

Chez nous

MCH EMPLOYEE NEWSLETTER

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A life-changing transplant for Alessandro

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Montreal Children's
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A life-changing transplant for four-year-old Alessandro

By Sandra Sciangula



► Alessandro Maniates sits in his mom's lap during a follow-up appointment with Angela Burns.

At four years of age, Alessandro Maniates has faced health challenges that most people will never experience in a lifetime. "The pregnancy went well and we were expecting a healthy baby but he was born with a rare syndrome that affected his kidneys," says Alessandro's mom Mina. The day after he was born, Alessandro was brought to the Montreal Children's Hospital (MCH) where his eventual battle against kidney failure would begin. "My son was a trooper throughout it all, my husband Harry, daughter Isabella and I had to stay strong for him," says Mina.

Tests and exams were done, and they revealed that Alessandro had a rare condition which carries a very high risk of cancer developing in the kidneys, as well as causing high blood pressure and eventually, kidney failure.

At nine months of age, an ultrasound revealed that there were lesions on his kidneys that were prone to becoming cancerous. As a result, Alessandro underwent chemotherapy and at one year old, his right kidney was removed. At two years old his left kidney was removed and he started a dialysis routine of 11 hours per day, seven days a week.

"Young children on dialysis require intensive treatment because early childhood is a crucial developmental period. Poor kidney function affects both cognitive and physical development," explains Dr. Beth Foster, Pediatric Nephrologist at the MCH. In order to be eligible for a kidney transplant, a child must be big enough to accommodate an adult donor kidney, therefore growth is crucial. "Dialysis nurse

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Sonia Champoux taught us how to dialyze Alessandro at home. She showed us how to use the Doppler machine to measure his blood pressure, and how to administer shots and other medications at home," says Mina.

Parents who dialyze their children at home have to act as nurses. "They have to know how to do everything," says Dr. Foster, "and complications are a real concern." Although dialysis is life-saving, it is very restricting. "Life on dialysis becomes very medical. The child's diet is controlled, activities like swimming are not possible, food doesn't taste good, and the risk of complications is very high," she adds.

At the age of three, Alessandro reached the necessary weight to receive a new kidney, and was put on the transplant list. On January 28, 2015, Alessandro's parents got the phone call at 4:00 p.m. confirming that a donor kidney was available.

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► Angela, Alessandro and Dr. Beth Foster.






***Chez nous* is published by the MCH Public Relations and Communications office**

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*On the cover: Alessandro and
Isabella Maniates
Cover photo: Owen Egan*

A life-changing transplant... (cont'd)



► Dr. Foster listens to Alessandro's heartbeat.

Mina and Harry immediately brought their son into the hospital and the next day, Alessandro received the transplant. "We were experiencing a mix of emotions," says Mina. "We were concerned because our son was in surgery, but at the same time, we felt hopeful that the transplant would be a success."

"There's a common misconception that once you have a kidney transplant, life goes on normally, but in fact, a transplant is not a cure for renal failure but rather a phase in the disease," says Angela Burns, MCH Transplant Nurse. Angela coordinates care for the transplant patients and works with families to teach them what to expect post-transplant.

Transplant patients have to take immunosuppressants for the rest of their lives and they always live with the risk of kidney rejection, viral and bacterial infections, and even a higher than normal risk of cancer. The medication ensures the body's immune system is not so strong that it rejects the donated kidney, but because the immune system is suppressed, it's

less capable of fighting off infection. "It's our job to make sure that we strike a fine balance so that both the risk of infection and the risk of rejection are avoided," explains Angela.

To strike that balance, patients must follow a very strict medication regimen and must be seen in the transplant clinic on a regular basis. "Families always live with the fear that the other shoe will drop, that a blood test will reveal rejection or infection. They always want the results of the blood test immediately so that they can breathe easy," adds Angela. "In most cases, however, rejection of the transplanted kidney can be treated with medication," explains Dr. Foster.

Despite the risks associated with a kidney transplant, quality of life post-transplant is much better, something that Mina can attest to. "My son can be a little boy now. Since his transplant, he is so full of energy, he runs around with his sister and cousins. It's as if he's making up for the first three years of his life," says Mina. ■



► Alessandro plays with his older sister Isabella who also attends all of his medical appointments.



Many teams, one goal

Staff from across the Children's meet ambitious target to improve patient care

By Maureen McCarthy



► Dr. Olivier Heimrath, Martine Lestage, Cynthia Boursiquot, Gabrielle Laderoute, Géraldine Morency Laflamme, and Dr. Mohamed El-Sherbiny.

