

# Chez nous

MCH EMPLOYEE NEWSLETTER

March 19, 2014

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# Growing up with juvenile arthritis

— By Pamela Toman

Arthritis isn't something you'd think a child could have, let alone an eight-month-old baby. But when Derek Macri was first brought to the Montreal Children's Hospital (MCH) five years ago to treat his recurrent fevers and rashes, pediatric rheumatologist Dr. Rosie Scuccimarri delivered baffling news to the infant's parents: their baby boy had systemic-onset juvenile idiopathic arthritis.

Juvenile idiopathic arthritis (JIA) is a chronic autoimmune disorder that can lead to the inflammation of one or more joints, but in Derek's case many of his joints were affected as well as some of his internal organs. "We tried multiple treatments, including heavy doses of steroid medications. Unfortunately, Derek did not respond to these therapies, and we couldn't control his condition with them," says Dr. Scuccimarri.

One of the most noticeable side effects of the steroid medication was facial swelling and poor growth which made Derek appear

heavier than he actually was. He was on a cocktail of medications—as many as 15 drugs when he was just two years old.

"He was very small for his age and he didn't walk until the age of three," says his mom Annik. "He had a lot of physical limitations because he struggled to move around due to the arthritis."

"It was very difficult at first," says Joey, Derek's father. "There were periods when his blood test results would come back and the levels were just upside down." This was especially true in March of 2010, when Derek's health took a turn for the worse on three separate occasions. He endured periods of lengthy hospitalizations and countless rounds of blood work.

## New drug offers new hope

After trying seven different drug therapies in an effort to stabilize his condition—none of which was successful—it was an experimental IV medication that began to show a great deal of promise for Derek.

"We began the treatment in October of 2011 and he showed gradual improvement. We were able to decrease the steroid medication to a negligible dose. By September 2013, he was doing really well," says Dr. Scuccimarri.

With his arthritis now stabilized, Derek, who is now five years old, has been able to make big strides when it comes to his overall growth and development. He can now do summersaults, hop on one foot and run around with his older brother Jamie—all physical feats that were impossible before his condition was stabilized.

*Continued >>>*



*Nurse Gillian Taylor talks with Annik Macri while Dr. Scuccimarri checks Derek's joints during a recent appointment.*



*(l. to r.) The Macri family, including big brother Jamie, Annik and Joey, keep Derek busy during a recent hospital visit.*

The family now visits the MCH’s Clinical Investigation Unit (CIU) once every two weeks so that Derek can receive his medication, which is administered intravenously and requires special observation by nursing staff.

### Managing a chronic condition

Given Derek’s extensive list of medications, Annik keeps a journal, or what she refers to as a “bible” that lists the names of all the drugs he takes and the dosage amounts for quick reference. She also keeps daily notes about what he ate and the symptoms he exhibited that day. And when it comes to their son’s improving health, Joey says they owe everything to the staff at the Children’s.

“Our rheumatology nurses, Gillian and Charlene, were patient and answered all my questions every single time I called. They are like an extension of our family,” he says.

As for Dr. Scuccimarri, the Macris are quick to express their gratitude. “We can’t put into words everything she has done for us. There’s nothing we can say to adequately thank her for saving our child’s life.” •

*On the cover: Derek is pictured with Maurice, his favourite stuffed animal. Maurice no. 5 stays at the hospital, and the family has four other Maurices in different spots to make sure Derek always has his best friend nearby.*

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# MCH social workers: key members of our healthcare teams

March is National Social Work Month and to mark the event, we asked several MCH social workers to tell us about their work and why they chose pediatrics. Here's what they had to say.



**Melanie Caron**  
Psychiatry and ER at the MCH

Melanie is a social worker at the Montreal Children's Hospital and is part of the MCH Psychiatry Department. She works on two different teams: the Mental Health Evaluation Team (MHET) in the ER for psychiatric crisis and the Mental Health Evaluation Liaison Team (MEL1) for outpatient psychiatry. "We help evaluate what resources the child and family require and make recommendations for follow-up. We ultimately help them gain access to the proper services and supports," she says.

