News

# Hospital @ Home—a new, nurturing way of caring for complex needs children

#### By Julia Asselstine

n health care, we have reached a new frontier—more and more children are living with complex, life-sustaining needs. The good news is these children have been given an opportunity at life. However, they require periods of extreme intensive care and until now there has been no community infrastructure in place to help these families cope.

"New technologies, improved intensive care and new discoveries on all medical fronts have contributed to this modern reality," says Dr. Hema Patel, McGill University Health Centre Director of the Intensive Ambulatory Care Service at the Montreal Children's Hospital (MCH) and Associate Professor of Pediatrics, McGill University.

"The Montreal Children's Hospital Intensive Ambulatory Care—a.k.a. "Home Care"—team has been at the forefront of this reality for a long time," says Dr. Patel. "What we know is that families are better off when their children are at home and children are better off developmentally—physically and psychologically—when they are at home. But what has happened is that hospital care has advanced quite markedly but the community situation and outpatient



care for these patients has lagged behind. Parents are asked to do a tremendous amount – and they do it. But unlike in the hospital where you have shifts of nurses, there are no shifts at home. A parent may be up all night and then have to work all day. Human beings can do this for a stretch, but it's not sustainable over the long term."

In response to what the Home Care team was seeing, and realizing that it was a province-wide issue and not just an MCH issue, Dr. Patel and her colleagues started to network with other provincial hospitals

and discuss advocating for more resources for these families. The result was a multidisciplinary task force called Hospital @ Home, with representatives from around the province and chaired by Dr. Patel. The task force, jointly mandated by The MCH and Ste-Justine's Hospital, addressed the issue of mobilizing resources for children with complex care needs to enable them to remain in the best environment possible their family home. The task force recently presented to the MSSS's Table Mère-Enfant and has received the endorsement of this committee and key stakeholders at the MSSS.

(Continued on page 2)

The task force looked at what is best for all involved, including the family, the children, the hospital, and also looked at related costs. The ultimate goal is to facilitate the transition from hospital to home and to work at strategies to minimize the duration of hospitalization. Designated funding and a program for these children to have home nursing and equipment support is the priority.

"You can't morally and ethically send children home unless parents can be supported," says Dr. Patel. "You can't say 'This is the level of care available in the hospital. Your child is not that sick—he or she is quite stable, so off you go.' Don't sleep, don't eat, lose your job, lose your home, but good luck. You just can't do that. The Canada Health Act tells us we have the responsibility to take care of our citizens. This includes these children and we need to meet their needs so that they can reach their full potential, whatever that may be."

The Canadian Pediatric Society (CPS) recently announced that Dr. Patel will receive the 2012 Victor Marchessault Advocacy Award. This Award, given every two years, is named after the late Victor Marchessault who served

as Executive Vice-President of the CPS from 1964 to 1997, a time in which the CPS became a political force with multiple advocacy achievements that contributed substantially to improved child health in Canada. Dr. Denis Leduc, a former CPS President and member of the MCH Department of Pediatrics, nominated Dr. Patel for this Award.

Dr. Patel will receive the award during the CPS Child and Youth Health Lecture, on June 7 at the CPS Annual meeting in London, Ontario.

### Donate and get your face up in lights!

After five years, the MCH Foundation has reached the home stretch of The *Best Care for Children* Campaign to help build the new Children's. We have created an exciting new way for you to help put us over the top: a giant, interactive night-time projection screen on the side of the Hôtel de la Montagne, giving you the opportunity to post your photo for everyone to see!

It's easy. For the entire month of May, if you make a donation through a special section of the Foundation's website, you will be asked if you want to post your Facebook photo on our giant projection screen. Click "yes" and your photo will become larger than life. It's our way of letting the whole city know that we appreciate your support!

For more information, please visit childrenfoundation.com.

# Cut down on visual clutter, cut down on stress

The visual clutter that surrounds you might be stressing you out.

