Managing life with sickle cell anemia — Page 2

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Queen Taire never knew that she and her husband Eddie both carried the gene for sickle cell anemia. Even though she was aware the disease was in her family, Queen had never thought of the possibility that it might one day touch her own life. So when she learned that her first-born daughter Tega had the disease, it came as a complete shock.

Sickle cell anemia is a type of blood disease that a child is born with. For couples who both carry the sickle cell gene, there is a one in four chance that each of their children will have the disease.

When red blood cells are healthy, they maintain a round shape, are flexible, and they carry oxygen throughout the body. In sickle cell anemia, the red blood cells are irregularly shaped, have a shortened lifespan, and they can inhibit blood flow and delivery of oxygen to various parts of the body. This can result in many different manifestations of the disease, most commonly episodic painful crises and increased risk of infection. Some children have more complications than others, often for reasons still not understood.

Tega was diagnosed with sickle cell at the age of seven months. The news came after a very difficult day. “She had been crying non-stop and I could tell she was in a lot of pain, so we decided to bring her to Emergency at the Children’s,” says Queen. “They did tests that day and that’s when we found out she had sickle cell disease. It was really devastating.” Afterwards Queen and her husband were tested as well. “The doctor told us we’re both carriers and that’s why Tega developed the disease.”

A stroke at age six
Tega’s most difficult period was when she was six years old. She had been sick and experiencing stomach pain, so her parents brought her to the Children’s. They learned that Tega had fluid in her lungs. She was admitted to the Pediatric Intensive Care Unit (PICU) where she was...

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intubated to help her breathe. Not long after, while still in the PICU, Tega had a stroke, a known complication of sickle cell anemia. What followed was a lengthy rehabilitation period, first at the Centre Marie-Enfant, then at the MacKay Center. “She was so determined to get better,” says Queen, “and she eventually regained her strength and started to walk again.”

Following the stroke, Tega was put on a chronic exchange transfusion program, a process which replaces her sickle cells with normal blood. She receives her treatment every six weeks in the hemodialysis unit at the Children’s, where they use an apheresis machine to help make the process efficient.

A simple test
Tega has a younger brother Chucko, aged nine, and sister Fejiro, aged seven. Chucko tested negative for sickle cell disease, but Fejiro tested positive for the disease before she was born. Fejiro has never been hospitalized or had any serious problems as a result of the disease.

Both sisters are followed in the sickle cell clinic at the Children’s, and see Dr. Sharon Abish and Marie Gale, a nurse in the Hematology-Oncology division, when they come for check-ups every three months. “The girls are doing very well,” says Marie. “Since Tega has been on the exchange transfusion program we haven’t seen her for emergencies as we did in the past.”

Tega and Fejiro are among 125 patients treated for sickle cell at the MCH. Marie explains that since November 2013, every baby born in Montreal and Laval is being screened at birth for sickle cell disease. The screening process is fairly simple and uses the same blood test that is used for all other screenings at birth.

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Family ties (cont’d)

Life at home

Queen is thankful that her daughters are able to enjoy normal lives despite living with the disease. Fortunately for the family, life at home doesn’t involve any complicated tests. The girls eat a healthy diet and drink plenty of water to stay hydrated. Queen knows what to watch out for, and if either of the girls ever has a fever or any pain, she knows to bring them to the Children’s right away.

Queen has high praise for the team at the Children’s. “Everyone here is so supportive of our family,” she says with a smile. “They’ve done so much for us and still do so much for us. Any time I ask for anything, they are always there and that is very important. They really see you through.” •

Another MCH love story!

The Children’s holds a special significance for newly engaged couple, Alex Paaren and Annie Bakopoulos. But funnily enough, the radiology technologist and pediatric nurse didn’t know they shared the same workplace until they met through an online dating website in December 2013. In just a matter of months, the pair became inseparable. They discovered they shared many similar interests, including photography and even started up their own business, called Annex Photography. This fall, they delighted their friends and family by announcing their engagement, and are now looking forward to an October 2015 wedding in Montreal.

FUN FACT:
On their first date, Alex admitted that he recognized Annie from the cover of Chez nous in May 2013!
Heart rates quicken as doctors, nurses, respiratory therapists, and OR aides all crowd around an infant in the Operating Room at the Montreal Children’s Hospital. A massive bleed has been detected somewhere in her little body and she’s crashing fast. The team has to react quickly or they’re going to lose her. “Time’s up,” calls Dr. Lily Nguyen. The team looks up and takes a deep breath. The 20-minute simulation is over.