A recent initiative at the Montreal Children's Hospital (MCH) to reduce elective surgery wait times has produced outstanding changes in just three months.

In December, at the request of MCH executives, a working group led by Lynn Lebel, Administrative Head, Ambulatory Services, and Karina Olivo, Nurse Manager of the OR, began the process of finding ways to reduce the number of patients waiting for surgery. At the time, over 270 children waiting over one year were on the list, and the group set a goal to reduce the number to 75 patients by March 31. The project brought together staff from over a dozen departments and services. "The results of our efforts are a great example of multidisciplinary work at its best," says Karina.

Input and solutions from many areas

The working group also included some of the hospital's senior management team, and representatives and leaders from the many departments and services involved in managing surgeries at the Children's such as Pre-op, OR, Anesthesia, Surgery, PACU, and the Operating Room booking (ORB) team.

Early in the process, Lynn, Karina, and Gabrielle Laderoute, ORB team leader, met with Dr. Jean-Pierre Farmer and surgeons from several different specialities. Within several services, the surgeons looked at how they could manage their cases differently. They also began producing a three-month calendar for assigning surgeries to allow greater flexibility in making appointments with families. At the same time,

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Many teams, one goal... (cont'd)



► Gabrielle Laderoute, Cynthia Boursiquot, Martine Lestage, and Louise Lemieux.

Dr. Pierre Fiset and the Anesthesiology team worked to provide more OR time to surgeons with the longest wait lists. "In addition, Pre-op had to increase capacity, and the recovery room had to increase the number of patients they receive," says Karina. "We also began using the Procedure Room for simpler cases, which increased our overall capacity." Karina further explains that a key factor in the project's success was bringing every team involved into the discussions. "In the past, the focus had always been on the need for the OR to increase its activity, but we didn't always think about the other areas such as Booking, Pre-Op, PACU, etc., that are affected by an increase," she says.

Lynn agrees that the input from all teams was essential. "Before we had the ORB office in place, much of this was done in silos with each surgical service managing their own list." Starting in January, weekly updates were also shared with the

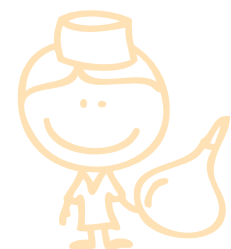
group, which was a significant motivating factor for everyone. "The line on the graph dropped every week from December to March. By March 31, we had successfully reduced the wait list to 77 patients, only two more than our target goal."

The ORB team books surgeries for ENT, Ophthalmology, General Surgery, Urology, Plastic Surgery, Gastroenterology (endoscopies), and some Orthopedic surgeries. The ORB staff streamlined some of the

procedures around booking, working with the surgeons to book patients who had been on the wait list the longest. They now also send the wait lists to the surgeons on a regular basis for verification.

"The physicians have done a phenomenal job of adapting to the changes we requested and helping us reduce the number of patients waiting for a procedure," says Gabrielle. "Thanks to everyone's input, we're in a very good position to maintain what we've accomplished and also tackle other wait lists when the time comes," says Gabrielle.

Lynn says the project continues to be an ongoing process, but its outstanding success in such a short time would not have been possible without every team working together and showing their commitment to making improvements. She meets weekly with Gabrielle and the ORB team, and also has weekly meetings with Karina. "We've discovered that we can solve a lot of issues just by the process of checking in regularly." ■





The PADw project:

The PICU successfully changes how it assesses and decreases pain, agitation and withdrawal in patients

By Sandra Sciangula



► Some members of the PADw team (top row, l. to r.): Frederic Nazair, Marie Antonacci, Nora Ruo, Maryse Dagenais, Sharon Cheong, Margaret Ruddy, Lalida Kongkiattikul. (Bottom row, l. to r.): Audrey-Anne Longpré, Dr. Samara Zavalkoff, Chrys Roussianos.

One year ago, Dr. Samara Zavalkoff assembled a multidisciplinary team in the Pediatric Intensive Care Unit (PICU) at the Montreal Children's Hospital (MCH) to embark on the PADw project – aimed to assess and decrease pain, discomfort and withdrawal in patients. PADw is an acronym for Pain, Agitation, Delirium and Withdrawal. Up until the launch of this project, there was no formal tool in place to measure discomfort, and although there were tools to measure pain and withdrawal, they were used inconsistently.