Do a little spring cleaning in your work area, nursing station, staff lounge, department coffee nook and other hospital areas by taking down and tossing out those old memos, outdated posters and invitations and torn or ripped notices. Ideally, managers should appoint someone in their departments or divisions to be in charge of the office bulletin board. All information important to staff can be placed in an inbox and once or twice a week the memos can be triaged and put up on the bulletin boards and the old information taken down. This will help improve communications ensuring everyone is aware of events and activities. Plus, as an added bonus it will alleviate a bit of stress.

### **Project Office Now Re-Opened**

We are pleased to announce that our project office, located at 5325 Crowley Ave. (second floor) officially reopened on **April 10, 2012**. The product of a collaborative effort between the McGill University Health Centre and its partner, Groupe immobilier santé McGill, the office will be open every Thursday from 9:30 am to 7:30 pm and every Friday from 9:30 am to 4:30 pm. The office is open to residents, business owners and anyone else who is interested in learning more about the Glen Site. Visitors are welcome to come to the office with or without an appointment.

Residents wanting to meet outside the hours of operation may call to make an appointment by leaving a message at **514-934-8317** or sending an email to construction@ muhc.mcgill.ca. We look forward to seeing you there!



It ONLY takes 20 seconds to sign your Medicare card to become an organ and tissue donor.

Please sign your sticker to help Vincent and kids just like him.

**#Aheart4Vincent** 



To learn more about how you can help, please visit www.childrenfoundation.com and follow us on Twitter @HopitalChildren

### The importance of communication

Patient and family centered care is not just "being nice". It is a direct and intentional effort to unequivocally communicate to patients that they are viewed as distinct and valuable individuals with a family and place in the community. Relationships between patients, families, and providers are essential alliances, and partnerships with each bring expertise to decision-making.

(From the Institute for Family–Centered Care)

### A message from Imma Gidaro, MCH Coordinator for Patient and Family Centred Care

Tel.: ext. 23992, Cell phone: 514-880-4038 (F-249) E-mail: imma.gidaro@muhc.mmcgill.ca; igidaro@sympatico.ca



~ The MCH is a patient and family centered care hospital. Why not feature some of your co-workers or departments by nominating them for the PFCC award which is handed out during the Townhall meetings. Please contact Imma by phone or e-mail to learn more.

# Continuing Education

### **Annual Research Day at The MCH**

Wednesday, May 30 8:00 a.m. to 12 noon Amphitheatre, D-182

The MCH community is welcome to attend presentations by graduate students, fellows and residents from The Montreal Children's Hospital on the progress of their research. A panel of judges will select the best clinical and basic research presentations.

Information: ext. 23023 or 24300

#### **RUIS McGill SYMPOSIUM 2012**

May 28-29

The inaugural RUIS McGill Symposium, A Network in Action, to discuss strengths and new directions in the continuum of care, education and patient engagement will take place on May 28 and 29 in Montreal. Also on the agenda: The official launch of the CvSSS Telehealth project!

Register online at medicine.mcgill.ca/symposiumruismcgill/

### "Creating Effective Patient Education Materials"

#### 2012 Workshop Program

Call for participation

The Creating Effective Patient Education Materials workshop program offers a series of sessions that engage participants on the topics of health literacy, plain language and patient-centered approaches to therapeutic communication. They highlight the challenges inherent in patient education that have changed today's learning, teaching and practice environments.

Participants will be provided with strategies and methodologies, based in instructional design and pedagogy, to support their current patient education initiatives and respond to these challenges. The ultimate goal of this workshop program is to establish a structure for clinical authors to create their own patient education materials and highlight the responsibility that all clinicians have to learn to teach.

What workshops are offered?

- Creating Effective Patient Education Materials (introductory workshop)
- Writing Clearly: The Art of Plain Language
- Patient Education: Successes, Challenges and Lessons Learned

Workshops are open to those holding either clinical or non-clinical appointments at the MUHC. All workshops will be held during **September**, **October** and **November 2012**.

