Chez nous

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Putting families first!

I-CCAN service helps families navigate the hospital

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Hôpital de Montréal pour enfants
Centre universitaire de santé McGill

Montreal Children's Hospital
McGill University Health Centre

ALSO IN THIS ISSUE:

I-CCAN: Putting families first!

There is never a good time for a pandemic. However, the COVID-19 pandemic provided the perfect time to put in place a project that had been maturing for years.

By Maude Samson

▶ Above: Care coordinators like Lise Gagnon (l.) act as liaison between the MCH and the families they help.

In the spring of 2020, the Intermediate-Complexity Coordination and Navigation (I-CCAN) service was finally launched at the Montreal Children's Hospital (MCH). I-CCAN was created for families of children with complex intermediate care needs who are followed by different health care specialists. The service is intended to help patients and their families navigate the health care system and facilitate access to coordinated hospital services.

"Like concierges in a hotel, who coordinate reservations and activities for their guests, care coordinators arrange appointments according to patients' schedules, check if ultrasounds are done beforehand, etc. They make sure that no patient is forgotten," explains pediatrician Dr. Sara Long-Gagné. "What makes them essential, apart from their great organizational skills, is their empathy and their ability to listen."

▶ From left to right: Dr. Sara Long-Gagné, Lise Gagnon, Isabelle St-Sauveur and Marie-Claude Proulx. Missing from picture: Dr. Hema Patel, Nadia Eldaoud, Kaitlen Gattuso, Loredana Martello, Laura Gagnon.

For the initiators of the project, Dr. Sara Long-Gagné, Nadia Eldaoud, Isabelle St-Sauveur and Dr. Hema Patel, this is the culmination of a long process. After years of waiting due to budgetary constraints, it was the temporary reassignment of both Lise Gagnon, Volunteer Coordinator at the Children's, and Kaitlen Gattuso, Child Life specialist, to the care coordination role that allowed I-CCAN to get underway. Since the launch of the program, the team has grown, with Marie-Claude Proulx and Loredana Martello lending a steady hand, and Laura Gagnon soon to take over as full-time Care Coordinator for I-CCAN.

Each week, coordinators Lise and Kaitlen spend several hours in contact with each family. They get to know them and identify the challenges they face. They then use their extensive knowledge of the hospital and their relationships with the various clinics to coordinate appointments according to their lifestyle

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On the cover: Tarek and his mother, Marianne

Cover photo: Maude Samson

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and needs. As Lise points out, the needs often go beyond appointments.

"Every family is different and comes to the Children's with different challenges. Whether it's living 10 hours away or juggling the schedules of three children, the important thing is to listen to them and ask how we can make their life in the hospital easier," explains Lise, who has worked as a Child Life specialist for 17 years. In her eyes, there are many similarities between her previous job and her new position. "At the end of the day, the idea is to help the child and the family cope in the hospital as best as possible," she says.

TAREK'S STORY

Tarek is one of the first patients to be taken care of by I-CCAN. He was born with Down's syndrome, Hirschsprung's disease and severe obstructive sleep apnea. Soon after his birth, he had to be admitted to hospital for a month. He came out with an array of medical appointments and a surgery plan.

In addition to his condition, the multiple medical appointments and time spent in hospital created a great deal of anxiety and uncertainty for his parents, especially his mother Marianne Dufresne. The I-CCAN service played a crucial role in supporting Tarek's family during the move from hospital to home and with providing access to needed services for the family, particularly at the time of his surgery for Hirschsprung's disease.

The I-CCAN service has enabled Marianne, a mother of five, to balance caring for Tarek with her responsibilities as a parent to four other children. "Being followed by six clinics, I am convinced that Lise, our care coordinator, has been able to accomplish things that I could never have done."

▶ Thanks to the I-CCAN service, little Tarek, followed by six clinics, benefits from coordinated care that facilitates his treatments.

Tarek's story is one of many success stories for I-CCAN. Turn to page 6 to read about his inspiring journey.

FAMILY-CENTERED CARE

The I-CCAN project is similar to that of the Montreal Children's Hospital Complex Care service, which is a national pioneer in comprehensive, longitudinal care. Without reinventing the wheel, its team is adapting proven strategies to meet the needs of a whole new category of patients.

