Celebrating our volunteers — Page 4

Also in this issue:
Waiting for a new kidney — Page 2
A paperless future at the new MCH — Page 10
Sixteen-year-old Amayrani remembers vividly the first time she came to the Montreal Children’s Hospital (MCH). She was at a family birthday party when her legs suddenly started to swell. It wasn’t long before her entire body was visibly swollen too. Her mother took her straight to the MCH Emergency Department. “The nurse examined me right away and after taking my blood pressure, she said she’d be right back,” says Amayrani. The nurse returned soon after with several doctors.

The nephrology team at the Children’s diagnosed Amayrani’s condition the same day. She had rapidly progressive glomerulonephritis (RPGN), which can be described as an inflammation of the kidneys that results in severe renal (kidney) failure over a short period of time. The kidney injury can be caused by a process which affects the small blood vessels in particular, which was the case with Amayrani. The disease, called vasculitis, leads to severe damage and widespread scarring of the glomeruli (filters) and the kidneys as a whole. Amayrani had a kidney biopsy which showed that the disease had already progressed so much she needed dialysis immediately.

Waiting for a new kidney

A teenage girl dreams about the transplant that will change her life

— By Maureen McCarthy

Amayrani receives dialysis at the Children’s three times a week.
Amayrani was admitted to the hospital right away and started three consecutive days of hemodialysis, a process that filters the blood to eliminate waste. She was hospitalized for one month before going home; she continues to come to the hospital for dialysis three times a week for five to six hours, which she’ll continue until the day she receives a kidney transplant.

At the end of each dialysis treatment, Amayrani is usually very tired and has a headache. She has to be careful what she eats, and she’s only allowed 800 ml of liquids a day which includes soups and certain fruits. Some of her favourite foods like tomatoes and potatoes are now off limits. She’s also had to cut back on sports including swimming, which she loves.

Amayrani came very close to receiving her long-awaited transplant in January when a donor kidney became available. Unfortunately she was fighting a sinus infection which meant her healthcare team couldn’t go ahead with the transplant. “You always have to be ready for the possibility of a transplant,” she says, “and be as healthy as possible beforehand.” Despite having to wait a little longer for her transplant, she is philosophical about what happened. “Everything happens for a reason,” she says. “I’ll get another chance.”

While Amayrani accepts that her week always includes three days at the Children’s, she sometimes finds it difficult not having a typical teenager’s schedule. She still attends school and makes up for lost time at lunch and after class. “When I’m at school, I don’t think that much about the hospital,” she says, “but when I have to miss something exciting at school because of dialysis the next day—that’s when it’s hard.”

A positive outlook and great support from her family and her boyfriend, Eduardo—who sometimes spends afternoons at the hospital with her—are the things that keep her going.

Amayrani hopes to become an interpreter when she’s older. She speaks Spanish, French and English, and has her sights set on learning Italian next. She’s also looking forward to getting back to the pool once she receives her new kidney. “Going swimming again,” she says with a smile. “Yes, that’s something I’d really like to do.”
Volunteers make a real difference in the lives of our patients, families and staff at the Montreal Children's Hospital. Earlier this month, the MCH celebrated National Volunteer Week and Chez nous is also celebrating by highlighting four of our special volunteers.

France Lespérance is a very active retiree. She spends her free time line dancing, walking, reading, working out and doing Zumba, but she gets the most joy out of volunteering at the Montreal Children’s Hospital. For the last three years, France has spent Friday mornings on 6C1, 6C2 and 7C. She starts the day by going from room to room to see if any patients or families are in need of some company.

As a mother of three boys and a grandmother of two, France says children are her life. “In 2004, my granddaughter was hospitalized right after birth,” she says. “She underwent many platelet transfusions and it was in that moment that I decided to volunteer once I retired.” She says that volunteering on Fridays is the perfect way to start her weekend and the best part of her day is seeing patients go home. She admits that some days are hard, especially when a child is not doing well, but she tries to be there for patients and families.

