# Chez nous

MCH EMPLOYEE NEWSLETTER

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# Mowing lawns: How one patient is tackling his cystic fibrosis

Hôpital de Montréal pour enfants Centre universitaire

de santé McGill

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# Riding tractors and mowing lawns

How one young patient's entrepreneurial spirit has helped him tackle his cystic fibrosis

By Stephanie Tsirgiotis



Respiratory therapist Isabelle Guevin helps Alek Leboeuf perform a pulmonary function test at his last visit. The test measures how well your lungs are working.

"Because I was diagnosed with cystic fibrosis at 10 years old, I don't think of myself as a sick kid, because I lived the first 10 years of my life as a normal one."

Every morning, 17-year-old Alek Leboeuf wakes up, does his exercises, eats a large breakfast and starts his day. But as a baby, his reality was very different. "Alek was constantly in and out of the hospital for infections, bronchitis, and pneumonia," recalls his mother, Mélanie Guérin. After suffering from a near-fatal infection, he was transferred to the Montreal Children's Hospital where a team of specialists followed him very closely, but nobody could figure out what was ailing the young boy.

#### THE DIAGNOSIS

In 2011, his doctors made a huge breakthrough. Alek was diagnosed with a rare, variant form of cystic fibrosis (CF). "We test for this disease through sweat tests and genetic testing, but Alek's results never fit within our criteria," says Dr. Larry Lands, director of Pediatric Respiratory Medicine and the Cystic Fibrosis clinic at the Children's. On average, children who suffer from cystic fibrosis have five times the amount of salt in their sweat; Alek has two-and-a-half times the amount of salt. "These variant forms tend to be a lot milder, and often present later in adolescence," says Dr. Lands.

Cystic fibrosis is a multi-system genetic disorder that affects the digestive system and lungs. The disease affects the

body's exocrine glands and leads to the overproduction of an abnormally thick mucus. Patients suffer from respiratory infections because the mucus blocks the body's pancreatic ducts, intestines and bronchi. Without proper treatment and exercise, these ongoing lung infections can lead to the destruction of the lungs and loss of lung function.

#### THE TREATMENTS

Specialists recommend certain airway clearance techniques to help CF patients loosen and cough out the thick, sticky mucus from their lungs. Clearing the lungs not only helps decrease lung infections, but can also improve lung function over time. One of these techniques is called percussion, but it is more commonly referred to as "clapping." Twice a day, Mélanie had to clap on Alek's chest, back and stomach to help loosen the mucus. "We did this technique when he was younger and it took us about 20 minutes to complete," says his mother.

Currently, Alek is using a positive expiratory pressure (PEP) machine to help break up his mucus. Every morning he breathes into a handheld mouthpiece that allows him to breathe in easily, but makes it difficult to breathe out. Breathing against the resistance helps push the air behind the mucus and away from the lungs and airway walls. "I prefer this technique because I get to do it completely on my own," says Alek.

Regular physical activity and good nutrition are also ways that patients can better manage their CF. "Because mucus builds up along the patient's intestinal



Dr. Adam Shapiro was impressed by Alek's lung function during a recent appointment. At each visit, Alek is also met by physiotherapist Nancy Alarie and nurses Debbie Fertuck and Sophie Vallée-Smejda. continued >>



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Photography:

Owen Egan Melanie Nixon

Stephanie Tsirgiotis

French translation: Joanne Lavallée

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On the cover: 17-year-old Alek Leboeuf Cover photo: Owen Egan

## Riding tractors... (cont'd)

walls, it becomes difficult for the pancreas to break down food properly, which is why our patients have such a hard time gaining weight," explains Dr. Lands. CF patients are also at a high risk of malnutrition, because their bodies don't absorb food properly. Normally, people absorb 95 per cent of the fat they eat, whereas CF patients absorb closer to 50 per cent.