Melanie has worked in adult psychiatry, youth protection, and domestic violence, but has always loved working with children, especially after spending five years in Korea as a kindergarten teacher. So she came back to do her Master's of Social Work and was then hired at the MCH, first in complex care, and now in psychiatry. "I love working with children because of the elements of hope and change," she says. "Families and children are resilient, and with the right help and support they can make great gains in their quality of life."

Melanie has always had a strong understanding and compassion for mental health issues, and the stigma attached to them. "We still have a long way to go as a society in terms of understanding and accepting mental illness," she says. "It's my passion, and I want to be part of that change. As social workers we are so privileged to be a part of the lives of the families we work with."

When Melanie reflects on her proudest moments, she says every day there's something to be proud of. "I've had many experiences that have shown me a lot about the difference that one gesture or one person can make. Over time, it has taught me to continually advocate for families even when it seems impossible."

**"Every day there are small interventions that make a big difference."**

*Continued >>>*



## Melinda Di Minno Neurology and Trauma at the MCH

“People laugh when they ask me, ‘is there anywhere you *haven’t* worked??’” Melinda first started her career as a Therapeutic Recreation Specialist at the MCH, but went on to work in several health care settings and non-profit organizations such as the Alzheimer Society of Montreal. She returned to school and completed her studies in Social Work which led to working at the MUHC adult sites. After completing her Master’s of Social Work she knew she wanted to return to the MCH to pursue her career in a pediatric setting.

“I really love what’s possible in pediatrics,” she says. “We work with a family, not just the patient, and we can accomplish great work—a lot of change in fact—when we have access to the whole family.” But she also points out that change is not limited to the family. “Working in pediatrics means you always have to be creative and be open to change. And working with young people means we can jump on board with them, always being aware of the newest trends as we create a working relationship.”

Melinda is currently assigned to Neurology and she covers for the Trauma social worker as needed. Her role involves meeting a family early on in the process. “First, we assess how the family is coping, and evaluate their needs. We discuss resources available such as support groups, government and community programs. We provide psychosocial support, and even meet with teachers and other community partners who are involved to provide education and outreach,” she says. “We provide support on an ongoing basis. The family’s reality changes as the child grows and develops. It’s about having compassion towards the family, meeting them where they’re ‘at’ and understanding their mindset.”

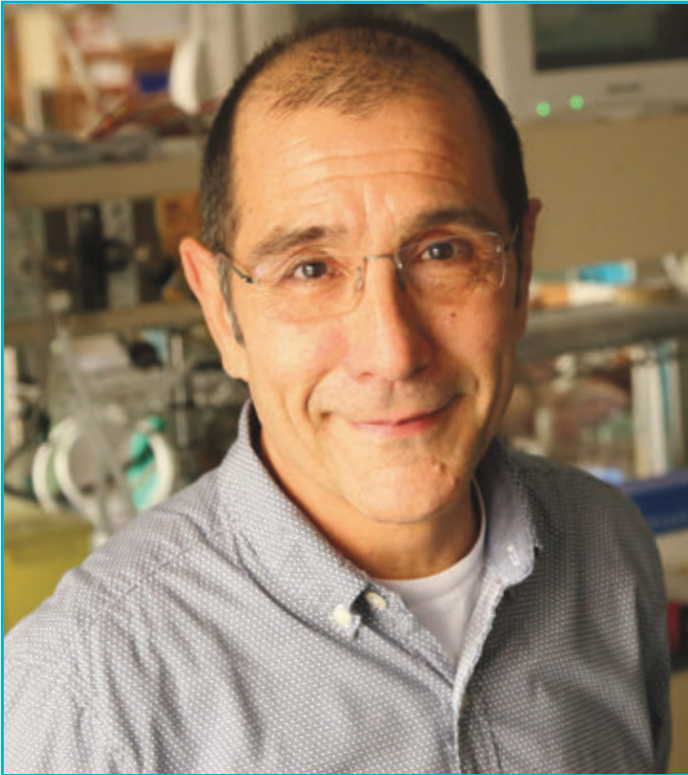
When a child has a chronic condition, the family lives with it for years, often long after their child turns 18. “The family becomes the specialist who knows their child best,” says Melinda. “As a social worker I remain in the shadows, but I empower the family to have the confidence to manage their child’s health.”