“Sometimes parents need a shoulder to cry on, but I am always amazed by their positivity,” she says. “I have been very fortunate in my life and it’s important for me to give back. Volunteering brings me immense happiness.”

Continued >>>

France Lespérance
“Smile though your heart is aching, smile even though it’s breaking, when there are clouds in the sky, you’ll get by,” sings Danielle Traversy as she rocks a newborn baby to sleep. “Grand-maman tendresse,” as she calls herself, has been volunteering at the Children’s for a year and a half. She spends three hours every Wednesday after work on 6C1 and 6C2. “I love singing the song ‘Smile,’” she says. “For some reason the babies really connect to that song.” At the beginning of every shift, Danielle looks through a list of all the patients who are either alone or whose parents haven’t left their side and also passes by the nursing station for suggestions on which babies need to be taken care of. She tries to persuade the parents to go for a walk or to grab a cup of coffee while she looks after their child.

“I’m inspired every day by these patients and by other volunteers,” she says. “Seeing sick children really makes you appreciate your health and everything in your life. I instantly felt at home the moment I walked through the doors of the Children’s, and I am so grateful for this experience. It makes me want to give back even more to these patients.”

As an Air Force medic in the Vermont Air National Guard, Donald Gilbert is used to spending time in remote, dangerous parts of the world. But during a recent deployment to Iraq, Donald was faced with a new challenge: working with children. “A lot of kids were coming to the trauma centre where I was stationed,” he says. “But because I was used to working with adults, I had to develop a completely different approach for children.” After his experience abroad, Donald decided to start volunteering at the Montreal Children’s Hospital in order to increase his exposure to working with sick children. During his downtime as a volunteer firefighter in Kahnawake, Donald tries to spend at least three hours a week on 6C1, 6C2 and the NICU. “I think I get a lot more out of volunteering than the patients do,” he admits with a smile. “I really enjoy being around babies and toddlers, because I have so much fun making them laugh!” Donald also loves the challenge of trying to calm down a crying infant or restless toddler and as a father of 22-year-old triplets, he definitely has the experience. “At this point, I can’t wait to retire so that I can spend even more time volunteering at the hospital!”

Continued >>>
Andrew Sharp always knew he wanted to volunteer at the Montreal Children’s Hospital. “My own children were hospitalized here a couple of times and I was interested in volunteering, but didn’t have the time,” he says. “So I decided to sign up after retiring.”

For the last five months, Andrew has been spending a few hours on Mondays and Wednesdays with two patients in particular. On Monday morning, he keeps a three-year-old entertained in Dialysis and on Wednesday afternoon, he heads up to 7C1 to play with Loïc.

“Mario, the little boy in dialysis,” he says. “He is so lively and he really loves music. He’s got a great sense of rhythm and sometimes he starts dancing by just listening to the sound of the dialysis machines!”

More recently Andrew has also been spending time with Loïc, and the two of them enjoy having sword fights in the hallway. “It’s all about developing friendships with these children and taking the workload off the staff. The first time I met Mario he was afraid of me, but now he gets excited whenever I walk into the room because he knows I’m there to play with him.” Andrew also credits the dialysis nurses for helping him get to know Mario better and for giving him hints on what he likes and doesn’t like. “I have always loved being around children. I love making them laugh and seeing them develop so quickly,” he says. “It’s been good training for if or when I become a grandfather!”

Thank you to all our volunteers (cont’d)
Kelleigh Coombs and her five-year-old daughter Madison have been inside the operating room of the Montreal Children’s Hospital 13 times in the last two years. Madison has a large birthmark, called a Port-wine stain, over her right temple. The purple mark starts at her eye and spreads out to her hairline. Dermatologists in their hometown of Winnipeg, Manitoba, do not offer the treatment needed to remove the birthmark so they referred the family to the Children’s.

Every couple of months the family flies to Montreal, where Madison receives anesthesia and Dr. Bruce Williams performs low-level laser treatment on her face – a long and slow process due to the sensitivity of the region. Unfortunately, the regular OR visits began to take their toll on Madison. Her anxiety became so pronounced that she would refuse to get on the plane because she knew that a plane meant Montreal, and Montreal meant the hospital. “Once we were here, we had problems getting her into the OR,” says Kelleigh. “She suffered from extreme separation anxiety.”