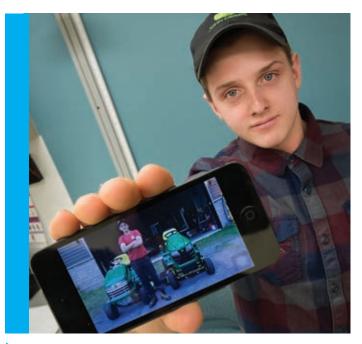
#### **THE DRIVE**

After learning about the benefits of exercise, Alek thought of the perfect way to stay in shape. At 13, he decided to start mowing lawns for his neighbours during the summer months. "I started a little side business called 'Éco-Pelouse' in my hometown of Saint-Sabine," he says. "I wanted to be eco-friendly, because of my cystic fibrosis, so I used a battery-run lawnmower." By the following summer, his confidence had grown and he started printing business cards. Then last year, he borrowed some money from his grandmother and bought himself a brand new tractor. "I went from five to 15 customers in one summer, and my neighbour and mentor Stephan Cabana, is showing me how to do snow removal too," says Alek. "I've already managed to pay back my grandmother most of the money."

He is so devoted to his company that he even created a company logo, and has printed promotional material including magnets, hats and pens. "I also put decals on my tractors and pickup truck," he laughs. He is now planning on pursuing a career in landscaping and agriculture. "I also have ADHD so running my own company has helped me focus. It has given



Alek and his mom, Mélanie.



Alek proudly shows off his brand new tractor.

me a goal. It also helps that I have so many ideas running through my head and a ton of energy to burn!" he says. "I love working with my hands and I definitely want to do this as my career."

Alek has also started training with a personal trainer, and the combination of both lawn mowing and bodybuilding has improved his lung function tremendously. He has even managed to gain weight by consuming 6,000 calories a day. "Alek can handle eating that much, because he burns so many calories with everything he does," says Dr. Lands. Even a recent surgery on his spine didn't stop him. "Alek also suffers from double scoliosis and underwent a big surgery last November to straighten his back," says his mother. "Plus he was back in the operating room a week later with appendicitis. That's my Alek! There's never a dull moment. He is the most determined kid I have ever known and he doesn't let anything stop him."

Alek's determination to stay healthy has not only been noticed by his family. His entire healthcare team often refer to him as an inspiration. "Alek's resilience is remarkable. He has overcome so many medical challenges and continues to go out of his way to keep himself healthy," says Dr. Lands. "He doesn't believe in turning himself into a victim and that is very inspiring to see."

# A day in the life of a... medical imaging technologist



Chez nous learns about interventional radiology from a medical imaging technologist By Stephanie Tsirgiotis



(l. to r.) Medical imaging technologist Vicky Fortin and interventional radiologist Dr. Karl Muchantef.

From a young age, Vicky Fortin had dreams of working in an operating room, but she wasn't interested in pursuing a career in medicine or nursing. She had her heart set on becoming a medical imaging technologist; and while interning in St-Jérôme, she discovered a field of medical imaging that merged her love of technology and the OR: interventional radiology.

#### **NAVIGATING THROUGH THE BODY**

Interventional radiology is a medical specialty where radiology is used to perform minimally invasive procedures. Medical imaging technologists assist interventional radiologists by using ultrasound and a type of X-ray, known as fluoroscopy, to guide small instruments, like catheters and needles, though veins, arteries and

organs. "Fluoroscopy is an imaging technique that uses X-rays to track the movement of an object in real-time," explains Vicky.

In pediatrics, interventional radiology is most often used for the placement of peripherally inserted central catheters (PICC lines). "If we know a patient will need long-term IV access for antibiotics, we use this procedure so that we don't have to poke them every day with a needle," she says. "We also use this procedure when a child has poor IV access, because they're too sick or too small."

Certain medical imaging technologists, including Vicky, are certified to insert PICC lines independently. If a vein is hard to find, she will use ultrasound to locate the vein and puncture it. She

## A day in the life... (cont'd)



► Certain medical imaging technologists, including Vicky, are certified to insert PICC lines independently.

then uses fluoroscopy to help her navigate the guide wire and catheter through the vein and directly to the heart. "The tip of the catheter needs to sit above the heart in order to give nurses central access," explains Vicky. "This allows the catheters to remain in place longer, and certain medicines are best delivered in a central location."