“Today’s youth are tomorrow’s leaders so when you help a family,  
you can help make a difference for tomorrow.”

*Continued >>>*



## MCH social workers *(cont'd)*



**Kevin Brady**  
NICU at the MCH

Kevin Brady is one of two full-time social workers assigned to the MCH Neonatal Intensive Care Unit (NICU). Patients are sent to the NICU for intensive evaluation and treatment, and the social workers provide assessment and service to almost all families who are admitted. "Having a newborn in intensive care adds stresses to the family, and we accompany them during the process," says Kevin.

Kevin says he always dreamed of working with children. "As long as I can remember, it was something I wanted to do." Before becoming a social worker, Kevin studied science. He says that working in a hospital allows him to combine both his interests: the technical as well as clinical. He finds the NICU an exciting place to work, and says the teamwork approach is what keeps him motivated.

"Although all professionals strive to provide the best treatment possible, it's ultimately the family that has to adapt to providing care for their child," says Kevin. "Every family is different, and it's important to carry out a comprehensive assessment to attend to the individual needs of each family." That means taking into consideration the family's make-up and structure, their support system, their cultural and religious beliefs, their adaptation and coping skills, and their education. The social worker also facilitates communication, attends to instrumental needs, researches community resources, and helps with discharge planning, all of which makes them an indispensable partner in the family's care.

**"Parents are particularly vulnerable at this time, and it's a privilege to be included in their care."**

## Memorial service

A memorial service is being organized to remember the children who have died recently at the MCH. We shall also be commemorating the children who have died of SIDS. All staff members are warmly invited to attend this service, which will be held on **Tuesday, March 25 at 2:00 p.m. in the Amphitheatre (D-182)**.



# Celebrating our Child Life specialists

## during Child Life week - March 24 to March 28

### THE MONTREAL CHILDREN'S HOSPITAL'S CHILD LIFE PET THERAPY PROGRAM IS CELEBRATING ITS 10<sup>TH</sup> ANNIVERSARY THIS YEAR!

Every Wednesday, Gaia, a little brown poodle from Zoothérapie Québec, plays with patients in the Family Resource Centre from 10:00 a.m. to 3:00 p.m. "Some kids like to pet or play with the dog, while others enjoy just holding her," says Marie-France Haineault, coordinator of Child Life Services at the MCH. "It really depends on the health and physical ability of the child, but Gaia is great at adapting herself to the state of the child." In order to participate, child life specialists identify hospitalized children from medical, surgical and oncology units who they believe could benefit from the experience. Once approved by their family and physician, the child gets to spend 30 minutes with the dog. "The program helps children feel less isolated and gives them an opportunity for normalization during their hospital stay," adds Marie-France. "In some cases, we can even bring the child down in their hospital bed!"



*Vanessa Akl loves spending time with Gaia and even brought her a toy to play with.*

### Did you know?

- Over the last 10 years, 3,000 patients have benefitted from the MCH's Child Life Pet Therapy program.
- The dogs are handled by a certified animal-assisted therapist from Zoothérapie Québec.
- Gaia is strictly reserved for the Children's and is not allowed to visit any other health centre in order to reduce the spread of infection.
- The dogs are washed before every shift.
- Our second furry friend, Jazz, retired a few months ago, and a new dog is currently being trained.

Join Gaia and the entire MCH Child Life team as they celebrate the program's 10<sup>th</sup> anniversary with an open house on **Wednesday, March 26 in the Family Resource Centre from 10:00 a.m to 3:00 p.m.**

### THE MCH'S CHILD LIFE DEPARTMENT WINS FELLOWSHIP FUNDING FOR NEW PROJECT!

Our Child Life department is in the process of developing a new program for children undergoing radiation treatment. The pilot project was made possible thanks to funding by the Kids Health Link Foundation and the Canadian Child Life Fellowship Awards Committee. Over the next year, a child life fellow will be responsible for creating and implementing an efficient system of preparation and support for patients and families receiving such care.

