families.

These positive stories are already shared regularly with the media and are posted daily on our social media sites, but it’s more important now than ever to come together and show the media that even though we are going through a period of change, we continue to offer our patients the very best care in a brand new setting.

Even though some of the facts being reported do not reflect reality, we are following up on the issues that have been raised by your departments. We are making immense headway and I’m excited that we are all moving forward.

We have a lot to be proud of. We successfully and safely completed a complex patient move, we picked up and moved our departments to a new location, we’ve dealt with challenging clinical cases this summer and we’re adapting to our new environment better and better every day.

Sincerely,

Martine Alfonso
Associate Executive Director
Montreal Children's Hospital
Summertime fun at the Children’s

We blinked and summer was over, but at least our patients had a great time!

CARNIVAL DAY

In case you missed it: on July 28, our patients and their families were treated to a special Carnival Day, and the smiles and laughs were contagious! Organized by our Child Life department in partnership with the Starlight Foundation, patients were invited to enjoy some snacks, games, face painting, a show with Lil’ John the Clown and some arts and crafts in the Montreal Children’s Hospital Atrium (now called the P.K. Subban Atrium).

A TASTE OF ODYSSEO

On July 30, our patients and families, along with staff members, got a taste of Odysseo, the popular show by Cavalia, with a private musical and acrobatic performance that brought wonder and amazement to audience members both young and old. Members of the cast previewed some of the dancing, drumming and a few of the acrobatic feats they perform in their live show. Our patients were even treated to special gifts and got to meet the performers afterwards. They also surprised 300 patients and parents with free tickets to their brand new show!

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SUPERHERO DAY
At the Children’s, we believe each and every one of our patients possesses the resilience and courage of a true superhero. And thanks to our friends at the Starlight Foundation, our little champs got to meet their very favourite superheroes in person on August 27 during Superhero Day! Patients even got to snap photos with Elsa, Spiderman and Batman.

THE FORCE WAS WITH US ON AUGUST 14!
Our patients, families and staff members were all smiles after getting a special visit from their favourite Star Wars characters.

An afternoon with Jouri and Robert
What do you get when you pair a patient with their favourite volunteer? Pure silliness, that’s what! Check out the latest adventures of six-year old Jouri and her friend and MCH volunteer, Robert. Stay tuned for more kid reporter videos on the MCH Facebook page. They will be posted regularly on facebook.com/lechildren
Chez nous and the Children’s Facebook page have teamed up for a new feature called #THUMBSUP. Every week we post stories that highlight our remarkable patients and the different milestones and challenges they continue to overcome on a daily basis.

First up is Valeria Ocampo. Proud mom, Carolina, shows off her nine-month old daughter, Valeria, who started to crawl two months ago while she remains hospitalized in the Montreal Children’s Hospital’s Neonatal Intensive Care Unit (NICU). Little Valeria was diagnosed with a genetic condition known as Congenital Central Hypoventilation Syndrome when she was born. The disorder causes a lack of communication between her brain and her lungs when she falls asleep, and requires that she be hooked up to a ventilator during periods of sleep. Despite her illness, however, Valeria is a curious infant who loves discovering all the nooks and crannies of her big bright patient room on the 6th floor of the hospital. “She’s a sweet baby girl,” says her mom, Carolina. “We look forward to many other milestones to come!”

Take the Chez nous survey for a chance to win!

The Public Relations and Communications office at the Children’s would like to know what you think about Chez nous. It only takes a few minutes to answer the survey and your feedback helps us keep Chez nous a valuable and practical way to communicate news about the Children’s. Completing the survey is easy: just visit surveymonkey.com/r/chez_nous_en and answer the short questionnaire.

Make sure to include your name, email and extension number for a chance to win our grand prize of a $75 gift certificate to spend on Amazon.

It’s easy to fill out the survey on your smart phone or tablet too! DEADLINE IS OCTOBER 6, 2015.
I FIND THE NEW CHILDREN’S VERY PLAIN AND LACKING IN KID PERSONALITY. IS THERE A PLAN TO DECORATE THE UNITS AND MAKE THEM MORE KID FRIENDLY?
Yes, a plan is in place to give the hospital more “kid personality.” The Pediatric Environmental Design Committee will oversee the creation and installation of pediatric-friendly art and furniture in our new space. This group of MCH staff members and volunteers will ensure that the choices are safe for our patients and easily maintained or installed. The committee must also ensure flow and continuity of design, colours, and themes throughout our facility. These choices must also adhere to the new rules and policies regarding execution of work and installations at the Glen site.

The committee was active at our former hospital site and has been in existence for more than 20 years. It will begin its new mandate this fall, but if you walk around, you’ll already see many fun decorative decals around the hospital, especially in the Child Life playrooms, Medical Imaging, OR, and Cardiology. The goal is to have a pediatric feel without cluttering the walls, and the decals must be easy to remove in case painting or maintenance is required.

New location for MCH ombudsman

Please advise your patients and families that the MCH ombudsman, Stéphanie Urbain, has been relocated to an office in Block A of the Children’s. Her new office is A RC.2002. She can also be reached at stephanie.urbain@muhc.mcgill.ca or at ext. 22223 to make an appointment.
Another successful Mock Code Orange

The Montreal Children’s Hospital took part in a Code Orange simulation on September 10 to test and fine-tune the hospital’s response to a major external emergency. Over 120 staff and volunteers worked with simulated patients (actors and mannequins) to help test the Glen site’s emergency measures plan, including our new decontamination tents. Even the Canadian Armed Forces were on site to help with the "moulage", the process of applying the mock injuries! Over the coming months, all comments and suggestions that were raised during the debrief will be looked at and analyzed. You know what they say, practice makes perfect!

Over 60 nursing and respiratory therapy students took part in the simulation and acted as distraught patients, worried family members, and even nosy journalists.

Each simulated patient was greeted by a triage nurse and security guard before moving down to the "contaminated area."