The insertion of a PICC line takes about an hour and parents are invited to stay with their child during the procedure. Patients under seven months of age are sedated with sucrose, which tends to have a natural soothing affect, while the arm is frozen with local anesthesia. For older babies and toddlers, chloral hydrate is used for sedation and they end up sleeping through most of the procedure, but for children aged three to five, general anesthesia is administered.

Biopsies are also common in interventional radiology. In these cases, ultrasound is used to help localize and retrieve tissue from the organ or mass in question. The sample cells or tissues are then sent directly to pathology.

#### THE ROLE OF A MEDICAL IMAGING TECHNOLOGIST

On average, Vicky will see 15 to 20 patients a week; most of them newborn babies from the Neonatal Intensive Care Unit (NICU). "There are four medical imaging technologists who work in this sector, but we always work in pairs, because one of us works alongside the radiologist while the other one stays beside the patient," says Vicky. In interventional radiology, medical imaging technologists are very involved in each procedure from beginning to end. "We have no nurses or Child life specialists in our sector, so the prep and interaction with patients is up to us," she says.

Before every procedure, Vicky will organize the sterile table, prepare the patient and set up all the monitors and equipment. During the procedure, she assists the interventional radiologist by providing them with the right material, all while positioning, immobilizing and imaging the patient and controlling the quantity of radiation used. "We take four X-rays per second, but we don't want to overexpose the child to unnecessary radiation, so it's up to me to limit the area exposed to radiation," she says.

All of the interventional radiology suites sit across the hall-way from the OR on the third floor. The space is shared by the Children's team and the adult sector. "There are a total of four interventional radiology rooms. Three of them belong to the Royal Victoria Hospital, and one is dedicated to pediatrics," she says. Procedures take place three days a week on Mondays, Wednesdays and Fridays, but Vicky is on-call 24/7 for emergency situations.

# THE USE OF INTERVENTIONAL RADIOLOGY IN TRAUMA CASES

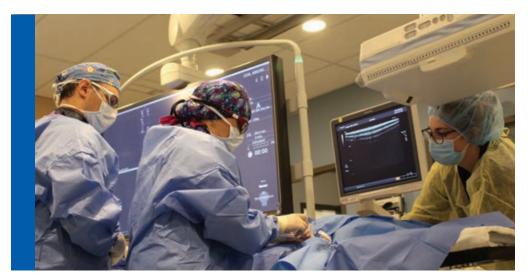
In trauma cases where internal bleeding is a critical factor, patients undergo a CT scan in order to localize the source of the bleeding and then are immediately transferred to interventional

radiology for an emergency procedure. Once there, fluoroscopy is used to navigate the guide wire and catheter. Contrast is injected into the bloodstream to better highlight the affected area on the imaging monitor and once the catheter is placed near the injury, tiny metal coils or foam particles, known as embolization particles, are released into the bloodstream and attach themselves to the affected area in order to coagulate the blood and stop the bleeding. "The particles dissolve and are absorbed by the body, but the coils stay there for life," she says.

Another critical case is when a patient presents with a narrowing of a vein or artery, thus causing high pressure in a vessel. In order to lower the pressure and reestablish proper blood flow, a catheter is inserted along with a deflated medical balloon. "The balloon is mounted on the catheter and is delivered over the wire until we reach the narrow section. At that point, we inflate the balloon and it opens up the vein or artery, and blood flow goes back to normal," she explains. "We have different size balloons depending on the size of the child." Both of these cases are rare in pediatrics,

> but do occur on occasion and Vicky is always ready to jump into action.

> "I love my job, because I get to be hands on and I can see the positive impact my work has on these patients," says Vicky. "It's important to figure out what you don't want in life, in order to clarify what you do want. There is a whole psychological element to working in pediatrics. It's not only about placing a child on a table and taking a bunch of X-rays. It's about talking to them, and connecting with them, so that they understand why you need to insert a needle into their arm. It's hard work, but it's rewarding work."



Medical imaging technologists are very involved in each procedure from beginning to end.



Procedures take place three days a week, but Vicky is on-call 24/7 for emergency situations.



