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Published by Public Relations
and Communications

www.thechildren.com

MCH EMPLOYEE NEWSLETTER

December 17, 2012

News

Catching up with our former patients

By Maureen McCarthy

For the many MCH staff who see their patients for weeks, months, or even years at a time, there inevitably comes a day when the child no longer needs to come to the MCH. Sometimes it's because they've finished their treatments, other times it's because they reach the age of 18 and move on to one of the adult sites. For many of these teens, it also means moving on to CEGEP, university, or their first job. Dr. Jean-Pierre Farmer recently had the pleasure of catching up with not one, but three former patients who are now in their late teens and early 20s. Read on to see what they're up to now.

Jean-Michel Laforest-Lussier



Anita Raj



Ali Ammar



Photo: Daniel Héon



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Following in Dr. Farmer's footsteps

Anita Raj's parents celebrated New Year's Eve, 1993, by welcoming Anita into the world. She was a healthy child and reached many milestones such as walking and talking early on.

When Anita was six years old, she started to experience severe headaches and vomiting. Her parents took her to Emergency at the Children's, and after undergoing a number of tests, Anita was diagnosed with a craniopharyngioma, a type of brain tumour. The news came as a shock to the family, and although everything happened so fast, they were relieved to see the MCH team respond so quickly. Anita was admitted, and immediately had a shunt inserted in her brain to drain the fluid. Four days later, she spent 11 hours in the operating room to have her tumour removed. Her recovery was lengthy and very difficult at times but eventually she was able to return to school.

What children experience after a craniopharyngioma can vary greatly. Some lose their sight, others gain weight, and still others have trouble with their hypothalamus, which controls many functions of the human body. Anita's surgery left her with only about 10 per cent of her pituitary gland, a fact that has meant taking five different synthetic hormones, which she'll do for the rest of her life. Following her surgery, she had regular check-ups and an MRI every three months. When she was eight years old, Dr. Farmer discovered a regrowth of the tumour. This time stereotactic external beam radiation therapy was recommended—and it was only available at the Montreal General Hospital. "I was the only child being treated at the MGH," says Anita. "I'd go for my treatments every morning and then be back at school in the afternoon." Unfortunately, there was still one more chapter to come in her care at the MCH: in 2008, Anita had another surgery to replace the shunt. She is now followed by physicians at the MNH and RVH.

Despite the reality of potential problems with memory and concentration, Anita did very well in school. She received many awards throughout high school and CEGEP including the Governor General's Academic Medal upon graduating high school, and gold medals at the Bell Montreal Regional Science Fair for two experimental projects on brain tumour research. She also loves to teach with interests as diverse as math and origami. And she even found time to volunteer at the Children's, playing with kids as young as she was the first time she was admitted. She has also volunteered with the MCH Foundation over the past few years, helping out at many events and raising money for the Foundation at her CEGEP.



Dr. Jean-Pierre Farmer with Jean-Michel

Photo: Daniel Héon

In June, Anita was accepted and offered a scholarship to the Med-P program in McGill University's Faculty of Medicine, news that she couldn't wait to share with Dr. Farmer. "I have been so inspired by the people who treated me at the Children's," she says. "They've been such a great influence!" Anita already knows that she wants to pursue a career in pediatrics since she wants to help children just like her. No doubt she'll bring a very special perspective to her future patients.

At the head of the class

Jean-Michel Laforest-Lussier was still a baby when he had his first surgery to receive a shunt for hydrocephalus. By the time he was six years old, he was having multiple refractory seizures every day despite taking multiple medications. He underwent a left (language dominant) hemispherectomy to cut the signal from the left side of his brain in an attempt to stop the seizures he had been experiencing. It was a risky procedure, and the surgery lasted 13 hours.

For some children, having this type of surgery could have meant significant changes in their language abilities but Jean-Michel proved that where there's a will, there's a way. His memories of the hemispherotomy surgery are not vivid—what he remembers more are the many hospital visits that came in the months and years after that. Dr. Farmer followed Jean-Michel in clinic every six months. Jean-Michel also made frequent visits to the neurology clinic, ENT, ophthalmology, occupational therapy and physiotherapy, as well as the Shriners and the Mackay Centre. He has not had a seizure since the day of his surgery and his language abilities and global development have continued to progress.