"The difference between complex care and I-CCAN is in the medical fragility of the patients," says co-initiator Nadia Eldaoud. "These patients don't necessarily need oxygen at home or special technologies, but they do need care coordination so they don't fall through the cracks," she adds.

According to Nadia, I-CCAN is truly a family-oriented service. While Complex Care patients require advanced medical care, the families assisted by I-CCAN mostly need a person within the hospital who acts as a point of contact between them and the different clinics treating their child.

ELIGIBILITY CRITERIA

To be eligible for I-CCAN, the patient must be followed by a minimum of three clinics for at least twelve months. In most cases, clinics identify patients, but families who meet the criteria can register on the service's webpage.

> Any clinic wishing to refer a patient is invited to contact the team at **iccan@muhc.mcgill.ca** for a consultation.

A PROMISING FUTURE

Thanks to the involvement of the Montreal Children's Hospital Foundation, the program, which has already been successfully implemented with more than 75 patients, will soon be able to move on to Phase 2. The creation of a permanent position of care coordinator and a nurse practitioner who will provide medical care will make it possible to handle consultations and medical follow-ups for nearly 300 patients. In a few years, Dr. Long-Gagné also envisions Phase 3, the creation of satellite centres within the community, which would allow the coordination of care for more than 1,000 patients. While the service has been in place for less than a year, Dr. Long-Gagné is particularly proud of the work her team has accomplished in a short period of time.

"The success of the I-CCAN service is largely due to the dedication and enthusiasm of the team, and this enthusiasm is certainly contagious! As the I-CCAN service grows, so do the number of health professionals and other staff at the MCH who are willing to work with our team in a family-centered approach. I am truly proud to work in a hospital that encourages initiatives such as I-CCAN and where it is a pleasure to work as a team to provide the best quality of care for our patients and their families," she says. ❇

A significant investment

Following the launch of the project, the I-CCAN team received significant financial support from the Montreal Children's Hospital Foundation and Opération Enfant Soleil. With this support, I-CCAN is on the verge of becoming a permanent service and will continue to evolve. Our sincere thanks to our donors.

"Thanks to the generosity of donors across the entire province, we are able to support important projects such as the Intermediate-Complexity Coordination and Navigation service. We are proud to support this program which helps families navigate the health care system. This personalized service makes life easier for parents of sick children and adolescents, and improves access to pediatric care, which is at the heart of our mission."

– Julie Lemieux,
Chief Executive Officer of Opération Enfant Soleil

Coordinated care keeps Tarek smiling

By Maude Samson

In 2019, Marianne Dufresne became pregnant with her fifth child, her first baby boy. The pregnancy was going normally, until the twenty-week ultrasound revealed that her little Tarek had Down syndrome. At 37 weeks, he stopped moving. Worried, Marianne was rushed to the Joliette hospital for an emergency C-section. This is how she welcomed Tarek on August 22, 2020.

A MONTH IN THE HOSPITAL

"About 48 hours after his birth, Tarek still hadn't evacuated his meconium," explains Marianne. That's when doctors at the Joliette Hospital realized something was wrong. They transferred him to the Children's for more advanced testing and diagnosis. "

Due to pulmonary hypertension, Tarek spent the first month of his life in the hospital, dependent on an oxygen concentrator to breathe, but the crisis fortunately resolved. During this difficult time, the medical team determined that the newborn had Hirchsprung's syndrome, which is prevalent in children with Down syndrome and causes severe constipation in the baby, who also battles severe occlusive apnea.

According to Dr. Sherif Emil, the surgeon who operated on Tarek

▶ Top: I-CCAN helps Tarek's family navigate the hospital and get the best possible care, and thanks to our donors, more kids will be able to benefit from their expertise.

when he was only two months old, Hirschsprung's disease affects about 10 per cent of children with Down syndrome. Tarek had a more severe form of the disease, affecting about half of his colon. Consequently, Dr. Emil and his team had to monitor the baby's progress and growth very closely to determine if he could undergo a single operation, without an incision in his abdomen and without a colostomy, which is the creation of an artificial anus by surgically connecting the large intestine to the skin. While waiting for surgery, the parents had to administer a treatment called rectal irrigation several times a day to prevent further obstruction.

