

Chez nous

MCH EMPLOYEE NEWSLETTER | Published by Public Relations and Communications | www.thechildren.com

SPRING 2023

United for Thomas

MCH breaks new ground to care for this unique patient

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Hôpital de Montréal pour enfants
Centre universitaire de santé McGill



Montreal Children's Hospital
McGill University Health Centre

Life at the MCH after the pandemic

Dear colleagues,

It's high time to put the pandemic behind us, to celebrate all that we have accomplished through some incredible struggles and to get on with whatever the "new normal" is going to look like. Our focus now is on what is most important to us: our patients and our personnel.

To do this, we are working on five key issues: human resource stability, growth development and training, culture and sense of belonging, patient engagement and access to services.

We have already embarked on an aggressive strategy to ensure that there are more of us on our amazing teams, with recruitment outreach, job fairs and open house events. We are also rolling out over the coming months a workplace experience survey (on the iMatter platform) to learn from everyone what we enjoy about our environment, and what can be improved. Every one of us has an important role to play in ensuring the Montreal Children's Hospital (MCH) remains a wonderful place to work.

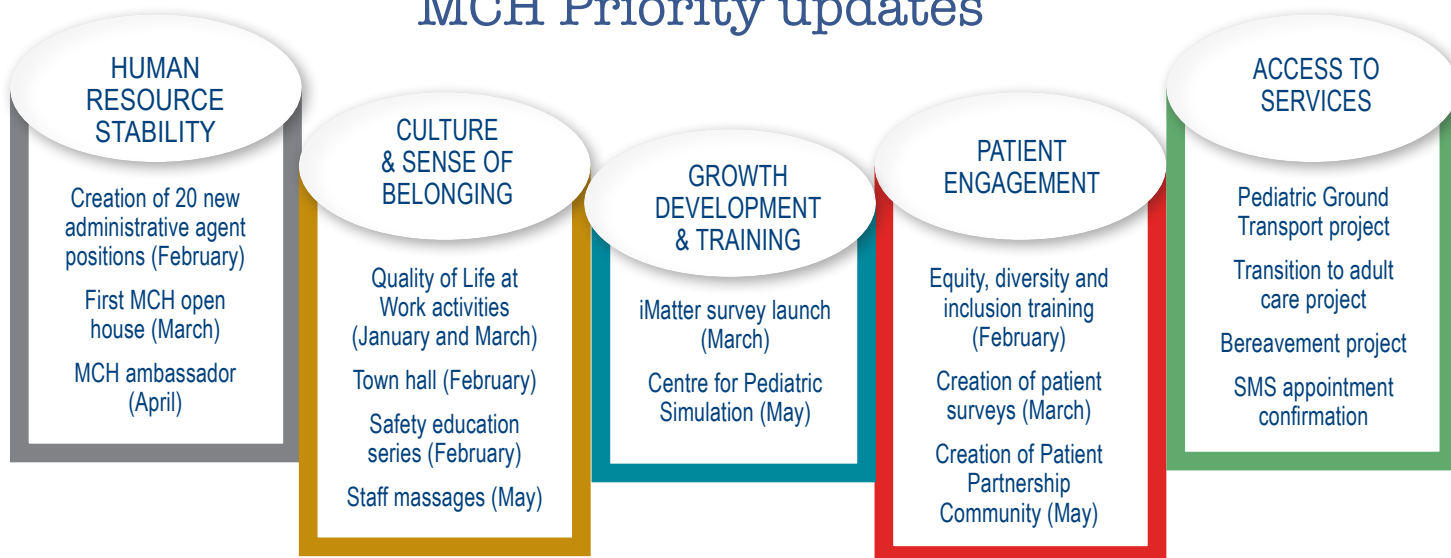
There are many professional development initiatives underway or planned. Notably, on May 10, the MCH will open the doors of its brand new Centre for Pediatric Simulation to further train staff members.