# Celebrating our hard work over the past year By Maureen McCarthy and Stephanie Tsirgiotis

With a new fiscal year starting this month, *Chez nous* takes a moment to highlight some of the past year's achievements at the Children's. Congratulations are in order for the many things we've accomplished over the last 12 months. The Children's community is made up of innovative and forward thinking people who consistently find ways to develop new

opportunities and learning experiences even when faced with challenges and roadblocks.

If you're proud of an achievement in your department or service and would like to share it with the MCH community, please email us at mchpr@muhc.mcgill.ca.



## OFFERING FREE LEGAL SERVICE TO PATIENTS AND FAMILIES IN NEED

As of January 2017, the Montreal Children's Hospital became the first pediatric hospital in Quebec to offer free legal services to patients and families thanks to Pro-Bono Québec. The services are offered to low and medium-income families who are referred to Aude Exertier by the MCH Social Services department.

To date, 49 patients and families have been helped.

Aude Exertier (left) from Pro-Bono Québec worked with social worker Patricia Gauthier (right) to launch the service at the MCH.

# IMPROVING NSA PATIENT SERVICES AND ACCESSIBILITY TO SPECIALIZED SERVICES IN THE COMMUNITY

The term "niveau de soins alternatifs (NSA)" is used to describe patients who, for various reasons, continue to occupy a hospital bed even though they no longer require the level of resources and services provided at the hospital. With help from the MSSS and community partners, an interdisciplinary team from Complex Care Services at the Children's led by Dr. Hema Patel, Soo-Lin Ng, and Isabelle St-Sauveur, identified appropriate community services so that five NSA patients with complex needs could go home instead of continuing to live at the hospital. Work is ongoing with the MSSS to formalize this process so that future patients will have access to these specialized services at home or in their community.

This past year, the MCH was able to reduce the number of NSA patients from eight to three.



The "Lunch and Learns" are attended by a variety of MCH staff and physicians.

#### **CONTINUING TO TRAIN MCH STAFF IN LEAN SIX SIGMA**

Over 400 hospital staff, family partners and physicians have obtained their yellow belt training and certification. Lunchtime workshops are also being offered to staff members who cannot attend the full-day workshop. These "Lunch and Learns" are used to examine specific tools in the Lean Six Sigma methodology.

All upcoming sessions are currently full, but more will be offered this fall.



#### PATIENTS AND FAMILIES LOVE US

The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey is sent out to 60 patients and families six weeks after being discharged from the hospital and is used to assess a patient's hospital stay. It covers communication, general satisfaction, cleanliness, discharge process, and pain management, among other topics.

Most recently, 92% of patients and families said they would recommend the Children's to family and friends.

#### THE MCH EXPANDED ITS CAPACITY TO PROVIDE CENTRAL PHYSIOLOGICAL MONITORING TO ALL PATIENT **ROOMS ON B7N, B8, AND B9**

Technological monitoring is essential for clinical teams to safely care for the patients admitted on these units, which include acutely ill patients, patients with critical airway problems, and high-risk populations such as premature infants with multiple disorders or medicallyfragile children with chronic illnesses.

The hospital's leadership, including Chantal Souligny, MUHC Director of Nursing, Josie Revuelta, B9 Nurse Manager, and Dr. Mylene Dandavino, Program Head of Medical Inpatient Services at the Children's, worked very hard with the MCH Foundation to make this happen.



(l. to r.) Dr. Mylene Dandavino, Josie Revuelta, and Chantal Souligny.

## Celebrating our hard work... (cont'd)

#### THE JFK SIBLING PARK SUPPORTS FAMILIES WHOSE CHILDREN ARE ADMITTED TO THE HOSPITAL'S INTENSIVE CARE UNITS

The program, which provides supervised activities to the brothers and sisters of ICU patients, takes place in the play room on S1. It was launched last summer by the Just for Kids (JFK) Foundation in collaboration with the MCH Volunteer department. Care coordinators and assistants, supported by volunteers, hold activities ranging from themed events to baking parties.

Plans are underway to offer expanded opening hours during the upcoming summer months.



Raphael builds a train track with Kaitlen Gattuso, one of the care service coordinators.