Parental Presence at Induction

Then a couple of months later, everything changed. Sabrina Drudi and Lise Gagnon, certified Child Life specialists working in the perioperative setting, were in the process of implementing a new practice at the Children’s called Parental Presence at Induction (PPI). The first of its kind in Quebec, PPI allows a parent to be by their child’s side while they undergo anesthesia through mask induction. “Research shows that having a calm parent present during this process can help a child cope better,” says Sabrina. “And thanks to the collaboration and support from the Anesthesia department, MCH Foundation, PPI committee, OR staff and Family Advisory Forum we can now make this happen.” Dr. Nathalie Buu, an anesthesiologist at the MCH, says this team approach is key in the development and execution of the program. In fact, one of the Foundation’s major donors recognized the importance of this innovative program and has generously committed to funding it for the next three years.

Not for everybody

Children know when their parents feel overwhelmed; therefore it is important to choose a parent who can remain calm during the process. To help with the approval process, an interdisciplinary protocol was developed with specific criteria for participating in PPI. Ultimately, the parent’s role is to provide emotional support to their child, especially if the patient must undergo recurring inductions, as in Madison’s case. In order for PPI to be successful, both the child and parent need to be well-prepared. Child Life specialists tailor each teaching session depending on the patient’s age, developmental stage, level of

Continued >>>
The Association of Medical Microbiology and Infectious Disease Canada recently announced that Dr. Caroline Quach, pediatric infectious disease specialist and medical microbiologist at the Montreal Children's Hospital, will assume the role of President Elect of the association from 2014 to 2016, followed by a two-year mandate as President from 2016 to 2018.

Dr. Lily HP Nguyen, from the division of Otolaryngology—Head and Neck Surgery, was awarded the 2014 Canadian Association of Medical Education (CAME) Certificate of Merit. The aim of this award is to promote medical education in Canadian medical schools and to recognize and reward faculty’s commitment to medical education. The award will be presented at the Canadian Conference on Medical Education (CCME) in Ottawa on April 27, 2014.

Side by side (cont’d)

anxiety and prior medical experiences. They also meet with the parent prior to the day of surgery for their personalized teaching session, which includes a short video.

How it works
The video helps prepare parents by answering questions like: what do I wear in the OR, where do I stand, and when do I leave? It also addresses potential reactions to anesthesia, including the excitement phase. “This phase can be scary for parents who are not prepared for it,” says Sabrina. Prior to the deeper stage of anesthesia, most children will experience the excitement phase. The patient may move their arms or legs around, or roll and blink their eyes as they go to sleep. Their breathing may also change, but these are all normal and expected reactions to anesthesia. “We address all of these reactions during our one-on-one session and we also help the family establish a coping plan for induction,” says Lise. In Dr. Buu’s opinion, preparing parents and children for PPI plays a crucial part in the overall success of the family’s surgical experience. “The work going on behind the scenes by Child Life is unbelievable and it makes all the difference,” says Dr. Buu.

Since being introduced to the PPI program, Kelleigh has noticed a complete change in her daughter. “Madison now looks forward to her visits to Montreal,” says Kelleigh. “She not only knows what to expect upon entering the operating room but more importantly, she knows that I will be by her side.”

Awards and nominations

The Association of Medical Microbiology and Infectious Disease Canada recently announced that Dr. Caroline Quach, pediatric infectious disease specialist and medical microbiologist at the Montreal Children's Hospital, will assume the role of President Elect of the association from 2014 to 2016, followed by a two-year mandate as President from 2016 to 2018.

In other news

The 2012-2013 Annual Report of the Research Institute of the MUHC at the Montreal Children’s Hospital is now available online at www.thechildren.com/research. In this issue, the latest work of researchers and trainees at the Montreal Children’s Hospital (MCH) is presented under the theme of “Child Health Research: Science That Connects.” Your feedback on this report is welcome. Please send comments to Alison Burch at alison.burch@muhc.mcgill.ca.
An intensive care unit is a bustling place, to say the least. Because patients hospitalized in critical care units require close observation and treatment, clear and frequent communication is key. Yet with so many different professionals working within the team, ensuring effective communication can be challenging. Thanks to a new app called V-Sign Flow, however, this challenge is being addressed with a unique solution.