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There were other surgeries for Jean-Michel too: one for an ENT procedure, the other on his leg. “You could say I was a V.I.P. in the operating room!” he says with a laugh. Despite his many appointments, he didn’t miss much school over the years since his family always made an effort to plan his hospital visits around his school’s ped days. Jean-Michel is now 19 years old and he’s hoping there will be a lot more school in his future—especially when he moves to the front of the class. He’s currently studying Humanities at CÉGEP André Laurendeau and his plan is to become a high school teacher in French or History. “I’m a good communicator,” he says, “I really like talking to people and working with children so it seems like the ideal choice for me.”

Given that Jean-Michel is weak on his right side, he experiences difficulty doing certain things. He doesn’t have the same ability in his right hand as he does in his left hand which can make it hard to do everyday tasks like chopping vegetables. “But I don’t constantly think about my handicap,” he says. “I don’t want to live in the past so I move forward. I find ways to do new things.” Jean-Michel also says his parents have really helped him. “They continue to be there for me,” he says.

Jean-Michel’s goal for the future is to become more independent and he’d like to one day have his own place and start a family. “One day at a time,” he says. “We’ll see what happens when the time comes.”

A rising star

Ali Ammar was very young when he first came to the Children’s. He and his mother had recently arrived in Canada. “She was in her early 20s at the time,” says Ali. “She put a lot of trust in the doctors we met, and lucky for us everything turned out really well.” Ali first visited the Shriners, and it was there that he was referred to Dr. Farmer.

Ali suffered from a form of cerebral palsy and Dr. Farmer made the decision to perform a selective dorsal rhizotomy to treat spasticity. “I think I was one of Dr. Farmer’s first patients to have this surgery,” says Ali. “It’s maybe a bit silly to say this but I really think Dr. Farmer and his team changed my life. My life would have been completely different otherwise.”

After his surgery, Ali had to do many hours of physiotherapy and a lot of occupational therapy. He still trains to this day. “When I was young, the training was very difficult,” he says. “Today, I dedicate an hour a day to it. Other than skating and skiing, I can pretty much do anything.”



Dr. Jean-Pierre Farmer with Anita and Ali

Photo: Daniel Héon

“There were moments when I was younger that it was difficult,” says Ali. “When I was very young, it was hard, but growing up and getting past my adolescent years, it’s much better now. I use to tell myself as much as every good thing comes to an end, every ‘not so good’ thing comes to an end too.”

When Ali was 20 years old, he was offered the opportunity of a lifetime. While studying psychology at CEGEP he received an email from a staff member, the person responsible for helping handicapped students at the school. The email said that a Montreal film director was looking for a young man, preferably with a handicap, to appear in a feature-length film. Ali went for an audition. One week later, he was chosen for the role. “I was completely shocked,” he says. “I met with the director again and told him my story and what it’s really like to have a handicap. He was touched by this.”

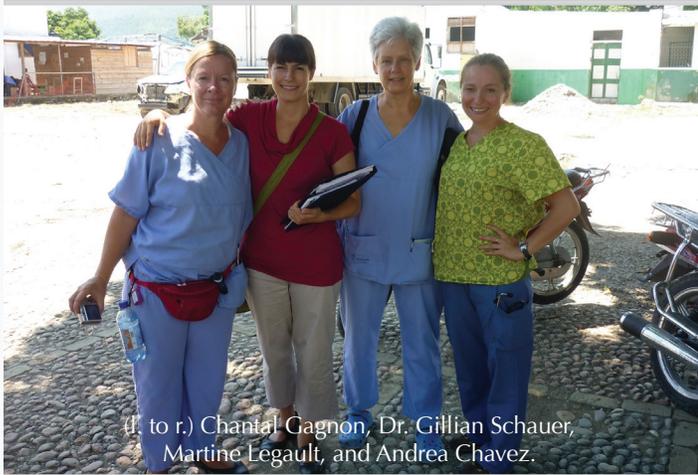
In September 2010 *Roméo onze* began production. The film was a critical success and eventually played at 20 film festivals and received six international prizes. “I was really well directed in the film, and I gained a lot of confidence thanks to the experience,” says Ali. He has thought about the possibility of a career as an actor, but has also given a lot of thought to work that will allow him to help people like himself. “I think we live to do things like this,” he says. “It’s important to give. Just to see a child smile, there’s nothing better than that.”