#### THE MCH EXECUTIVE COMMITTEE (EXCO) TEAM HAS SET UP A SALLE DE PILOTAGE, A TOOL USED IN LEAN TRAINING, TO TRACK **OBJECTIVES ON ONGOING PROJECTS**

A "Salle de pilotage" is a designated space where detailed information on projects is displayed on a large board, allowing team members to see the "big picture" on current objectives, and any challenges to achieving them. The Salle de pilotage helps overcome the top reasons why projects fail: lack of visibility, resource workload requirements, and communication gaps. The EXCO team members identified a number of objectives from the hospital's 2017 strategic planning exercise, then defined specific projects for the Salle de pilotage, which is located in the A3 meeting room. On a monthly basis, the EXCO members meet to review projects.

By the end of 2020, the MCH plans to implement a minimum of 15 Salles de pilotage throughout the hospital.

#### **WEEKLY OR BED HUDDLE IMPROVES ACCESS FOR PATIENTS**

Staff members from the PACU, PICU, B8 and B9, along with OR nursing management and the OR booking team meet every Friday to review the planned surgeries and corresponding admissions for the coming week. The team's goal is to ensure patient access is optimized and minimize any last-minute cancellations of surgical procedures. The weekly meeting allows them to review scheduling and bed availability, and inform parents in advance of any possible changes to their child's surgery.

Results are significant: in the past few years due to the OR bed huddle collaboration and efforts from frontline staff, the PICU has seen a reduction in OR cancellations from 17 per cent to five percent.





(l. to r.) MCH physicians Dr. Catherine Nolin, Dr. Nadine Korah, and Julie Grenier, assistant nurse manager on B9. Absent from photo: Thanh Huynh and Catherine Bouchard.

#### THE B9 PEDIATRIC INPATIENT UNIT BEGAN **CONDUCTING JOINT MORNING ROUNDS**

With the primary goal of facilitating interdisciplinary participation, namely to allow the presence of bedside nurses, the B9 teams now conduct morning rounds between 10:00 and 11:30 a.m. The later start time allows medical teams, bedside nurses, pharmacists, as well as patients and families, to take part in the discussions, decision-making and teaching that take place daily at the bedside. It also created an opportunity for the clinical teams to focus their attention on acute patient issues, as well as discharges and admissions, earlier in the day.

Encouraging interdisciplinary patient rounds is in line with the hospital's focus on family-centered care and the delivery of safe, effective, and efficient care.



#### MCH SURGE PLAN: **MANAGING HIGHER THAN NORMAL PATIENT NUMBERS**

A strategic goal of the hospital's patient flow committee is to develop and implement a plan for significant patient surge and overcapacity events, with the goal of maintaining adequate access for patients. The Surge plan has a colourcoded scoring system to help determine the surge level on any given day and the corresponding action items for hospital staff at each level. The Children's has a dedicated Surge working group made up of approximately 20 members from different disciplines who assure reassessment and ongoing improvements. Goals include improving both transfer times and bed turnover, and decreasing OR cancellations.

Currently, the Surge working group is looking at ways to better educate frontline staff on the process.

#### THE MONTREAL CHILDREN'S HOSPITAL HOSTED TWO BIG CONFERENCES THIS YEAR

The annual Canadian Association of Pediatric Health Centres (CAPHC) conference was co-hosted by the Children's and the Shriners from October 22 to 24. Themed "Engaging Children, Youth, and Families: Are You Ready to Move Beyond Good Intentions?", 340 professionals from across Canada representing 71 pediatric health organizations attended the conference.

Sociocultural Consultation and Interpretation Services also held a symposium in October on issues and advances in equitable access to healthcare for diverse populations.

## Celebrating our hard work... (cont'd)



#### **PROCEDURE ROOM: FASTER, MORE ACCESSIBLE CARE**

The Procedure Room on B3 was set up for children who need sedation but don't require the sterile environment of an operating room (OR). The service provides pain management for patients while improving accessibility for short uncomplicated procedures. Averaging 350 procedures annually, an estimated 80 per cent of these cases would have previously gone to the OR.

The benefits are many: parents can be in the room with their child while sedation takes place, and post-procedure recovery is usually quicker and easier than general anesthesia.