Since Spring 2014, the Interprofessional Perioperative Simulation Working Group has been meeting regularly to organize simulations for OR and PACU staff. Dr. Nguyen, a pediatric surgeon and otorhinolaryngologist, and Dr. Rachel Fisher from the Anesthesia department, along with a number of dedicated colleagues, including assistant head nurse Toni Carriero, have been leading this program. “We get input from our interprofessional working group every step of the way, because we do not want these simulations to be physician-led. Everyone has an equally important part to play,” says Dr. Nguyen.

The group spends over 20 hours organizing each simulation. A real-life scenario is mapped out and then a dry-run rehearsal is conducted at the Arnold and Blema Steinberg Medical Simulation Centre (SIM centre) on Parc Avenue, followed by another dry-run at the hospital. Six to seven OR/PACU staff are then invited to take part during rounds on Monday mornings.

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Practice makes perfect
New training program leads to positive change

— By Stephanie Tsirgiotis

(l. to r.) Tony Franco, Olena Doronina, Toni Carriero, Dr. Lily Nguyen, Dr. Indrani Lakheeram, Jess Ghaleb, David Dufour and Sonia Guilbeault. Missing from the photo (and key members of the team): Dr. Catherine Paquet, Dr. Rachel Fisher, Dr. Vincent Collard, Sophie Maranda, Geraldine Laflamme, and Kim Thibeault.
The session starts off with a 20-minute preparation course, followed by the 20-minute hands-on simulation, then finishes with a 40-minute de-brief period. During the simulation, staff work on an infant-sized mannequin, one so real-looking they can actually feel, hear and see changes in its behaviour. “It’s real enough that people really get into it,” says Dr. Nguyen. “You can intubate it, hear if there’s an obstruction in its breathing and even see its pupils dilate.” During the simulation, engineers from the SIM centre can manipulate the mannequin’s breathing, heart rate and blood pressure, among other vital functions.

To date, eight simulations have already been completed, and two more have been scheduled before the Children’s moves to the Glen. “When developing these scenarios we try to create crisis situations where a patient is deteriorating quickly and needs help from a number of different people,” explains Dr. Nguyen. “Simulation is a safe environment where we can make mistakes and learn from them. There is no judgment of people’s competence or marking of their performance. This is all about learning, team building and improving communication. By practising regularly, together as a team, we are aiming to provide the highest quality and safest care to our patients.”

The simulations have also helped the OR team identify system-based issues in the OR. After every session, the team looks at what went well and what could be improved. The detected issues are then noted and brought to the attention of the Perioperative Committee.

The official term for this type of simulation is ‘in situ’ simulation which means a simulation that is physically integrated into the clinical environment. Dr. Farhan Bhanji is another of our clinical leaders who strongly believes in this type of simulation-based education; he is working hard to include all departments and services in these simulations throughout the Children’s. The OR model for in-situ simulation is a great example of what can be done when working collaboratively. “We are fortunate to have some outstanding young educators, like Drs. Fisher, Bank and Nguyen, who care about inter-professional education and are using it to improve patient care,” says Dr. Bhanji, simulation lead for the MCH. “Simulation-based education has the potential to improve outcomes and even save lives. I think we have a lot to look forward to as we move to the Glen.”
Practice makes perfect (cont’d)

“To date, every change we have suggested has been implemented,” says Dr. Nguyen. During a recent simulation, a mock code was called and the team noticed ICU staff would take a while to change out of their regular clothes and into scrubs. So the group came up with a solution. Why not leave emergency zippered jumpsuits right outside the doors to the OR? It’s a simple solution that could save valuable seconds in an emergency situation.

The working group is also planning to set up an official simulation committee for both adult and pediatric hospitals once the Glen site is open. Since many errors occur during transport, their ultimate goal is to develop a scenario where the patient must be moved between different departments throughout the Children’s. “We would like to make these simulations hospital-wide by setting up simultaneous simulations in the Emergency department, OR, and Intensive Care units,” says Dr. Nguyen. “We work together in real life, so it makes sense to practice together in simulation.”

Awards & Nominations

DESIJARDIN GROUP AWARDS $1 MILLION TO PEDIATRIC RESEARCH AT THE MCH

Desjardins Group has generously committed $1 million through its Desjardins Scholarships in Child Health to support a number of candidates over the next 10 years who will further their education and build expertise in their chosen field by working with leading pediatric researchers at the MCH. By providing these funds to the MCH Foundation, Desjardins is helping the Foundation continue to support the excellent care provided by the Montreal Children’s Hospital through the advancement of research and teaching in pediatric medicine.