Approximately 70 MCH patients receive radiation treatment a year, but they must undergo the treatment at the Montreal General Hospital (MGH). This can sometimes lead to anxiety because patients and families are not familiar with the new

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## Celebrating child life... (cont'd)

space. The program hopes to reduce this fear by better preparing the children for the experience. This will mean creating bilingual education resources for the families, all while working in conjunction with the radio-oncology team at the MGH. The child life fellow will act as a liaison between both clinical teams and will travel with the family from the MCH to the MGH to make sure they are comfortable with the new personnel, environment and medical equipment. The radio-oncology team will also benefit from learning how to use developmentally appropriate tools and coping strategies when dealing with young patients and their families.

“Our goal is to create a link between both centres and this will only strengthen once we move to the Glen due to our closer proximity to the new Cancer Treatment Centre,” says Marie-France Haineault, coordinator of Child Life Services at the MCH. **The fellowship program is scheduled to begin in May 2014.** •

### FUN FACT:

In 1936, the Montreal Children’s Hospital became the first hospital in North America to open a Child Life department.

# Plan your wait with a text update

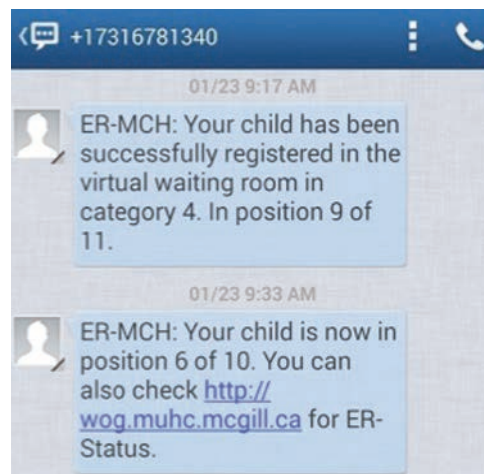
## New text message app lets parents know about MCH Emergency wait times — By Pamela Toman

Nobody likes spending hours and hours sitting around a crowded waiting room, not knowing who will be called next. So imagine if patients and families could be notified via text message about the number of patients ahead of them while grabbing a bite to eat, going for a walk, or even sitting in the comfort of their own home?

Thanks to a team of two engineers at the McGill University Health Centre, Jean-Pierre Cordeau and Jorge Pomalaza, along with Dr. Harley Eisman, Director of the Montreal Children’s Hospital’s Emergency Department, this ideal scenario is now a reality. The pilot project was launched at the end of January, and is the first of its kind in Quebec.

### How it works

Patients and families visiting the MCH’s Emergency Department (ED) can register via a kiosk located just outside the ED’s triage area or by a downloadable app available to all smartphone users. The app lets them “wait” in a virtual waiting room rather than a physical one with the help of their cell phones—something that’s sure to please more than a few stressed-out parents.