Parents like Geneviève, seen here with daughter Emmanuelle, can be with their child while sedation begins before a procedure.

## PRIX D'EXCELLENCE

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# Helping babies in need

## NICU nurses start non-profit to build neonatal intensive care unit in Africa







(l. to r.) Cynthia Garcia, Micha Mfuana, Dr. Louis Beaumier, Stephanie Mardakis and Maryam Mozafarinia.

Imagine giving birth to a 28-week-old baby and then jumping into a cab because there are no ambulances to transport you to the closest neonatal unit 15 minutes away. This scenario played out in front of Micha Mfuana, a nurse from the Montreal Children's Hospital's Neonatal Intensive Care Unit (NICU), during a recent visit to Kinshasa Kimbanguiste Hospital in the Democratic Republic of Congo. The scene stuck with her and upon her return home, she spoke about it to her MCH colleagues Stephanie Mardakis and Maryam Mozafarinia, as well as Cynthia Garcia from CHU Sainte-Justine.

The group of young NICU nurses was so moved by the story that they decided to create a non-profit organization called Une chance de vivre with the goal of opening a simple, yet functional level II neonatal intensive care unit for the hospital in Kinshasa. They also decided to team up with Dr. Louis Beaumier, a dedicated neonatologist from the Children's. "In the beginning we were all big dreamers. Our meetings consisted of talking about the equipment we'd like to buy, and all the things we'd like to do, but then reality struck and we realized just how big a project this was going to be," says Micha, the organization's president. "So for now, we talk about numbers at our meetings."

The team decided to focus on Kinshasa Kimbanquiste Hospital, because of its location in the most populated, yet poorest community in Kinshasa. The hospital has very little resources, in-

cluding a complete lack of neonatal services. Une chance de vivre hopes to open a NICU in the coming year with the initial capacity of operating five to seven beds. "Besides opening up the NICU, we also want to create a training tool for these nurses, something that will work for their needs and their reality," explains Micha. The organization seeks to work primarily in neonatology, but also intends to provide training in perinatology, obstetrics, and pediatrics.

Last May, Une chance de vivre met with the medical team in Kinshasa to present their action plan, and since then they've been granted their official status as a non-profit organization and charity. "Our mission is to promote the creation of an environment where good care practices can be developed to help

## Helping babies... (cont'd)



The team continues to meet bimonthly and updates Kinshasa Kimbanguiste's hospital personnel regularly via Skype.

premature infants survive and grow healthier," says Maryam, who acts as the organization's treasurer. "The life of each newborn has value and it is important to give each of them a chance to live without social, cultural or religious prejudice." Micha, Stephanie, Maryam and Cynthia continue to meet bimonthly and update Kinshasa Kimbanguiste's hospital personnel regularly via Skype. They are currently in fundraising mode and are eager to take their organization to the next level.

To learn more about Une chance de vivre, visit unechancedevivre.org

# Keeping it in the family

April 15-21 is National Volunteer Week, an opportunity to celebrate and thank our hundreds of volunteers—people who share their time, talents and skills with our patients, families and staff throughout the year.

Denise Bélanger and Nicole Lebrun are sisters who make volunteering a family affair. Denise started volunteering at the Children's last September after Nicole, who's been here since 2015, encouraged her to sign up. "One morning a week, I visit children and their families on the 8th and 9th floors," says Denise. Having worked in the day care setting for many years, she loves spending time with kids. "It's also a chance to help the parents, and I often ask them if they'd like to take a little break," she says. "They may be spending long hours with their child so changing their environment for a little bit is important. You really get the sense that they appreciate it."

Nicole always knew she wanted to volunteer with children in a hospital setting so after retiring, she applied to the Children's. She spends time with two patients on a regular

By Maureen McCarthy



Denise Bélanger (l.) and Nicole Lebrun (r.)

basis. "Being with the same children every week, I've got to know them and what they like to do, whether it's singing songs or reading stories," she says. "I really love it."

The sisters agree that volunteering gives them much more than what they put into it. "When you have a chance to comfort a child and make them feel better, it's very rewarding," says Nicole. "It gives you a great sense of well-being."