Patient safety has always been a driving force and a passion at the MCH, and this too will become even more structured over the course of the next year. We invite you to welcome and participate in upcoming initiatives, and contribute your own passion and expertise when called upon.

Many projects continue to develop in order to optimize access to care for our pediatric patients, starting with the creation of an Access Care Coordination Centre to facilitate calls and transfers with our partners in the community. Our pediatric ground transport team, in collaboration with CHU Sainte-Justine, will be launched in June to provide rapid response and transport for critically ill children in regional hospitals.

[continued >](#)

MCH Priority updates



After years of studying and discussing the challenges our adolescents and young adults face in transitioning to adult care, we are finally embarking on different projects to make this entire process more organized and successful. A program to enhance the support we offer to our bereaved families who have lost a child is

also well on its way to being launched in the upcoming year. It is everyone’s commitment to our patients and their families, and to one another, which makes the MCH such a fabulous place to make a difference in the lives of others. For that, and everything you do, we thank you.

Cindy McCartney

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On the cover:
Thomas Thériault

Cover photo:
Marie-Michèle Arpin

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Extraordinary measures for an extraordinary child

Thomas Thériault's treatment team has pushed passed the limits many times to care for him

By Christine Bouthillier

When her son was seven months old, Marie-Michèle Arpin was told what no parent wants to hear: "Get ready, your child doesn't have long to live." A verdict she refused outright. She turned to the team at the Montreal Children's Hospital (MCH) for a second opinion. Today, Thomas is seven years old. This is his story.

[continued >](#)

► Thomas Thériault (centre), with his mother Marie-Michèle Arpin, his brother Lucas and his father Jean-Rock Thériault.

Marie-Michèle had a smooth pregnancy and delivery. It was when Thomas was two months old that she realized something was wrong.

“He was crying a lot, he wasn’t sleeping. I felt it was different from my first child,” she says. “I went to the emergency several times, but no one could tell me what was wrong with him.”

When Thomas was six months old, during yet another visit to emergency, Marie-Michèle got angry and demanded to see a pediatrician. It turned out that

the baby had a growth delay and his liver was twice as large as normal.

The New Brunswick family was transferred to a specialized pediatric hospital. After several genetic tests, it was discovered that Thomas had an extremely rare and severe form of Zellweger syndrome.

The symptoms vary from child to child, but for Thomas, the disease involves progressive hearing and vision loss, abnormal coagulation, reduced absorption of fat-soluble vitamins, liver prob-

lems, intellectual and physical impairments, and neurological disorders such as epilepsy.

TURNING TO THE MCH

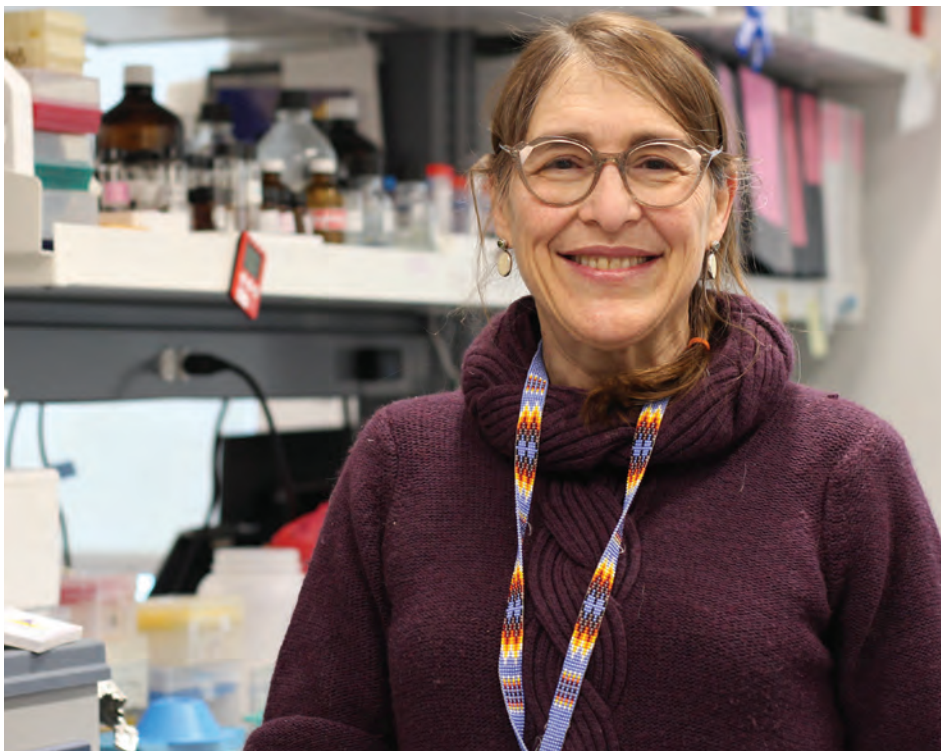
Marie-Michèle was told at the hospital that Thomas didn’t have long to live. Not willing to give up, she did a web search, which led her to Dr. Nancy Braverman, a medical geneticist at the MCH. Dr. Braverman agreed to take Thomas under her wing.