Ali is back at CEGEP now with plans to finish his degree. This past summer, he decided to take a Spanish course just for fun. “You know, just in case I have the chance to replace Antonio Banderas one day,” he laughs.

Dr. Farmer is pleased to have helped make a difference in the lives of Anita, Ali and Jean-Michel but attributes their respective successes to their courage and determination as well as that of their supportive families.

MCH Global Child Health initiative enters new era

By Suzanne Shugar



(l. to r.) Chantal Gagnon, Dr. Gillian Schauer, Martine Legault, and Andrea Chavez.



Temporary hospital facility, Jacmel, Haiti.

Photo: Courtesy of Dr. Schauer

The Montreal Children's Hospital of the MUHC is intensifying its longstanding tradition to help sick children around the world. Over the years, countless MCH health care professionals have volunteered in developing countries and remote regions in Quebec, but their humanitarian efforts were not part of a formal program. This is about to change thanks to the leadership of three devoted physicians.

"The interest in having a structured global child health program goes back many years. There was a long interval where nothing much was happening in this regard so we started a global child health initiative a few years ago. We formed a steering committee, including pediatric residents and nurses, set objectives and invited speakers, and now it's the beginnings of a program," says Dr. Harold Rich, the Associate Director of General Pediatric In-Patient Wards.

Dr. Rich co-directs the initiative with Dr. Martin Bitzan, the Director of Pediatric Nephrology. They will apply for official program status with the assistance of staff pediatrician, Dr. Gillian Schauer, who recently joined the leadership team.

Dr. Schauer is ideally suited for her new role. She has been actively involved in global health and human rights advocacy since medical school and she has travelled to several sub-Saharan countries as well as post-earthquake Haiti in 2010. She also has a Master's Degree in Public Health.

"The initiative started to take shape last year when we got involved in a major project. Thanks to the efforts of Stéphane Timothée (Associate Director at the MUHC) and Dr. Jean-Martin Laberge (pediatric surgeon at the MCH); we became equal partners with Hôpital Ste. Justine to assist in the reconstruction of Hôpital Saint-Michel in Jacmel, Haiti. It was destroyed by the devastating earthquake in

2010 and temporary structures have since been built at the site. We met with Ste. Justine a few times, and then we asked Dr. Schauer to spearhead the project for us," says Dr. Bitzan.

Dr. Schauer traveled to Jacmel in October to assess the training needs of health care personnel at the makeshift hospital and five community health centres in the region. She subsequently wrote an in-depth report for the Canadian Red Cross (CRC). "I travelled to Haiti in the company of three nurses from Hôpital Sainte-Justine: Martine Legault, Andrea Chavez and Chantal Gagnon. They were asked to submit a separate report but we worked together as a team to gather information."

"Our initiative has really taken off since Gillian got back from her fact-finding mission in Haiti. We are also pleased that she has global health as part of her work arrangement at the hospital. She is the very first person to have this status at the MCH," adds Dr. Rich.

The CRC, in collaboration with the Haitian Red Cross and the Haitian Ministry of Health in the Sud-Est Department, will build community health centres and part of the new Hôpital Saint-Michel. They will also put measures into place to allow for better maternity and pediatric care. "The CRC has enlisted the participation of several partners, including the Hôpital Sainte-Justine and the Montreal Children's Hospital. The first of three construction phases starts early next year and the training of personnel is a five-year plan that will involve our participation. The Japan International Cooperation Agency is also involved in the construction," explains Dr. Schauer.

Haiti is the poorest country in the Western hemisphere and the majority of its people cannot afford health care. Years of political instability, natural disasters and a drought of doctors have crippled the medical system.

“There is no better excess in the world than the excess of gratitude.”

Jean de La Bruyère, Les caractères, Du cœur (1688).

The holiday season is a time to celebrate but also to take stock and express our gratitude. Throughout the year you have successfully overcome many challenges, and I want to thank you on behalf of the entire management team. Without each and every one of you, it would not be possible to fulfill our mission. So I hope you will take a moment to give yourselves a pat on the back. At the same time, I would ask you to consider the people you meet at the hospital during your workday, your colleagues, who toil in the shadows but without whom our patients and their families would not benefit from superior health care. Remember to also show your appreciation to the children and their parents—by taking an active part in the care of their loved one, they teach us all vital life lessons. And don't forget those who have helped you accomplish your own goals. Last but not least, it is important to recognize our partners,



Photo: Daniel Héon

in particular the Montreal Children's Hospital Foundation; their funding enables us to obtain the equipment and devices we need to carry out our work.