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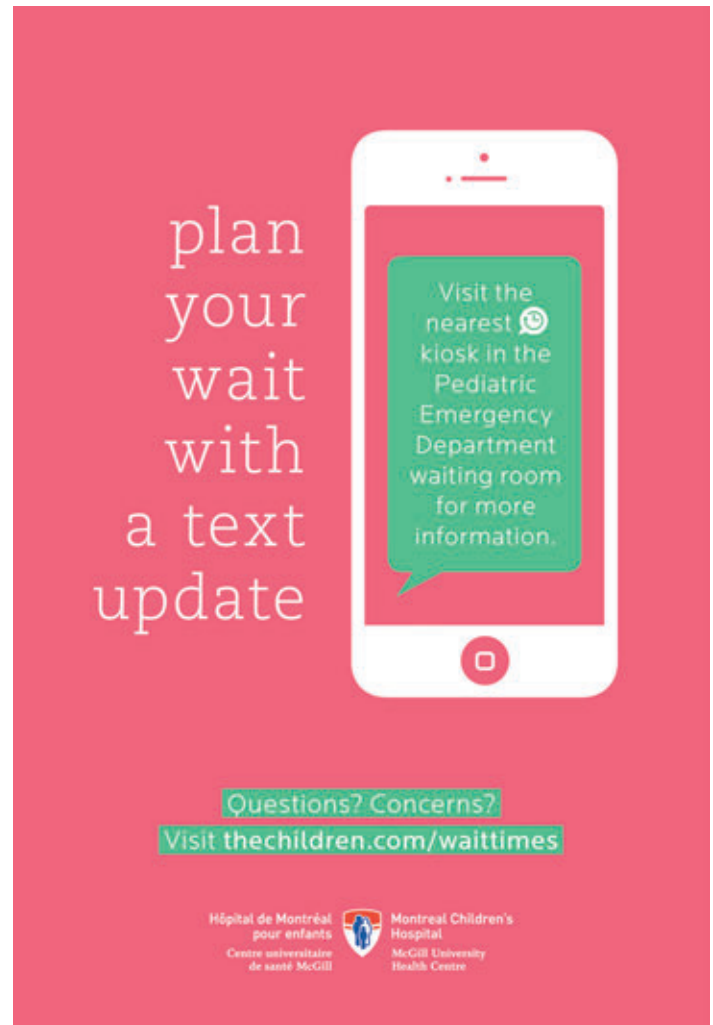
Using the service is very straightforward according to Jean-Pierre and Jorge. "Once a patient has been evaluated by the triage nurse, parents can input either their child's hospital card or Medicare card number to register for the text message (SMS) service via the kiosk or the website," says Jean-Pierre. "Parents must also provide a cell phone number and select French or English language preference. Once the information has been submitted, they will receive their first SMS within a few minutes, detailing a summary of their child's status in the Emergency Department."

Once the first text message has been sent, parents continue to receive updates on their child's position in the ED waiting room every five minutes to ensure they are kept up to date on any changes. Once there are only five or less patients ahead of them, the family will receive a text message notifying them to head back to the emergency room so as not to miss their turn.

### Putting patients' and families' needs at the forefront

The biggest benefits of the project will undoubtedly be felt among patients and families, who will now have more options when deciding how to best spend their time while waiting to see a physician.

"The goal is to make wait times more palatable for patients and families so that ultimately, they can make more empowered decisions," says Dr. Eisman. "Sometimes, this can mean that they decide to go for a walk, or get a bite to eat while they wait



instead of sitting in the waiting room, and other times, it may mean they decide to go home or seek care elsewhere. Ultimately, we hope that by giving parents more options with this new service, it will help to enhance the patient experience." •

### VIRTUAL WAITING ROOMS THROUGHOUT THE GLEN?

Given that many of the waiting rooms at the Glen site have been designed to be more intimate and will be located within clinical areas, this project serves as a valuable pilot that can be adapted for a variety of clinics and services at our new hospital. Jean-Pierre Cordeau and Jorge Pomalaza hope they can optimize the patient experience by implementing this service in more departments, encouraging users to visit outdoor areas, commercial spaces and common healing environments in the new buildings while they wait to see a specialist.



# Audiology services at the new MCH: a decade in the making — *By Maureen McCarthy*

MCH Audiology Professional Co-ordinator Anne-Marie Hurteau says the new Audiology facilities at the Glen will make a big difference to how they deliver care. “Everything has been thought out with the patient and family in mind,” she says.

Anne-Marie’s predecessor, Louise Miller, began the planning process for Audiology services at the new MCH over 10 years ago, which helped the Audiology team start thinking early on about how they could best address their professional needs to serve families. This involved looking at everything from how

to configure their screening and testing facilities to providing private, quiet space for families who are receiving their child’s diagnosis.