“She told me that he was indeed sick,” says Marie-Michèle, “but that they didn’t have a crystal ball and that Thomas would make his own way, that we weren’t at the stage of palliative care yet.”

Thomas’s case is unique in the world. There are 13 genes that can cause a peroxisomal¹ disorder such as Zellweger syndrome. Usually, a mutation in only one of these genes causes the disease. Thomas is the only known case of someone with two of these genes (PEX1 and PEX6) that are defective. This is why he is more severely affected by the disorder.

“The most severe cases have critical neurodevelopmental problems. They usually die within the first year of life. Thomas is in the intermediate category, which is very broad. Patients in this

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► Dr. Nancy Braverman.

¹ A peroxisome is a part of a cell that can notably eliminate certain toxins.

category have a 50 per cent chance of survival to age 15,” notes Dr. Braverman, who has extensive experience with over 200 patients with Zellweger spectrum disorder in her research.

At the MCH, Thomas was cared for by a large group of specialists, including in genetics, neurology, gastroenterology, otolaryngology, ophthalmology, hematology, physiatry, nephrology and endocrinology. He received hearing aids, glasses and orthotics. In an attempt to solve his liver problems, the team was able to convince a pharmaceutical company to donate for compassionate use an expensive drug, not available in Canada. Such treatment can cost more than \$10,000 per month and Thomas received it for a year.



► Dr. Ana Sant'Anna.

There was also a delicate balance to be struck in how to give him vitamin K, which is poorly absorbed by his system. “Because he has abnormal coagulation, Thomas regularly bruises. In the last few years, we’ve been trying to find the best combination between giving vitamin K intravenously, which is better absorbed but creates bruising, or giving it orally,” says Dr. Ana Sant’Anna, a pediatric gastroenterologist at the MCH.

For several years, Thomas’s condition remained stable. He was able to crawl, stand and use a walker. In November 2022, he even took a dozen steps without help for the first time. He could say several words and express himself with gestures. He ate purées by mouth.

A CHAIN OF EVENTS

Despite this, challenges began to mount. In December 2021, Thomas caught COVID-19. It caused him to have intermittent, life-threatening gastrointestinal bleeding. He was hospitalized several times for blood transfusions. In July 2022, a capsule endoscopy revealed gastritis, an inflammation of the lining of the stomach.

“We needed to know what else Thomas had. We couldn’t see where the bleeding was coming from,” says Dr. Sant’Anna. “We are fortunate to have an excellent adult hospital in the same building, the MUHC’s Royal Victoria Hospital, and good gastroenterologists willing to helping us.”

As a result, the boy became the first child to undergo a double balloon en-

doscopy at the MCH and one of the few children in Quebec to have one. The procedure, usually performed on adults for other health issues, allows for a deeper examination into the small bowel.