The new tool, known as an SBS, or State Behavioural Score, allows staff to measure a patient's discomfort level on a scale of -3 to +2. In addition to measuring comfort, the unit staff received training on how to use and implement SBS and withdrawal scoring. Remarkably, they were able to reduce the rate of withdrawal in patients from over 70% to 13%. "The success of this project relied on changing behaviour and then culture through weekly meetings, and by distributing and sharing data," says Dr. Zavalkoff. The committee would meet on a

weekly basis, even if they only had 15 minutes. "There was also constant follow-up on how the unit was doing in terms of measuring the SBS, pain and withdrawal scores, and in time, there were reminders to talk about PAD in patient rounds. We worked hard to close the gaps," she adds.

The MCH was one of thirty ICUs across Canada to collaborate on this project which was supported by the Canadian Patient Safety Institute (CPSI). The MCH PADw committee

members included Sharon Cheong, a patient partner whose daughter, Arya Law-Tong, spent 66 consecutive days in the PICU. Sharon thought joining the committee would be a great opportunity to speak up for other patients. "My hope is that because of my first-hand experience in the PICU, I can speak for other parents and contribute to making patients in the PICU more comfortable," says Sharon. Some of the methods to decrease discomfort include medication but also massages, distraction and a program to encourage families to hold their intubated child.

The CPSI has asked the MCH PICU to present their findings and conclusions nationally. Dr. Zavalkoff plans on launching the second phase of this project, called PADw 2.0, which may target patient mobilization or delirium. In the meantime, the PICU team aims to continue minimizing the clinical outcomes of pain, agitation and withdrawal by collecting and sharing data across the unit on an ongoing basis. ■

Volunteer profiles

By Pamela Toman

Join us in thanking all of our volunteers for the outstanding contribution they make to our patients, families and staff all year round!



Andrew Sharp

Before he became a weekly volunteer in the Hemodialysis Unit at the Children's, Andrew Sharp enjoyed a 40-year career as a civil engineer working around the world. But when it came time to retire, he knew he wanted to try something new. "Having once been a cancer patient myself at the Montreal General Hospital, I met many great volunteers while I underwent chemotherapy," he explains. "I really appreciated their presence, and when it came time to decide what to do when I retired, I thought of volunteering my own time in a hospital with kids."

For the past four years, Andrew has dedicated three to four hours per week to help in the Hemodialysis Unit, and sometimes moves around to other areas of the hospital as needed. The most rewarding part of the experience, he says, are the relationships he has built with staff members and patients along the way. "Just knowing that I'm helping make a parent's, a nurse's or a patient's day a little bit easier...that's what keeps me coming back." ■

Susan Murdock knows what it's like to have a child in hospital. Her son was 14 years old when he was diagnosed with Crohn's disease, and required life-saving surgery at the Children's that has allowed him to live a normal life as a now 22-year old. The experience had a big impact on Susan, who says she was motivated from that moment on to give back. "I always tell my friends and family that volunteering is the best paid job in the world," she says. "You get paid in gratitude, compassion, empathy and kindness. Yes, we may be helpful to patients and families, but I truly think we're the ones who benefit the most from giving our time." ■



Susan Murdock

continued >>>



Doris Albert

Doris Albert has volunteered exclusively on Sarah's Floor (the Hematology-Oncology Unit at the Children's) for the past six months. "I feel like I'm able to really make a difference by helping to provide a break to parents while I babysit their child for a little while," she explains.

Through her interaction with patients, Doris likes to get to know what games they enjoy and what might get a patient to smile or laugh. "I recently was visiting with a little girl who was very sad, and I had trouble reaching her. I decided to show her an animated movie about a little sandpiper bird; it's only about six minutes long...and it made her laugh! I really felt good about being able to offer her a few moments of laughter. Most of the time, I leave the hospital feeling like I've helped someone, and that's really what motivates me to keep coming back." ■

"I guess you could say that I started volunteering because I had to as a school requirement," says Yue Qi who started volunteering at the Children's over two years ago. "But now I come to willingly give my time, and it makes me feel good." Every week, he spends time with 14-year old Loïc, a resident patient at the Children's. The two like to chat about Japanese culture and anime and play with Loïc's growing collection of Styrofoam swords. "My goal is not only to encourage him to be active when we spend time together, but also to get him to talk about what's of interest to him," says Yue. "I find that I learn a lot from him. Despite being in the hospital, he has a huge capacity to learn things on his own, just by browsing the internet or reading things on social media. When he mentions something to me and I don't know about it, I'm motivated to Google it and learn more about it, and it challenges me to keep learning too." ■