Developed by the McGill University Health Centre (MUHC) Information Systems (IS) team, the V-Sign Flow project has been used by medical staff in the Pediatric Intensive Care Unit (PICU) since June 2013, and has more recently been slowly adopted by the medical team in the Neonatal Intensive Care Unit (NICU) as well. The app builds on technology that was initially introduced to keep track of patients’ vital signs. Using staff members’ personal smart phones, it keeps a record of short text messages about a specific patient’s status, treatment, test results or observations and recommendations that can be viewed securely and confidentially by all members of the team. A combination of ‘tags’ or filters based on keywords can also be applied to inform team members immediately of critical information regarding changes in a patient’s condition.

The result is that all participating team members can view the same information in real time. “It’s a wonderful way of having all team members on the same page,” says Dr. Saleem Razack, pediatric intensivist, who led the adoption of the project in the PICU with his colleague, Dr. Samara Zavalkoff. “From a patient care angle, it also provides much more timely access to information. I can view information remotely from home, and even call up a medication list for a given patient during rounds in the morning.”

The use of the app is currently limited to medical staff at the moment, but nursing has expressed an interest in participating, and the app could eventually be made accessible to a variety of health professionals in a multidisciplinary team.

Despite the fact that medical teams in the NICU have only just begun experimenting with the technology the team hopes to be able to tailor the technology to the unit’s needs. Dr. Thérèse Perreault, Director of Newborn Medicine, who has led the adoption of the project along with her colleague Philippe Lamer, Neonatal Nurse Practitioner, says this will be important, given that the NICU will eventually accommodate a much larger number of patients in their new facilities at the Glen.

In addressing some of the challenges, Drs. Perreault and Razack say that while the technology shows great potential for clarity, it is ultimately user-dependent and therefore requires a commitment on the part of its users to update information frequently. “Despite the challenges, I think the payoff is great. I don’t think the technology will ever replace rounds or face-to-face conversations when they are needed, but it will definitely save time and have a positive impact on the quality of care we can deliver,” says Dr. Perreault.

Learn more about the V-Sign project by visiting www.thechildren.com/VSign.
The move to the new Montreal Children’s Hospital is closing in on the ‘one year and counting’ mark and the hospital’s Medical Genetics group is already well into preparation mode for the transition to the new site. According to Lola Cartier, Clinical Manager of the Department of Medical Genetics-MUHC, the team really started to look at things differently when they learned that the Glen will be a paperless environment.

Lola meets regularly with the genetic counsellors and administrative staff on her team, who work at three MUHC sites (the Montreal General, Royal Victoria and Montreal Children’s hospitals). For many months now, the move has been a recurring item at the top of their meeting agenda. One of their most recent achievements has been developing new methods for patient records.

The Medical Genetics team has traditionally kept parallel charts for their patients. In an effort to address their present and future needs, Lola asked the team to create a working committee to develop a procedure to phase out charts and to ensure that the documents are rapidly accessible through OACIS. “Our patient files can be quite extensive,” she says, “and we refer to these charts in the process of consulting with patients.” The committee’s first step was to form a consensus on their goals for the project. They then talked about which documents should be kept permanently in the patient’s electronic hospital record. The committee set a deadline of April 1 this year to no longer produce parallel patient charts for their own department records. They are now implementing this, which will give them ample time to perfect the process before moving to the new hospital.

Using O-Word for greater efficiencies

As early as 2009, the team members started moving towards thinking “electronically” by creating an H:drive for the

Continued >>>
department, which is used to store call/clinic schedules, procedures, protocols and more. An added benefit was being able to create and save more templates for many aspects of their work which has improved efficiencies all around. More recently, the introduction of O-Word in OACIS has let them move to the next level. The genetic counsellors were recently trained on O-Word and are now using it for their chart notes and will soon be using it for consultation reports.