“It’s not an expertise developed in pediatrics because children don’t normally bleed as much,” adds Dr. Sant’Anna.

The team eventually realized that the bleeding was coming diffusely from the small intestinal mucosal lining, but they were unable to stop it because the mucosa was too fragile to be cauterized, clipped or injected.

“So we decided to implement a unique treatment to improve his quality of life, so unique that we had to explain it to the insurer to get them to agree to reimburse it. It was an extraordinary team effort between people from pediatrics, complex care, education and local caregivers,” says Dr. Sant’Anna.

The long list of medications included in this treatment helped stabilize the situation. Thomas has had only one bleeding episode since then.

“We are very happy with the results. We really went above and beyond for Thomas,” says Dr. Sant’Anna.

He also had a central line installed so he could receive his blood directly in New Brunswick instead of in Montreal. The hospital near his home does not offer pediatric services and couldn’t install it themselves. The MCH team coordinated with local staff and taught them so that

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► Thomas at a visit to the MCH.

Thomas could receive care without having to travel to another province.

“Thomas is such a sweet boy. I always see him smiling in spite of his obstacles. This family has been through so much... We are ready to push the limits for them,” adds Dr. Braverman.

HIS STRUGGLES CONTINUE

Despite this success, there were other obstacles in Thomas’s path. In November 2022, he had his first seizure, which put him in a coma for 36 hours. The boy developed a rare complication of his disease known as leukodystrophy, which could be the cause of the seizures.

Leukodystrophy is a disease that affects the nervous system and leads to degeneration of the white matter in the brain. Less than 10 per cent of patients with Zellweger syndrome have it. Since then, Thomas has lost many of his skills. He is now fed exclusively with a gastrostomy tube, he hears less, sees only light, is no longer mobile, and does not say words or make gestures.

Unfortunately, leukodystrophy can be terminal. There is no cure, only a medication that sometimes can diminish symptoms for a few months, but Thomas cannot take it because of his gastrointestinal bleeding. He is gradually declining.

Palliative care has been initiated. Although she is obviously devastated, Marie-Michèle wanted to share Thomas’s story to raise awareness about the disease that affects him and to highlight all that her child has brought to others.

“Thomas is much more than his disease,” she says. “He has taught us more than we have ever learned in our entire lives. He is a model of perseverance; even when he fell or was hospitalized, he would still find a way to laugh. Thomas has touched a lot of people and even though the situation is extremely difficult, we manage to see the positive in it.”

The family continues to raise awareness on TikTok (@lespetitspasdeThomas). Donations can also be made in Thomas’s honour to fund Dr. Braverman’s research by visiting the Montreal Children’s Hospital Foundation web page. ❁



Psychoeducation supports young patients at the MCH

By Roxane Gaudreault

Last fall, the Montreal Children's Hospital (MCH) opened a new Psychoeducation Department. To date, six professional psychoeducators have joined the team to provide services to children and their families at the MCH.

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► Above (l. to r.): Tamara Malinoff, Éloïse Forest, Émilie St-François, Andréane Aubert and Frédérique Lalonde. Absent from photo: Charlotte Paquette and Marie-Eve Royer.

Over the past few months, the department has slowly taken shape and is working to help more and more children. After starting out mainly with virtual meetings, the team is now well settled at the hospital and carries out assessments, follow-ups and clinical activities in person.

WHAT DOES A PSYCHOEDUCATOR DO?

The role of the psychoeducator is varied. Psychoeducators can intervene by preventive methods or when a child begins to have difficulties in adjustment that have an effect on their behaviour. This makes them versatile professionals who can be integrated into most clinical teams.

“Our patients in the hospital have to adapt to major changes,” says Andréane Aubert, coordinator of the Psychoeducation Department. “Children are far from having a regular schedule when in hospital — hygiene, routines, socialization, everything is disrupted. So we work to ensure that the patient adapts as best as possible and as quickly as possible.”