Recently, we have begun doing rounds of the care units early in the morning, before things get too busy. This has given you the opportunity

to tell us what works, what could be improved, and what might be replaced by more efficient, effective and safer alternatives. We hope to continue these fruitful visits.

We are on the cusp of a very exciting year! Let us not lose sight of our goal: a brand new hospital that will provide our patients and their families with better, more accessible and secure health care—and all of us with a comfortable and gratifying work environment. It may be a dream today, but it will be our reality in less than two years.

I wish you all a well-earned rest and a year filled with health, happiness, enthusiasm, and everyday pleasures.

Together, we are building excellence!

Dr. Micheline Ste-Marie

Interim Associate Executive Director
MCH

Canadiens' organization

On December 10, we had the pleasure of welcoming the Montreal Canadiens' organization to the hospital. Xavier Tristan Peloquin, a 5 year-old patient in the Hematology-Oncology unit of the hospital, was delighted to receive a visit from Chris Nilan (l.) and J.J. Daigneault (r.), former Habs' players, and Michel Therrien (2nd from r.), the former head coach of the team



Photo: Daniel Héon

Home for the holidays

Ten-week-old Rebecka Cousineau will get to celebrate Christmas at home with her family, after recently being discharged from the ICU. Rebecka was admitted over a month ago after doctors in Valleyfield noticed that her heart was quite enlarged. On arrival at the MCH ER, it was discovered that she was suffering from a coarctation of the aorta (narrowing of the aortic arch), as well as a ventricular septal defect (holes between the two pumping chambers of the heart).

Too weak for surgery, doctors decided to let her heart muscle rest for almost three weeks before operating. Her family feared the worst and asked Father Paul to baptize Rebecka in her hospital room. Soon after, Dr. Christo Tchervenkov managed to repair the aortic arch and closed the ventricular septal defect. Without a doubt, little Rebecka is a fighter and a survivor – in fact she is already smiling and breastfeeding. Everyone at the Montreal Children's Hospital is so happy to see her go home for the holidays. We wish the Cousineau family the very best for 2013!



Patricia, Rebecka, Francis, and Dr. Charles Rohlicek, one of the cardiologists involved in Rebecka's care.

Photo: Daniel Héon

Players visit MCH

Despite the lockout, six NHL players came to visit patients at the Montreal Children's Hospital on Friday, December 7. Mathieu Darche, Erik Cole, Brian Gionta, Josh Gorges, Francis Bouillon and Steve Begin visited with the children throughout the hospital handing out signed hockey cards, hockey sticks and caps. They brought a smile to the faces of hundreds of fans and parents.



▲ Erik Cole, Brian Gionta and Josh Gorges pose for a photo in the Hematology-Oncology Unit with Claudia, and her mom.

Jonathan and his mother meet Josh Gorges, Erik Cole and Brian Gionta ▶



Photo: Daniel Héon

How to manage kids' Holiday expectations

Here comes the Holiday season again. The days are getting shorter, and so are children's attention spans. Their Holiday wish lists, on the other hand, are getting progressively longer by the day. And who could blame them? Thanks to TV, social media, and their friends, today's children are constantly exposed to new toys, electronic innovations, and apps.

Meeting family needs is enough of a challenge today from a financial perspective. Adding in all those Holiday wish-list "wants" can be a real strain on both the budgetary and emotional fronts.

So, what to do?

Often it's just not possible to meet your children's every Holiday expectation. "The potential for disappointment is certainly there," says Marie-France Haineault, Certified Child Life Specialist at the Montreal Children's Hospital. "But at the same time, the Holidays present a great opportunity to bring families closer together, and to teach some valuable and useful life lessons.

"The first step to managing kids' expectations is to talk openly and honestly with them", says Ms. Haineault. Ask your children about their wish lists, and then discuss these together. If they're old enough, you can explain to them that they may not receive every item on their lists this Holiday season. And if they're still Santa Claus believers, you can tell them that the man at the North Pole is very busy, working to get toys and games to millions of children around the world. You can have them make a Top Ten or Top Five list, and get them to assign priorities to each item on the list. That is, after all, how things are supposed to work in a well-ordered grown-up world! (Well, at least sometimes anyway.)