"The parents were very important members of the team during this period," adds Dr. Emil. "Thanks to their efforts in administering the rectal irrigations and several other treatments, Tarek did well at home, and we were able to perform the surgery laparoscopically, making only very small incisions. It lasted nearly five hours, but we achieved the desired result."

However, the battle was not won yet. For children requiring complex care, follow-ups and appointments add up quickly. Faced with the complexity of the hospital system, parents can feel disoriented and left to fend for themselves.

I-CCAN'S INVALUABLE HELP

That's where I-CCAN, the new intermediate-complexity coordination and navigation service offered by the MCH, comes in.

As a mother of five children and residing more than an hour away from Montreal, it's safe to say Marianne Dufresne has a busy schedule. Days into the start of the school year, she spent entire weeks in Montreal with her youngest child while her husband stayed in Joliette with their daughters. Given the family's difficulties in balancing their daily lives with their many hospital visits, they were ideal candidates for the service.

In keeping with I-CCAN's mission, care coordinator Lise Gagnon ensures that Tarek's multiple appointments with the six clinics where he is followed are coordinated to facilitate Marianne's hospital visits:

"It was a pleasure to accompany Tarek's mother through the first few months of her hospital visits. Together, we established a great collaboration and effective communication. We were the point of contact to help the family navigate the hospital and all its complexities. I will always remember beautiful Tarek and his amazing mom!"

For her part, Marianne has nothing but praise: "I-CCAN has accomplished feats that I could not have achieved. I look forward to our joint future together."

A CLOSE-KNIT FAMILY

Marianne, who had already read a lot about the importance of family in the life of a child with special needs, realized how important it was after she gave birth. "Because of the pandemic, we haven't been able to have a babysitter or family members at home for a year. Fortunately, Tarek's sisters are very helpful," she says gratefully. "They each have their role with him!"

To this day, Tarek's family, the specialists who follow him and the I-CCAN team are unanimous. Tarek's daily progress is encouraging. Although he will always be closely monitored, Tarek will certainly be well taken care of and ready for anything! ❇

▶ Aged 3, 5, 12 and 15 years old, Marianne's four daughters each play a part in their little brother's life, much to their mother's delight.

The MUHC Neurofibromatosis 1 Clinic:

Treating patients across the lifespan

By Maureen McCarthy

Julie Anzini was eight years old when she was diagnosed with neurofibromatosis 1, or NF1 as it's commonly known.

"At the beginning it was really hard," she says, especially given her young age. "I was scared that I would look different. I definitely felt different than everyone else. I was the only one in my family to have this condition." But before long, Julie realized that having a diagnosis of NF1 wasn't really holding her back and she could still keep doing all the things she liked to do. Now married with three children, Julie is showing her kids that anything is possible, something that her oldest child Noah, in particular, can really take to heart.

A DISORDER AFFECTING THE NERVOUS SYSTEM

NF1 is an inherited condition which occurs in about one in every 3,000 people. It involves principally the nervous system, the skin and the eyes, but also a variety of other systems with different manifestations in different individuals. The most common symptoms are café-au-lait spots on the skin, tumours of the optic nerve or the nervous system, special pigmented spots on the iris, and sometimes multiple skin bumps called neurofibromas.

NF1 is variable in how it's expressed from person to person, partly because clinical manifestations of the disease change with age. Another reason has to do with the NF1 gene, which normally

▶ Top: (l. to r.) Stephan, Noah, Lily, Alex and Julie.

produces a protein called neurofibromin that modulates and controls cell growth. Every person has two copies of the NF1 gene: one inherited from their mother and one from their father. At birth, in patients with NF1, one of the two copies of the NF1 gene is not working due to a genetic change. Over time, genetic changes happen on the other NF1 copy causing a complete loss of function of the NF1 gene. This second genetic change happens randomly in different cells and in different parts of the body. Complete loss of neurofibromin causes the café au lait spots, neurofibromas or tumours.

NF1 also predisposes people to very rare tumours and cancers from an early age. While 80 per cent of those living with NF1 have mild or moderate symptoms most of their lives, 20 per cent of people experience severe medical complications such as cancers, and heart or blood vessel problems that require constant medical care and attention.