The Medical Genetics team also needed to look back in time to make decisions about storing filing cabinets full of recent patient parallel charts which are still on site. “Eventually the solution became clear,” says Lola. “We decided to pull key papers from each file and transfer them permanently to Medical Records. Some of our genetic counsellors, with the help of a volunteer, have agreed to go through the files, which is really helping us progress quickly on this side of the project.” The documents that are being retained include genetic test results, pedigrees (drawings of a patient’s family tree), and consultation letters. “We’re making sure these are accessible to any healthcare professional who may need to see them in the future.”

**Special bar codes solve unique problem**

Maintaining electronic records of the pedigree drawing posed a challenge for the Medical Genetics team. The pedigree is similar to a family tree, and a genetic counsellor prepares this while consulting with a patient, and then updates it during subsequent visits as needed. Printing these documents however, will not be possible at the new hospital. “We met with the OACIS team and Medical Records to see what we could do to facilitate the process,” says Lola. The solution was to create special bar codes and give the Medical Genetics staff special permission to print the pedigree drawing, so they can update and resubmit them to Medical Records for scanning.

Lola says that the move to the Glen has been the catalyst to tackle these projects, but it has also been a great opportunity for the team to revisit their document processes and rethink how they use, save and store their files. “We’re really thinking electronically now and being proactive about not saving paper,” she says. “I think we’re going to be in good shape come moving day next year.”

**What to toss, what to keep?**

*It’s time for a Clean Sweep!*

With little more than a year to go before our move to the new MCH, we all have to start thinking about re-organizing and cleaning up our administrative documents. The April Administrative Document Clean Sweep, available on the Intranet under ‘MUHC 2015’, has important information to help you get started. You’ll find other helpful documents in this section too.

The Document Management team is available to guide you through the process. You can contact Anna Colicchio (anna.colicchio@muhc.mcgill.ca or 42733) for any questions or help with details such as unlocking the grey recycling bins for quicker disposal of papers, or notifying her of shipments destined for storage at Iron Mountain.
You asked, we answered!

Answers to frequently asked questions about the Glen

What’s the new address of the Glen?
The new address is 1001 Boul. Décarie, Montréal, Québec, H4A 3J1.

How many cafeterias are going to be at the Glen? Will everyone have access to them, or will there be some reserved for the patients (and their families) and some for the staff?

There will be one cafeteria for staff, families and patients with a capacity of 400 people. It will be located in Blocks C and D. During warmer months, an outdoor terrace will also be open. The terrace can seat 150 people and is adjacent to the cafeteria. However, this area does not include commercial spaces. Commercial spaces, including coffee shops and restaurants, will be located along the Galleria and Atrium on S1 and RC. There will be two retail pharmacy locations and several other retail stores, including a bookstore, optician, dry cleaners, hair salon and florist*. Several vending machines will be distributed throughout the building as well.

*NOTE: our private partner, GISM, is responsible for leasing the commercial spaces. No retailers have yet been confirmed;

The kitchen is coming along nicely! Food services is located in D-S2.

these are just examples of the types of businesses that will be at the Glen site.

For more information on the Glen, please visit the MUHC 2015 section on our Intranet page.

Move date

It’s official! The MCH will be moving from Tuesday, May 12, to Saturday, May 23, 2015, and patients will be transferred on Sunday, May 24, 2015.

<table>
<thead>
<tr>
<th>S</th>
<th>M</th>
<th>T</th>
<th>W</th>
<th>T</th>
<th>F</th>
<th>S</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td>11</td>
<td>12</td>
<td>13</td>
<td>14</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td>17</td>
<td>18</td>
<td>19</td>
<td>20</td>
<td>21</td>
<td>22</td>
<td>23</td>
</tr>
<tr>
<td>24</td>
<td>25</td>
<td>26</td>
<td>27</td>
<td>28</td>
<td>29</td>
<td>30</td>
</tr>
<tr>
<td>31</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Moving days
Patient moves
Stat holiday