To reserve your place, email the following details to myrna.cabaluna@muhc.mcgill.ca by June 1, 2012: name, email, phone extension, position, department/unit, which workshop you'd like to attend, and language preference. If you have questions or require more information, please contact Myrna via email or ext. 71386.

### **International Pediatric Otolaryngology Update**

May 6-7, 2012 MCH Amphitheatre D-182

Keynote Speaker: Dr. Peter J Koltai

Honored Pediatric Otolaryngologist: **Dr. Melvin D Schloss** 

This conference is intended for practicing Pediatric and General Otolaryngologists interested in updating their knowledge on a broad spectrum of topics in the field of Pediatric Otolaryngology. An outstanding local and international faculty will provide a review of contemporary diagnosis and management techniques within their field of subspecialty expertise.

This event is an Accredited Group Learning Activity as defined by the Maintenance of Certification program of the Royal College of Physicians and Surgeons of Canada.

#### **Registration:**

http://www.thechildren.com/data/Events/en/720\_Doc.pdf



#### **MCH Auxiliary activities**

All sales take place on 2B

Wednesday, May 2 Books

Wednesday, May 9 Videos, books and toys

Wednesday, May 16 Knits

Wednesday, May 23 Miscellaneous

The Auxiliary AGM will take place on Wednesday, May 16.

#### **Nurses and Nursing Assistants**

Let's Celebrate Nurses Day Together!

Where: Cafeteria

When: Tuesday, May 8, 2012

Coffee and muffins starting at 7:30 a.m. Night staff welcome!

Buffet lunch from 11:00 a.m. to 2:15 p.m.

Activities including massage therapy throughout the day

from 7:30 a.m. to 2:15 p.m. **Over 100 Door Prizes!** 

Please remember to wear your hospital IDs!

# McGill Faculty of Medicine brings "15 000 Smiles" to the MCH Foundation

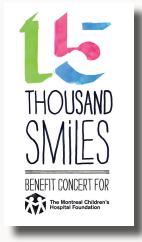
MCH physicians, McGill Faculty of Medicine students, members of *I medici di McGill Orchestra* and children from the school choir at F.A.C.E. will come together on May 11 for "15,000 Smiles", an evening of music to benefit the MCH Foundation. The goal of the event is to raise \$15,000 for the MCH Foundation.

Friday, May 11 at 7:00 p.m.

St-Patrick Basilica

454, boul. René-Lévesque W.

Tickets available online: 15000smiles.com



Chez nous is published by the MCH Public Relations and Communications office.

**Contributors:** Julia Asselstine, Lisa Dutton, Rebecca Fogel, Maureen McCarthy and Christine Zeindler

Graphic design: Jean-Claude Tanguay

**Photography:** Daniel Héon, Christian Lavigne and Dan O'Leary

To submit story ideas or texts to *Chez nous*, contact the Public Relations and Communications office at ext. 24307 or send your email to info@thechildren.com.





# Making Headlines

**Dr. Stephen Liben**, head of Palliative Care at the MCH, was interviewed for a feature article in The Gazette on the Mindfulness-Based Medical Practice program, which is part of McGill University's Whole Person Care

program for physicians. You can read the complete article at montrealgazette.com/health/Physicians+healing+themselves/6482206/story.html

### Awards and Nominations

**Dr. Hema Patel** is the 2012 recipient of the 2012 Canadian Pediatric Society Victor Marchessault Advocacy Award. This award will be presented on June 7th at the annual meeting of the CPS.

**Joe Derocher** is now Operations Manager of Housekeeping for the MCH in addition to his current responsibilities at the MGH, RVH, MNH and MCI. He can be reaced at joe.derocher@muhc.mcgill.ca, or ext. 44941, MGH Room BS1 112.