The eight candidates selected as this year’s recipients are: 
Dr. Bahaaeldin AbdRabo, Kelly Benisty, Kyle Dickinson, Marie-Lyne Fillion, Dr. Nancy Lévesque, Dr. Joanna Merckx, Dr. Namrata Varma, and Laura Whidden.

NOMINATION

Dr. Saleem Razack has been appointed the Division Director of Pediatric Critical Care Medicine.
Getting to work after battling an hour of traffic and then spending 30 minutes looking for parking is never a good way to start the day. Luckily, there will be an additional 350 spaces for employees at the Glen than what’s currently available at on-site and off-site parking lots at the Royal Victoria Hospital, Montreal Children’s Hospital, and Montreal Chest Institute combined.

Are there really enough parking spaces for everyone?
Block F is reserved for employees and contains 1,270 spaces over eight stories, including 14 designated handicapped parking spaces located on the ground floor of the building, right next to the elevator. There are also 31 additional spaces reserved for motorcycles as well as indoor bike parking. The parking garage is a covered structure, which on top of saving money for snow removal, provides greater safety for users through better lighting, security cameras, panic buttons and elevators.

If I have a parking pass now, will I get one at the Glen site?
Parking spaces at the Glen will be assigned to existing permit holders at our legacy sites, and then allocated to accommodate new requests. Information regarding how to transfer your existing parking pass or apply for a new one will be circulated near the end of March or early April.

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I heard parking will be more expensive. Why?
Parking is a service not subsidized by the government. Since the Glen site’s parking structure is a self-financed construction, parking revenues will cover the investment and the maintenance of the infrastructure. As of May 24, the monthly rate for MCH employees will be $115 and $230 for physicians.

Moving forward, the MUHC Parking Services intends to continue to keep their rates as reasonable as possible for our patients, employees, physicians and users. Yearly, the MUHC undertakes a rigorous evaluation process by comparing rates in surrounding neighbourhoods and at other hospitals and public institutions in Montreal. As a result of these analyses, prices undergo an annual rate adjustment. Revised rates are approved by the Operations Committee.

The MUHC also encourages the use of alternative transportation to access the Glen site, which is one of the advantages of being located near the Vendome intermodal station.

How will it work with all these employees coming to and from work at the same time?
The parking structure has two entrances and two exit gates. Should congestion build up during exit “rush hour”, one of the entrance lanes can be reversed and used as an exit to ease the flow of traffic. This arrangement of exit/entrance gates, and the fact that staff start and end their working hours at different times of the day, should facilitate the flow of traffic in and out of the staff parking structure.

How do you access the parking lot?
The employee parking lot at the Glen site, accessible via Saint-Jacques St. or Decarie Blvd., is situated right next to the hospital and connects to the Research Institute and hospital via a covered, elevated walkway. A navigational tool indicates the number of vacant spaces per level. Staff will be able to park and walk into the hospital via Block E (Research Institute).

It takes approximately 5 minutes to walk from the parking elevators in Block F to the Montreal Children’s Hospital main entrance (located on the opposite end of the Glen site).

What about visitor parking?
The Glen site visitor parking lot (Block G) is accessible via Décarie Blvd and located directly underneath the main plaza. Reserved for patients, families and physicians, it contains 1,582 spaces (including 28 handicapped spaces) as well as a navigational system that directs visitors to vacant spaces by identifying the specific level, zone and lane. It is directly connected to the hospital via elevators and stairs, so there is no need for visitors to walk outside to access the facilities. Parking will cost $25 for one entrance/exit within 24 hours. As is currently the case, patients and families, in specified circumstances, can request a 2-week or 4-week pass at a discounted rate.

The corridor to the employee parking lot in Block F.
Volunteers

In our current facilities at the Montreal Children’s Hospital, volunteers who dedicate their time to helping our staff members, patients and families must sign in at a designated area in the hallway of the 5th floor C-wing. But as we look ahead to our upcoming move, they’ll enjoy a much larger, more private space, equipped with a seating area and a kitchenette. The new location is close to both the Social Service and Child Life departments, located directly off the new hospital’s atrium.

Continued >>>
Check out the brand new waiting area in our new hospital at the Glen site. With high ceilings, an entire wall of windows to bring the natural light in, an adjoining terrace to enjoy in the summer months and child-friendly furniture and play kiosks, what’s not to love?