The joy of giving is a gift itself

"You can also give your children another wonderful Holiday gift," adds Ms. Haineault. "You can instill in them a strong sense of the joy of giving. That includes gifts in the traditional sense of the word, but also their

time, effort and compassion."

For starters, you can give each child a Holiday to-do list. Tasks will include helping you prepare for the Holidays – as well as acts of kindness, such as visiting an elderly relative, or volunteering at a local food bank. This will help them to develop a greater sense of responsibility toward self, family and community. You might also give your children an advance cash gift – with the suggestion that they should donate all or a portion of this to a worthy charity of their choice.

For those children who haven't yet earned money of their own, that advance cash gift can also be used to buy gifts for other family members. If they cannot afford to buy small gifts for each family member, you can assign one gift recipient to each junior gift buyer.



A universal message

And what if these Holidays are not your family's Holidays? Keep in mind that there's some common ground here. Look at all those bright lights during the shortest, darkest days of the year – a symbol of hope in many cultures.

And then there's the Golden Rule – doing unto others as you would have them do unto you. That's one of the main tenets of most of the world's cultures and faiths.

Pilates at the MCH

For employees

When: Mondays, and/or Wednesdays, 5:00 to 5:55 p.m., starting Jan. 14 and 16, for 7 weeks.

Where: Rm D-292, MCH

Cost: \$70 once class per week, \$140 two classes per week

Registration: Contact Karen at (514) 489-7717 or karenkunigis@gmail.com before January 10

Our People

Drawn to serve others for over 25 years

A longtime MCH volunteer, Mr. Georges Martineau uses illustration to connect with patients

It is an extremely humbling experience to be in the presence of Mr. Georges Martineau. The soft-spoken gentleman has been volunteering at The Children's for over 25 years, and admits he rarely takes a week off from roaming inpatient units on the 6th and 7th floors.

"It changes up my routine," he says of the weekly visits, "and I really enjoy my exchanges, especially with older children and teenagers."

A 58-year member of a religious community housed in the Maison des pères du Très-Saint-Sacrement on Mount Royal Street in the Plateau neighbourhood, Mr. Martineau's life has been dedicated to serving others. He is one of seven Catholic brothers still living in the community and embracing monastic life, and commits a few hours a week to visiting hospitalized patients.

"I've been here for years," Mr. Martineau jokes, "even Rose, the hospital's volunteer coordinator, has almost been here as long as I have!"

Every Wednesday afternoon at 3:30 p.m., the devoted brother contributes a few hours of his day



to zigzagging the hospital corridors, saying hello to patients and family members, and engaging in some friendly conversation. But what he is most known for are his detailed drawings – portraits, scenery depictions or sometimes colourful landscapes -- he creates and leaves with patients after visits.

Once upon a time, Mr. Martineau recalls having taken a few drawing classes to improve his skills, but the drawings he creates during his rounds, he insists, are more about making patients happy than anything else.

"The older patients seem to really enjoy receiving them," he says, "and I give them whatever I've drawn to keep as a souvenir."

Throughout his 25-year commitment as a volunteer at The Children's, Mr. Martineau says the biggest change he has noticed is the length of patient stays.

"I remember when I first began volunteering, I used to visit a handicapped patient who ended up remaining hospitalized for many years, until his adolescence."

"Today, I am surprised if I get to see the same patient two weeks in a row. The length of hospital stays is now much shorter, but I get to meet more patients."

More than just sketching portraits and landscapes, Mr. Martineau's commitment to The Children's is a perfect illustration of his lifelong devotion to being of service to others, and spreading his gentle kindness to everyone he meets.

Awards and Nominations

Dr. Charles Scriver and **Mr. Arnold Steinberg** received the Medal of Honour from the Rx&D Health Research Foundation for their outstanding contributions to health sciences and public health innovation. With Mr. Steinberg, Dr. Scriver worked to ensure the addition of vitamin D to milk in Quebec starting in the early 1970s, reducing the occurrence of nutritional rickets in children from over 1,000 cases/year to almost none. He and Mr. Steinberg also collaborated on the development of the National Food Distribution Centre for the Management of Patients with Hereditary Metabolic Disease. This work has had extraordinary impact on the health of young Canadians.

Dr. Audrey Lovett has been named Director of the Division of Pediatric Dermatology at the MCH.