Audiology will be located on the 1<sup>st</sup> floor of the A block at the new hospital with adjacencies to their closest working partners. “Even though we are part of the Allied Health group, it made the most sense for our services to be located near Otolaryngology,” says Anne-Marie, “since they are the team we work most closely with in terms of care and treatment for our

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*(l. to r.) Audiologists Julie Tran, Audrey Hardy, Anne-Marie Forget, Christine Lemay, Suzel Julien, and Anne-Marie Hurteau discuss their new facilities at the department’s weekly meeting. Absent from photo: Ellen Rishikoff.*

patients.” Currently, the two services are on different floors at the MCH. At the Glen, patients will be able to move easily between the two departments with a connecting corridor near the back of the departments. “Some of our administrative staff will even be side by side, so the communication between our two services will be better than ever,” says Anne-Marie. Other neighbours on the floor include ambulatory clinics and the Family Resource Centre.

### Perfect timing for provincial training mandate

Several years ago, the Audiology teams from the MCH and the Royal Victoria Hospital (RVH) launched the Newborn Hearing Screening Program for all babies born at the RVH. Babies who do not pass the screening tests are referred for comprehensive audiological evaluation at the MCH. Every year, one out of 1,000 babies is born with a significant hearing loss. Since it was launched, the MUHC screening program has identified more than 15 babies with a significant hearing loss.

Soon after the MUHC program was launched, the Quebec Ministry of Health announced a universal hearing screening program. The MCH Audiology team is now playing an important role in the province-wide program. “Our department has been given the mandate to train all audiologists in Quebec who will be responsible for evaluating the hearing of newborns who do not pass the screening test,” says Anne-Marie. “We will support them regularly, and provide services such as second readings of their evaluation results.” The timing couldn’t be better: part of the program funding allows for an additional soundproof room, which is included in the plans for the new MCH. “In addition to training audiologists at other centres, we’ll also see a much greater number of babies who are born at our RUIS birthing centre partners.”



*Anne-Marie Hurteau*

### Updated equipment

Like many other services at the MCH, the Audiology department at the new MCH will be receiving various new equipment. “All of our new equipment will have a computer data processing link,” says Anne-Marie. “Our profession requires that we keep detailed records of our patient assessments and evaluations, so the new equipment will greatly help with that.”

The audiologists are really looking forward to moving to their new space at the Glen. “Our new department will be very colourful and family-oriented,” says Anne-Marie. “We will really be able to offer a welcoming, comforting environment for our patients and their families.” •



# 'Bed management' meetings

help improve patient flow — *By Stephanie Tsirgiotis*

As a tertiary care hospital, our mandate is to provide short-term, high-level care, and this will be especially true once we move to the Glen. In order to achieve this, many of us have been asked to modify the way we work. Departments are working closer together and the term 'interdisciplinary' is part of our everyday vocabulary more than ever. And yet this culture change doesn't only apply to our clinical units, but to the hospital as a whole. Case in point: how we manage our beds on a daily basis.

Lucy Caron, nursing administrative manager for inpatient services, and Dr. Harley Eisman, medical director of the Montreal Children's Hospital's Emergency Department, have both been instrumental in reinventing the early morning "bed huddle". The concept of nurse managers meeting every morning to plan patient transfers and discharges for the day has been common practice for years, but the duo had bigger plans. "The timing worked out really well, because bed management became a hospital priority," says Lucy. "And we already had ideas on how

to evolve the bed huddle into something even more efficient." An 'interdisciplinary team' approach was suggested as a way to optimize and better coordinate patient flow. "Basically everyone who participates in admissions, transfers and discharges is invited to attend this daily meeting," says Frédéric De Civita, project manager of the SERVE Patient Flow working group.

Before attending the daily bed management meeting, each unit meets with their respective teams to determine which of their patients will likely be transferred or discharged and at what time during the day. They then share this information with the other teams during the 8:15 a.m. session. "Most admissions and transfers tend to happen during the evening and nightshift when the wards have less staff," explains Dr. Mylène Dandavino, program head of the medical inpatient units. "Our goal is to move these activities to when teams are at their maximum working capacity—during the day. The bed management meeting allows us to better coordinate our day by knowing what the specific hospital needs are for beds, but also to help other units who might be under more pressure than usual."