The psychoeducator contributes to a child’s care by studying the patient’s behaviours and/or identifying triggers related to their symptoms. They can also recommend effective strategies to improve the course of treatment for a child with challenging behaviour.

The psychoeducator analyzes the situation and ensures that the patient and their parents have the necessary tools and information to adapt to a changing or new situation.

“No young person is disrespectful for the sake of it,” explains Andréane. “These behaviors have a function and psychoeducators hold the key to understanding the reason behind problematic behaviour. We look at it as the person in front of us is always doing their best.”



Psychoeducation is for people of all ages. In a pediatric hospital setting like the MCH, psychoeducators work with children and adolescents who are hospitalized, or receiving frequent care that may be invasive or painful, or living with mental health problems, as well as other conditions or issues. Hospital-based psychoeducators differ from their community peers in that they focus specifically on issues related to children’s medical conditions.

AMBITIOUS PLANS FOR THE FUTURE

Andréane wants her small team to grow: “My goal is that we will soon have more presence within the treating **continued >**



► The team had a kiosk in the P.K. Subban Atrium for the Psychoeducation Days event in February.

teams themselves, that we will be more on site to be able to help the maximum number of patients.”

This integration into the clinical teams makes the psychoeducators’ work very organic, as they participate in meetings, discuss cases, and can very effectively target patients and families who need follow-up. They are also able to see children and adolescents referred by a

physician or other health professional in the community.

While other professions are connected to psychoeducation, it has no equivalent outside the province. It’s a field that was developed and is currently only taught in Quebec.

The new department is therefore faced with a significant challenge: making the

profession known to patients and families and also to physicians and professionals who practice at the MCH.

“Creating a department is a lot of work. Everything has to be done, even integrating it into the MUHC’s computer software! However, we already have a great team and the process is going well,” concludes Andréane. ❄

Émile’s story

Émile Demers, 11 years old, has been in hospital many times since he was born.

For the past few months, he has been receiving a new treatment, one that has been particularly difficult, causing him discomfort and pain. He is now experiencing anxiety before each treatment, adding an extra challenge to his already demanding daily life.

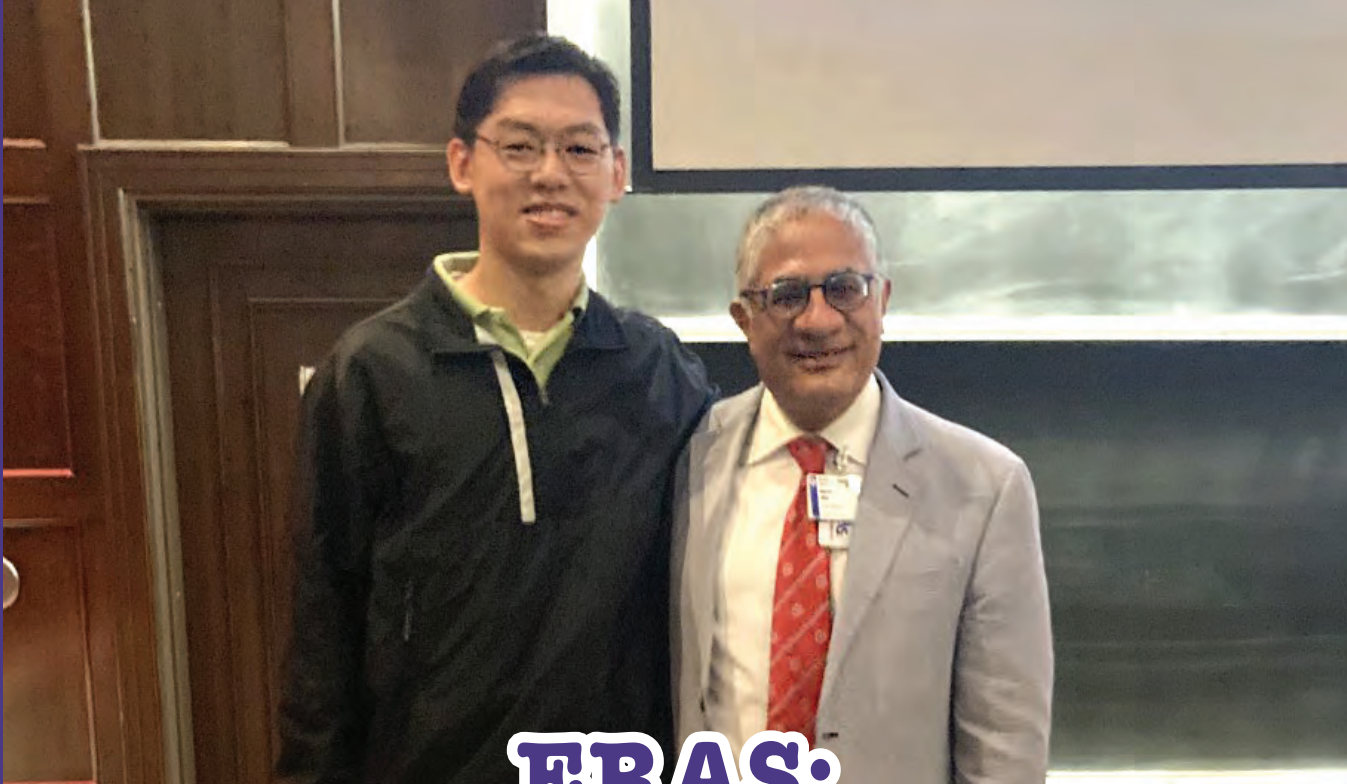
Referred to the Psychoeducation Department in November, he received prompt help from Éloïse Forest, who put in place a plan to manage Émile’s anxiety.