The rate of spontaneous change in the NF1 gene is one of the highest in any genetic condition, which explains why almost 50 per cent of patients with NF1 are the first in their family to be diagnosed with the disease.

A MULTIDISCIPLINARY APPROACH FOR A MULTI-SYSTEMIC CONDITION

Dr. June Ortenberg and Dr. Daniela D'Agostino direct the pediatric and adult components of the NF1 Clinic in the Division of Medical Genetics at the MUHC (Glen site). "Our clinic is essentially a medical home for children and adults with NF1 where we provide patient-centered, expert, lifelong care to individuals who are referred to us from primary care physicians and specialists," says Dr. D'Agostino. The clinic actively follows around 400 patients—half in pediatrics, half in adult care—for all aspects of their overall health.

The care team also includes Dr. Geneviève Legault, a pediatric neuro-oncologist at the Montreal Children's Hospital (MCH), and Dr. Marie-Noëlle Hébert-Blouin, a neurosurgeon at the Montreal Neurological Institute (MNI) who specializes in peripheral nerve surgery. Dr. Hébert-Blouin receives consultations at the MNI for NF1 patients needing surgery, and actively follows about 200 adult patients with NF1, half of whom also see Dr. D'Agostino at the Glen site.

The pediatric service was launched over 30 years ago when Dr. Ortenberg, a pediatrician, first started treating and caring for children with NF1. At the MUHC, the clinic entered a new era about five years ago when Dr. D'Agostino, a medical neurogeneticist, began treating

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▶ (l. to r.) Dr. June Ortenberg, Noah, Julie Anzini, Dr. Marie-Noëlle Hébert-Blouin, and Dr. Daniela D'Agostino.

adults with NF1 as well as some children seen by the service. "Our clinic really embodies the values of the MUHC to provide seamless continuity of care over a patient's lifespan," says Dr. D'Agostino. "It is more than just being in the same physical space, it's that we have a global philosophy for caring for our patients throughout their lives."

Dr. D'Agostino explains that NF1 is the type of condition that naturally fosters collaboration. "NF1 is really a multisystemic condition so it requires a whole-person care approach which gives us a chance to liaise with multiple specialties," she says. "The Medical Genetics Division is the ideal place for the clinic because we follow patients from conception to old age. Our oldest patient right now is 75 years old."

"We have great collaborations with some of the neurosurgeons in both pediatric and adult care, as well as specialists in plastic surgery, ophthalmology, endocrinology, dermatology, psychiatry and orthopedics to name just a few," says Dr. Ortenberg. "It's wonderful how everyone pulls together to help our patients."

For Dr. Hébert-Blouin, the clinic's multidisciplinary approach also enhances what she can offer her patients. "Adults with NF1 often have a lot of lesions and the patients I see are generally of a more complicated nature," she says. She sees her patients at least once a year depending on their condition, but knowing they can see Dr. D'Agostino for other issues makes it more collaborative. "What's more, my specialty is peripheral neurosurgery, so when patients have lesions in the brain or the spine I can also bring in some of my neurosurgery colleagues who specialize in those areas."

"Our clinic really embodies the values of the MUHC to provide seamless continuity of care over a patient's lifespan."

▶ (l. to r.) Lily, Noah and Alex. Noah was diagnosed with NF1 at four weeks old. Almost two years later, twins Lily and Alex were born but neither of them has NF1.

EVERY PATIENT IS UNIQUE

The clinical variability of NF1 makes patient management complex. "The tumours can occur anywhere in the nervous system," explains Dr. Ortenberg. "Our patients can develop problems with their bones, arteries, optic nerves, or circuitry of the neurons, and they can also have learning and developmental issues. It all stems from the dysfunction of the NF1 protein, but what happens after you're born and what other complications you have in life is very variable. No two patients are alike."

Dr. D'Agostino emphasizes the importance of doing a thorough evaluation of everyone referred to the clinic. "We create a baseline for each patient through tests, exams and consultations, so if at any point a patient tells you something is different or feels different, that's a red flag to investigate further."