Yue Qi

PFCC Star of the Month: Maryse Dagenais

Advanced Practice Nurse, PICU

By Maureen McCarthy



PFCC STAR OF THE MONTH:

MARYSE DAGENAIS
ADVANCED PRACTICE NURSE
MONTREAL CHILDREN'S HOSPITAL



Donna Drury and Maryse Dagenais have worked together in the Pediatric Intensive Care Unit (PICU) for many years. "Maryse is a great multidisciplinary team member, and respected by everyone who works with her," says Donna.

"I nominated her for the PFCC Star award because of her ability to guide the team to focus care on the child and family, which she achieves by listening to families and including them in the decision making for their child. She really makes enormous contributions to what we do."


Maryse feels the idea of patient and family-centered care has been an essential part of her practice since she began her career. "Just a few months


after I started working at the Children's, I met a mom who really taught me a lot about a parent's role in looking after their child," she says. "As I gained experience, it made more sense to me that taking care of a patient was easier if you're working together with their parents."


In her first couple of years at the Children's, Maryse transferred to the PICU where Dr. Franco Carnevale became her mentor. "He shared a very valuable idea that families are not visitors on the unit," she says. "I feel strongly that if parents want and need to be here with their child, then this is where they belong." She adds that she and her colleagues are there to help parents in whichever way they want to be helped.

continued >>>

Our PFCC Stars are featured on the Children's Facebook page. Here's what people had to say about last month's star, Donna.

 **Nancy Alarie**
You do deserve this Donna, you are a role model for what family centered care should be!! It's been great working with you!

 **Patricia Gauvin**
Thanks Donna for helping Anthony stay healthy for the last 16 years. The Murphy family xxx

 **Nathalie Fleury**
Congratulations Donna. You really deserve this. You do extraordinary work with the cystic fibrosis patients. Continue the great work, and never change.

 Like  Comment  Share



Even though Maryse has been in the PICU for more than two decades, she never stops learning. “Every situation is new,” she says, “so even though we may have seen a child’s condition before, their experience and their family’s experience will be unique.”

Kim’s son Jake has been in the PICU since he was born. “Maryse is excellent,”

says Kim. “My son has a heart problem, and that’s often our biggest focus, but Maryse looks at the big picture to make sure he’s growing properly and look after all the other things that need to happen.” Kim also appreciates Maryse’s ability to provide reassurance and comfort about what Jake is going through. “She’s really there for you all the time, and she’s a great advocate for the patient.”

Maryse has always liked working in intensive care. “The pace and the complexity make a lot of people think that it’s very far from family-centered care,” she says. “But the opposite is true. It doesn’t make sense for us to do our work without taking care of the family too.” ■

Free legal services for families

Patients and families can now consult with a triage lawyer at the Montreal Children’s Hospital at no charge thanks to a medical-legal partnership between Pro Bono Québec and the MCH that was formed in January 2017. The service is meant for families facing socio-legal issues and problems impacting their child’s medical situation. To benefit from the service, families must be referred through the MCH [Social Service Department](#). For more information, call [ext. 24455](#). ■

Teens Taking Charge

In March, the website teens.aboutkidshealth.ca/JIA was launched across Canada for teenagers with Juvenile Idiopathic Arthritis. Dr. Sarah Campillo, Pediatric Rheumatologist at the MCH, participated in this multi-centre research project aimed at providing adolescents with arthritis an internet-based tool to help them manage their disease. The website provides teens with valuable information about the disease and the various treatments available, as well as strategies to manage and cope with their symptoms. They can also get on-line support through the site. ■



Awards



Dr. Mirko Gilardino named Montreal's Person of the Year

On March 23, Dr. Mirko Gilardino, Director, H.B. Williams Craniofacial & Cleft Surgery Unit at the Montreal Children's Hospital, was honoured with the **Canadian Italian Business and Professional Association (CIBPA) of Montreal's Person of the Year Award**.

The Person of the Year award is given to an individual who demonstrates exceptional dedication to public welfare. In the past, it has been awarded to the likes of Jean Drapeau and Joey Saputo. Dr. Gilardino is well regarded for being innovative in his practice, and managing extremely complex cases. The families of patients treated by him say he goes out of his way to show their children tremendous care. Congratulations to Dr. Gilardino for receiving this great honour.

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