#### New members of the MUHC Internal Communications team

The MUHC's Public Affairs and Strategic Planning (PASP) office is pleased to announce the promotion of Lisa Dutton to Manager of MUHC Internal Communications and Interactive Media. Lisa will also be providing communications support for the MUHC's Patient Engagement initiatives. Lisa will continue in her role as Manager of Public Relations and Communications for the Montreal Children's Hospital (MCH).

Lisa joined the MUHC ten years ago and has in-depth knowledge of the organization. She and her team have won awards for the MCH website from the Office québécois de la langue française, the Société québécoise des professionnels en relations publiques du Québec, and Canada's Health Care Public Relations Association. Lisa brings a wealth of experience to her latest role and we are excited about her new position with the PASP office.

Lisa will be working arm-in-arm with Patricia Lemoine, our new Communications Officer, Internal Communications. Patricia is the second generation of her family to join the MUHC; her father was a pharmacist at the MCH for over 30 years. Patricia has both a bachelor's degree in Civil



hoto: Dan O'Leary

Law, and in Cinematography. Patricia was first hired by the organization in 2011 as an Information Officer at the Direction de santé publique de l'Agence de la santé et des services sociaux de Montréal. Prior to her career at the MUHC, she has held roles in communications and development for non-profit organizations such as Multiple Sclerosis Society of Canada, Quebec Division, and worked as a freelance journalist reporting on Health, Lifestyle and Beauty.

# It's a tea party..and you're invited

Join us on June 6 from 2 p.m. to 4 p.m. for tea and to congratulate the winners of the *Best care for children* awards.

This year's awards honour the MCH staff and physicians who helped design our new hospital.

Come join us in the cafeteria!



# Our People

### Working to the beat of the heart: Perfusionist Christos Calaritis shares his passion for the job

#### By Christine Zeindler

"Every day has its surprises," says Christos Calaritis, a perfusionist at The Montreal Children's Hospital (MCH) of the McGill University Health Centre (MUHC). Perhaps it's his 12-year experience at the MCH or his competitive sports background that keeps him rolling with the punches. Or more than likely, it's his love of the job. While assisting during complicated surgeries and putting in long hours monitoring the machinery that keeps patients alive, Christos has a positive and upbeat attitude.

"I don't consider it a job – it's more than that – it's a vocation. I find my work very rewarding and I get a lot of satisfaction from taking care of patients with heart or lung disease. It's what I do."

#### Perfusion: Keeping the oxygen flowing

At the MCH a perfusionist must fulfil three main functions. The first is to run the heart-lung machine that artificially replaces a child's heart or lung functions during open-heart surgery. This machine pumps oxygenated blood through the body.

The second is a key involvement in the Extra Corporeal Membrane Oxygenation (ECMO) program at the MCH. "This program provides support for babies and older patients that might have lung or heart problems and are not able to provide the body with enough blood flow and oxygen," says Christos. During ECMO, blood is circulated outside the body and it is filled with oxygen by an artificial



lung and circulates with the help of an external pump, allowing the heart or lungs to rest. This is similar to the heart-lung bypass machine used during open-heart surgery. The MCH is the only provincial referral centre for neonatal respiratory ECMO, and receives patients from throughout the province.

Lastly, MCH perfusionists are also experts in other life-support equipment, such as ventricular assist devices (VADs). These devices, such as the Berlin Heart, are mechanical hearts, which bridge patients to heart transplants.

#### Patients are the reward

"Babies are not necessarily small adults," says Christos. "Our patients are anywhere from 3 to 100 kgs, so we have to stay on our toes when caring for them. Treating this wide range of patients is an added challenge that I enjoy and keeps me engaged."

"What makes my job so rewarding is seeing a patient recover. The resiliency of children is really amazing." Christos remembers a patient who was born with a heart defect and a few years later ended up in the ICU with a malfunctioning heart. The patient was connected to a Berlin heart for 109 days, until he received a heart transplant. "The final surgery was 10 years ago and the patient still comes to see me. It is these successful outcomes that keep us going. People don't realize how many hours, days and weeks that we have to invest so that we have results as good as these."