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AUDIOLOGY

Located on the 1st floor of the A block, right near the Otolaryngology clinic, the design of the Audiology department will allow patients to move easily between the two areas through a connecting corridor near the back of the departments. The new space will also include a cozier waiting room and a greater number of screening and testing rooms, a total of 5 rooms compared to 3 in our current facilities.

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Answers to frequently asked questions about the Glen

**WHAT TYPE OF APPLIANCES WILL BE AVAILABLE IN THE STAFF LOUNGES AND KITCHENETTES AT THE NEW HOSPITAL?**

There are a total of 24 staff lounges and kitchenettes throughout the Montreal Children’s Hospital buildings at the new site, with a larger number of them located in Block B. All the areas designated as staff lounges include kitchenettes but there are also some stand-alone facilities which are just kitchenettes.

Most of these staff lounges are equipped with a full range of appliances to accommodate employees who want to bring food to work. Staff will have access to a fridge, microwave, toaster and coffee machine. The use of small appliances in individual offices and workstations will not be permitted; one key reason for this is that small appliances consume a significant amount of energy. The kitchenette facilities will contribute to energy efficiencies in terms of both electricity usage and expense.

**WILL THERE BE ENOUGH CONFERENCE ROOMS FOR EVERYBODY? AND HOW DO YOU BOOK THEM?**

Our new health centre at the Glen site has more than 140 conference rooms and teaching spaces of varying sizes, including five large meeting rooms capable of accommodating 60 to 100 people. As well, approximately 70 per cent of the rooms are equipped with videoconferencing capabilities.

You will soon be able to reserve conference rooms at the Glen using the new Online Room Booking System (ORBS). The online booking system has been designed to facilitate the shared approach being implemented at the Glen site. Although meeting rooms are located on each floor and unit, they are expected to be shared by the MUHC community at large.

Initially, all designated meeting rooms will be included on the room booking system to ensure access for everyone. Room bookings will be monitored by Multimedia attentively for the first six to 12 months in order to determine patterns of use, which may result in some rooms being removed from the booking system.

The Research Institute at the Glen site will be responsible for managing their own conference rooms. These rooms will therefore not be on ORBS, with the only exception being the Amphitheatre and the rooms located on E 4 and 5, which are within the lab area.

The ORBS system should be up and running by March, at which time the policies and procedures will be posted on the Intranet and staff will be provided with access to book meeting facilities and equipment. •
From foreign to familiar
What employees can expect in terms of training for the Glen

It takes a while to get used to a new work environment, especially if you’re directionally challenged. Where’s the bathroom? How do I get to the elevators? Or, more important, where’s the crash cart? To make sure staff at the McGill University Health Centre are prepared to deliver safe care in their new space, a number of training initiatives are currently underway or in the process of being organized.

General Training and Orientation
Everyone moving to the Glen site, including physicians and residents, will receive this training between March 30 and April 15 (early clinical activators have already completed the training). The General Training and Orientation Day at the Glen site encompasses a 2.5-hour information session, a 1-hour tour of the Glen site, and 3.5 hours of Common Clinical Practical Training. The main goal of this session is to orient and train participants on what’s new in terms of services at the Glen.

At the Common Clinical Practical session, participants will learn about infection control, patient rooms, pneumatic tube system, and the nurse call system/code blue. This session is mandatory and most sessions will take place during the day. However, there are some training sessions on evenings and Saturdays to accommodate different work schedules. Only managers can register their employees on the Learning Management System (LMS) and will advise staff of the date/time of the training. Everyone attending the training day will be paid as a work day and parking is free.

Simulations
A number of different simulations are also in the process of being organized. The first of these will be to test patient flow into and across the Montreal Children’s Hospital at the Glen site. A table-top exercise will take place in early March, followed by simulations at the Glen site towards the end of March. Participants from many departments will take part in this training exercise in order to test all aspects of patient flow.

Unit-specific training
In order to help staff feel comfortable and familiar with their department space, unit-specific training will also be organized in the coming months. The goal is to have MCH employees trained in their respective units in order to function as an integrated team and deliver safe patient care as of May 24, 2015. Training will be delivered in several phases between February and June 2015. Staff will be informed shortly about how these training sessions will be carried out.

Research Institute at the Glen
OPENING DAY: FEBRUARY 26, 2015
FLOORS: 5
SQ. FT.: 400,000
WORKSTATIONS: 864

A new era begins as researchers from the Montreal Children’s Hospital will now work side by side with colleagues from the Royal Victoria, Montreal General and Montreal Chest hospitals.