Optimal surgical activities depend on well coordinated patient flow, while discharges or transfers depend on the physical health of the patient and on any outstanding tests that need to be done before going forward. Johanne L'Écuyer, chief technologist of Medical Imaging, says the daily meeting gives her a better idea of how many upcoming tests need to be scheduled and which priority patients need to take precedence. It also helps sort out miscommunication between teams. "In the past, when paperwork was

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*Representatives from all over the hospital meet every morning to plan out the day.*

missing for a particular test, our department would spend a lot of the day playing phone tag," she says. "I can now bring up this issue at our morning meeting and it's resolved quickly. This reduces frustration, speeds up the process and ultimately cuts down on delays."

Dr. Dandavino hopes this new process will reinforce the role admitting physicians can play in managing patient flow. "For example, we can ask our team to anticipate and predict

discharges the day before, and to bring completed paperwork to rounds," says Dr. Dandavino. "This is a complete culture change, but in order for this to succeed, we all have to work together as a team." Dr. Harley Eisman, clinical leader of the SERVE Patient Flow working group, also sees the shared value of this new structure. "By having so many different representatives in the same room, everyone has a better understanding of each other's obstacles. It allows us to recognize the reality of all the units and to use our resources to the best of their ability," he says. ●

# You asked, we answered!

## Answers to frequently asked questions about the Glen

### How will medications and blood samples be transported within the new Children's?

The central pharmacy at the Glen will be linked to both adult and pediatric hospitals and is located in Blocks B (pediatric) and C (adult). The distribution process for medication will closely resemble the current process for inpatients and outpatients:

- Prescriptions will be hand-written by physicians until Computerized Physician Order Entry (CPOE) is widely deployed.
- Teams are discussing whether prescriptions will be scanned or a copy will be sent by the pneumatic tube system directly to the pharmacy in order to prepare the medications.
- On regular adult inpatient units, there is one medication cart for every six beds, and these carts will be stored in the alcoves. There will also be one fridge per unit. At the MCH, there will be one medication cart per unit.
- For ambulatory clinics, medication carts will be available, but different medications will be provided depending on the clinic. This information is presently being discussed, and should be presented shortly.

The pneumatic tube system will also be used for transportation of samples and will be particularly useful for clinical labs. There



*The interior spaces are quickly coming together. Here's a recent shot of the Atrium in Block C—also known as the cafeteria!*

is also a satellite laboratory located on B6 to support the NICU and PICU. For more information on the pneumatic tube system or any other questions you might have about our transition and transfer to the Glen, please visit the **MUHC 2015** section on the Intranet. ●



# ANNOUNCEMENTS

## Conference on ADHD

The Education and Training Committee of the Division of Child Psychiatry of McGill University is organizing a conference on Attention Deficit Hyperactivity Disorder (ADHD) on **Friday, April 11 from 8:15 a.m. to 4:30 p.m.** at the Douglas Mental Health University Institute/Douglas Hall Pavilion. For more information, contact Rita Riccio from Child Psychiatry at **x22470**.

## Walk 5km or run 21km

with the Montreal Children's Hospital Foundation at this year's Scotia Bank 21k & 5k Charity Challenge at Parc Jean-Drapeau on **Sunday, April 27, 2014**. Dedicate your run to the young patients of the Children's and ask your friends and family to support you. For more information, visit [www.canadarunningseries.com](http://www.canadarunningseries.com)

## NEW PILATES COURSE FOR MCH EMPLOYEES

- When:** On Tuesdays, 12:05 p.m. to 12:50 p.m. for six weeks
- Where:** Rm D-292, MCH
- Cost:** \$65 — begins April 15
- Registration:** Contact Karen at (514) 489-7717 or [karenkunigis@gmail.com](mailto:karenkunigis@gmail.com) before March 28.

*(Note a minimum of 10 participants is required.)*

## New location for Pediatric Transition to Adult Care checklists

In our February 14 issue, we featured an article on the Pediatric Transition to Adult Care Program run by Dr. Lorraine Bell and Dale MacDonald. The materials, which were previously available on the global S:drive, will now be available on the MUHC portal. They are easy to find from the e-MUHC home page, just click on: [Resources/Departments and Services/Transition to Adult Care](#)

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