There is evidence that the rate of breast and nervous system cancers is higher among individuals with NF1 compared to other people. Even benign tumors can cause problems in patients with NF1. "A great deal of my work involves removing benign tumours," says Dr. Hébert-Blouin, "because if they're pushing on nerve fibers either in the limbs or where the nerve comes out of the spinal cord, they can still have consequences even if it's not cancer."

The clinic has established careful guidelines for all its patients including earlier screening for several cancers. In pediatrics, there is a specific schedule and algorithm for which tests should be done at what age. Adult patients with NF1 are seen at least once a year, and they become an active part of the medical team: monitoring their own symptoms and being aware of any issues is an important part of managing their condition. Dr. Hébert-Blouin ensures that any of her patients who have a lot of lesions are seen regularly and get MRIs every year.

In terms of NF1 research, the landscape has changed significantly in recent years, and the MUHC team is working to promote collaborative research with other NF clinics in Quebec, Canada and internationally. "When I started the clinic 30 years ago, it was a mystery condition and nobody knew anything about it," says Dr. Ortenberg. "But now so many more people are interested in it and the research is exploding." She further explains that new knowledge of tumour formation mechanism can be applied to other areas such as oncology so there's increased collaboration on many levels. "Therapies are now being invented and it's a very exciting time for NF1 patients. Before, we had nothing to offer them, but we're hoping in the next decade or two that will really change." The promise of new discoveries and treatments makes ongoing support vital.

The team is also grateful for the support from the Association de la Neurofibromatose du Québec (anfq.ca). "They do wonderful work to educate about NF1, support the NF1 community and promote research in Quebec," says Dr. D'Agostino.

▶ Noah and Julie.

JULIE AND NOAH: MOTHER AND SON

Julie is now 39 years old and has been living with NF1 for more than 30 years. Over that time, she's had close to 10 surgical procedures to remove tumours. She's currently followed by Dr. Hébert-Blouin and Dr. D'Agostino. Her son Noah is followed by Dr. Ortenberg and Dr. Legault.

Julie and her husband Stephan knew there was a 50 per cent chance of their children inheriting NF1, meaning a one-in-two chance with every pregnancy. Their first-born son, Noah, was diagnosed with NF1 at four weeks old. Almost two years later, twins Lily and Alex were born but neither of them has NF1.

Their family's experience at the NF1 clinic and elsewhere at the Children's has been incredibly positive. "We've

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been treated so well, with such care. Everyone really listens to our concerns and answers our questions," says Julie.

Noah underwent his first surgery to remove a tumour last December. Julie says everyone—from the Child Life specialists to the surgical team—took such good care of him. "We were so proud of how he handled it. He's only seven years old but he wasn't scared. He refers to his scar as a "scratch" and takes a certain amount of pride in saying that we both have scratches now," she says with a laugh.

Julie and Stephan are also happy that Noah leads an active life along with his brother and sister, and enjoys taking part in soccer, karate, swimming and skiing. "The older I got, the more I understood about NF," says Julie. "And now that I'm married and have a family, and work full time, I can show my children what's possible when you have NF."

EASING THE TRANSITION

Making the transition from pediatric to adult care for any health condition can pose problems and challenges for people, but the NF1 clinic model is helping to solve some of those issues. "Young adults in our care shift from having their parents take care of everything to doing it themselves," says Dr. D'Agostino. "The fact that patients can continue to come to the same place and already know many of the team members goes a long way to ease their concerns and make the transition smoother."

If anyone understands the importance of transition to adult care, it's Julie. "I know how reassuring it is for me to be followed here," she says, "so to think that once Noah turns 18, he'll continue to be followed in a place that knows him so well is something that gives us real peace of mind." ❇

▶ (l. to r.) Dr. Daniela D'Agostino, Dr. June Ortenberg, and Dr. Marie-Noëlle Hébert-Blouin. Dr. Ortenberg and Dr. D'Agostino direct the pediatric and adult components of the NF1 Clinic in the Division of Medical Genetics at the MUHC (Glen site). Dr. Hébert-Blouin, a neurosurgeon at the Montreal Neurological Institute (MNI) receives consultations at the MNI for NF1 patients needing surgery, and actively follows about 200 adult patients with NF1, half of whom also see Dr. D'Agostino at the Glen site. (Absent from photo: Dr. Geneviève Legault, pediatric neuro-oncologist at the MCH.)