Christos is also very impressed with the children's optimism. Currently he is monitoring Vincent Lambert, a young man who has been waiting for a heart transplant since September 2011. "Although these patients are very sick, they still think about others and are a joy to be around."

#### Team work

"We are fortunate to have such an excellent medical team," adds Christos. "They are the very best." The team is also fortunate to have Christos as one of the players. In the fall of 2010 Christos received the MUHC's Director General's Award, acknowledging his commitment to the Institution, and six months later he received The Montreal Children's Hospital's Award of Excellence. "I'm a hard worker, and I do this gladly for the patients," he says.

**Correction:** please note in the profile of Sabrina Drudi which appeared in the April 5 issue of *Chez nous*, her title (in French) should have read *éducatrice en milieu pédiatrique* and not *psychoéducatrice* as was indicated.



# Our Heroes

# Growing older with a challenge

By Rebecca Fogel

s a kid I was fairly happy. I was raised in a very solid and grounded family, with rules but still very open. My family is the reason I am still here. As I grew older I became wiser, but not to any great extent. Though I thought I knew everything, and I was the master of my body, in reality, on my 14th birthday, I started to no longer feel like my old self. In April of 2008, I was diagnosed with Benign paroxysmal positional vertigo, or BPPV. It was the first time I ever had to see a specialist at The Montreal Children's Hospital more then once. I was hoping that would be the first and last time I would need serious medical attention. Boy was I wrong.

January 2009: I came down with a serious cold, and noticed an odd rash on both forearms. Concerned about the rash and why I was not getting better, my father called our family doctor. That day, I saw my doctor and explained what was going on. He started with the normal examination, until he got to my arms. I could see the concern in his eyes.

"Rebecca, how long did you say you had this "rash"," he asked.

"I've only noticed it in the last few days," I replied.

"This isn't a rash," he began "this is what we call PETECHIAE."

My facial expression went blank. In total confusion I asked, "which means?" "I just need to do a few blood tests. Nothing to worry about," he reassured me.

Concerned, but fearless, I left the doctor's office.

The next morning my father brought me for the blood test and then off to school just like any other day.

The catch was, when I came home, my world turned upside down. My father called and told me we had to go to the hospital; the doctor said I was low in platelets. Having no idea what a platelet was, I was just informed I am low in them. I feared the worst.

Another test was done at the hospital, and my count had dropped again in a mere six hours. Upon getting this news, I was directed to the hematology/oncology clinic. We were gently warned that we might see children who had lost their hair because this clinic is where children with cancer are treated. Hearing the "C" word makes your heart skip a beat, but my parents and I were quickly reassured that I DID NOT have cancer.

Back at home, a long night turned into day, and I went back to the Montreal Children's for another blood test. Since the time I was young I've been petrified of needles, but I have to say I handled being poked really well. Not too long after blood work was done, the doctor pulled my mother and me into a room, and said:

"It seems what you have is ITP (Idiopathic Thrombocytopenic Purpura)."

ITP is the condition of having an abnormally low platelet count of unknown cause. A very low platelet count can lead to an increased risk of bleeding.

We were shocked by the news. The doctor proceeded to tell us ITP is a very serious condition that needs to be watched carefully. I can remember this moment like it was vesterday. Day after day, my platelet counts would just continue to drop, until the day came where my count had dropped so low the simplest of paper cuts could have caused me to bleed to death. A healthy person's platelet count is from approximately 150 thousand to 450 thousand per micro litre; my count went down to six thousand per micro liter. That is when the doctor proposed two different treatments:

- Steroids
- IV-IG treatment (transfusion)

There was no way I wanted to go on steroids, so I picked the transfusion. The whole process went well, and it truly helped. From that day my platelet count hasn't moved, and I am grateful for that.

~ Stay tuned for part two of Rebecca's Challenge in the next edition of Chez nous.