Together with Émile, the psychoeducator broke down, step by step, what happens during treatment. For example, they made a chart that maps out the course of care. This strategy makes the moment more predictable for Émile, who then knows what to expect and, as a result, experiences less anxiety.

At the same time, the psychoeducator is offering follow-up to Émile and his family regarding other changes which are anticipated as he approaches adolescence, a phase in which many adaptations are often needed.

Émile’s mother, Amy Loignon, is delighted with the help offered to her child: “The results are very positive, the stress is easier to manage now. I would not hesitate to recommend the service to families and children living in situations similar to Émile’s.” ❄





ERAS:

A new era in pediatric surgery

Full-day conference on April 28

By Maureen McCarthy

Dr. Sherif Emil is very excited about the future of ERAS in pediatric surgery. ERAS, short for Enhanced Recovery After Surgery, is a multi-modal, peri-operative care pathway designed to achieve early recovery for patients undergoing major surgery. The Montreal Children's Hospital (MCH) will be hosting the first Canadian conference dedicated to pediatric ERAS on Friday, April 28 to inaugurate an ERAS culture into pediatric surgical care, and to share pediatric applications of ERAS with a wide audience.

With six core, evidence-informed principles such as patient-family engagement and pain management with fewer narcotics, ERAS supports better outcomes for surgical patients. These outcomes include an improved patient experience, reduced length of hospital stay, decreased complication rates and fewer hospital readmissions.

According to Dr. Emil, the McGill University Health Centre (MUHC) has been very much in the forefront of ERAS for some time. "In the last decade, [continued >](#)

► Above: Daniel Chow (l.) pictured here with Dr. Sherif Emil, is one of two patient speakers who will present at "ERAS: A new era in pediatric surgical care" on Friday, April 28. Daniel, who is currently enrolled in McGill University's medical school, will give his perspective as a patient who underwent a Nuss procedure pre-ERAS.

Drs. Liane Feldman and Franco Carli have really been among the world leaders in ERAS implementation.”