Dr. Beth Foster:

Looking forward to her new appointment as Pediatrician-in-Chief of the McGill University Health Centre and as Chair of the Department of Pediatrics at McGill University.

By Sandra Sciangula

A pediatric nephrologist at the Montreal Children's Hospital, Dr. Foster will be assuming her new roles on September 1, 2021 and is happy to have been selected. As Pediatrician-in-Chief, Dr. Foster plans on consulting with members of the department to help her set priorities for the coming years. Two of her own priorities are to further develop transitional care and improve access to care and quality of care for patients in remote communities.

"We need to take advantage of the unique position the Children's has as a hospital within a hospital," says Dr. Foster. The Royal Victoria Hospital is located on the same site, just a corridor away from the Montreal Children's Hospital. "This is a major advantage for patients with chronic illnesses who have to transition from pediatric to adult care and I see potential for us to become a national or international leader in models for transitional care."

Another priority for Dr. Foster is improving access to care and quality of care for patients in remote communities. The Montreal Children's Hospital cares for patients in the Réseau universitaire intégré de santé et services sociaux (RUISSS) McGill spanning 63 per cent of the territory of the province of Quebec. Oftentimes, patients who live in remote communities have to travel by plane in order to get to the hospital and have to deal with the difficulties of being far from their communities.

"We need to work with Indigenous leaders, patients and parents to improve our ability to provide care within their communities and to

provide high quality, culturally-appropriate care within the hospital," she says. "The pandemic has pushed for care to be delivered remotely but more needs to be done to keep patients close to home when possible. We also have work to do to improve inclusion of Indigenous people in designing culturally appropriate care."

Dr. Foster recognizes the significant improvements to the governance structures, transparency, and sense of community Dr. Michael Shevell achieved in his 10 years as Pediatrician-in-Chief. "I hope to continue building that sense of community within the department," she says.

In addition to becoming Pediatrician-in-chief, Dr. Foster will continue to practice nephrology and see her patients on a regular basis. ❇

A new record for our annual Kangaroo-a-thon!

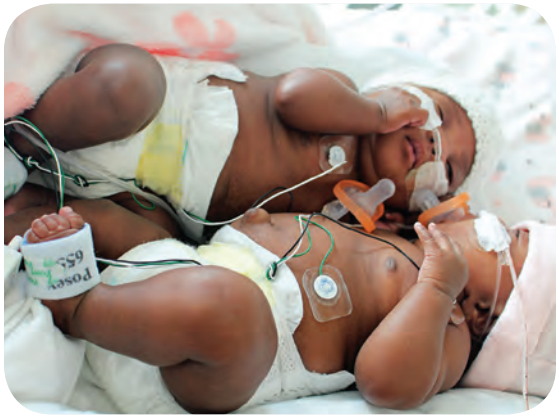
By Maude Samson

May 9 to 16 was the Neonatal Intensive Care Unit's (NICU) annual Kangaroo-a-thon, one of the most adorable events of the year. During this special week, parents in the unit are encouraged to practice kangaroo care with their babies by holding them to their chest in skin-to-skin contact. The organizers closed the event with a new record: 2.8 hours of kangaroo care per baby per day. This is a significant jump from the NICU's last record of 2.1 hours. The unit has accumulated a total of 707 hours of kangaroo care, performed by 50 families.

▶ Daphmy enjoys practicing kangaroo care with her daughter Amayah, because it allows her to feel their connection.

In addition to being a tender moment between parents and their newborn, skin-to-skin contact is a beneficial practice in more ways than one, especially for premature babies. Benefits include improved weight gain, better sleep, reduced signs of stress and more. On the parents' side, kangaroo care promotes attachment and reduces stress during the newborn's hospitalization.

▶ After waiting weeks to hold her premature twins, Faith and Hope, Betina feels privileged to now be able to do so. She has performed the most hours of skin-to-skin contact, with a total of 43 and 45 hours.



▶ Twins, like Faith and Hope, can also practice skin-to-skin contact.

Heartfelt congratulations to the NICU team, the NICU lactation consultants and educators for this new record and for an initiative that is as appreciated by parents as by newborns! ❄