A CHILD’S RECOVERY IS A FAMILY’S RECOVERY

The introduction of ERAS in pediatric surgery however is a much more recent concept. Dr. Emil, who holds the Mirella & Lino Saputo Foundation Chair in Pediatric Surgical Education & Patient and Family-Centred Care, explains that some of the key issues and questions for adults undergoing surgery do not come up when talking about children. “Adults need to know when they’ll be able to return to work, or resume their other responsibilities, but similar questions haven’t been traditionally asked for children.”

Dr. Emil has been interested and invested in ERAS for a long time, and the impetus to develop it further came from his role as Saputo Foundation Chair. “One of the mandates of the Chair is patient and family-centred care, and it’s obvious that ERAS aligns perfectly with getting kids back to their families sooner, and family members back to work sooner.” He credits the MCH Foundation for their commitment to a capital campaign to fund ERAS as part of a surgical quality project.

In December 2018, the first international meeting on pediatric ERAS took place in Virginia. “It was the first time that pediatric surgeons even started talking together about ERAS,” says Dr. Emil.

Shortly afterwards, pediatric surgeon Dr. Kurt Heiss, an early advocate of ERAS, spoke at the MCH pediatric and pediatric surgery grand rounds, as the 2019 Frank M. Guttman Visiting Professor. “At that point we had started to develop ERAS protocols and were planning a huge retreat for May 2020, but of course, it had to be cancelled because of the pandemic.”

COVID-19 put a hold on starting new ERAS protocols, but the surgical team continued to plan for the future. “In the past few

years, we’ve actually developed a couple of ERAS protocols: one in scoliosis and one in chest wall anomaly surgery that have been very successful,” says Dr. Emil. “Patients getting chest wall surgery, who used to stay six to seven nights, are now leaving the hospital the next morning.”

A number of new team members have been hired, including three nurse practitioners who, in addition to providing care, are building new programs, with ERAS being one of the most prominent.

Dr. Emil adds, “Representatives from the Ministère de la Santé et Services sociaux (MSSS) also approached us to learn more about our ERAS development and after several meetings authorized a full-time nurse coordinator to lead the whole plan. We also currently have a graduate student — a surgical resident — who has decided to pursue ERAS as her master’s topic.”

RAISING AWARENESS ABOUT PEDIATRIC ERAS

And now that so many activities put on hold by the pandemic can resume, the Division of Pediatric Surgery is looking forward to hosting the upcoming multidisciplinary conference **ERAS: A new era in pediatric surgical care on Friday, April 28.**

The full-day conference will feature lecturers from the MCH and the MUHC, as well as representatives from the MSSS, patients, and experts from elsewhere in Canada and the US.

The department’s goal in hosting the conference is to bring the principles of pediatric ERAS to a wide audience. “We want to launch a movement that will benefit the thousands of children in Quebec who will be receiving surgical care in the future, as well as our entire healthcare system,” says Dr. Emil. “I often say that ERAS is the great disruptor of our era, and this is our turn to disrupt!” ❄️

ERAS: A new era in pediatric surgical care

Friday, April 28, 2023 • 7:45 a.m. to 6 p.m.

Sylvia and Richard Cruess Auditorium • RI-MUHC • E S1.1129

If you would like to attend the conference, please email Dr. Julia Ferreira at

Julia.Ferreira2@mail.mcgill.ca

MCH gets into spring mode!



By Christine Bouthillier

The Quality of Life at Work Committee at the Montreal Children's Hospital (MCH) has made sure to put winter far behind us by organizing some fun activities for staff. Here are some highlights if you missed out!

Thank you to the Montreal Children's Hospital Foundation for funding the committee.



EVERYONE'S IRISH ON ST. PATRICK'S DAY

For St. Patrick's Day, MCH staff were invited to dress in green. Barbara Mayo (first place, left) from the ENT Department (Otolaryngology - Head and Neck Surgery) and Charlene Richards (second place, right), from the Division of Cardiology, were the big winners of the costume contest!



SOMETHING SWEET AT THE MCH

To celebrate the arrival of spring, the P.K. Subban Atrium was transformed into a sugar shack for the afternoon. Even the sun came out to brighten the day!

