News

National Organ and Tissue Donor Awareness Week April 22 to 28, 2012

The beat goes on...

Vincent waits, albeit impatiently, for a new heart

By Lisa Dutton

Standing in Vincent's hospital room you can hear his heart beat. It makes a loud sloshing noise. It's not his real heart. That's pretty much dead. The noise is the sound of his temporary mechanical heart. If you stand close to Vincent you can see his body twitch with each artificial beat. One hundred beats per minute, not one more, not one less.

Since September 18, 2011, Vincent has been kept alive by a mechanical heart—a Berlin heart. He's celebrated Christmas in hospital; he celebrated New Year's in hospital; he celebrated his 15th birthday in hospital.

He's been waiting and waiting for a heart transplant operation. The donor heart might come from any one of a number of provinces. He is at the top of a pan-Canadian transplant list. So far, nothing.

This doesn't discourage his health care team who are extremely optimistic that heart will become available if not today, than maybe tomorrow. Children in need of heart transplants with his blood group wait, on average, six months to one year for the heart to become available.

It all began when Vincent was three months old. He caught a virus that attacked his heart. His heart has been in slow decline ever since. In doctor speak, the adenovirus caused a myocarditis infection of the heart. For many years the symptoms were mild. Vincent was followed closely in cardiology by Dr. Luc Jutras and the cardiology team.



oto: Claudio C

April 5, 2012

The situation changed dramatically in the spring of 2011. Vincent was in full blown heart failure. For the first time he had to come into the intensive care unit (ICU) for treatment. Medications helped for a while, but by fall it was clear his heart was giving out. His heart was beating a mile a minute, but it didn't have enough strength to pump the blood.

In September, a team of medical specialists conferred and decided to put Vincent on a mechanical heart.

It didn't go well. There were all kinds of complications: bleeding, blood clots, kidney failure. He was in and out of surgery three times. He was also emaciated. He weighed only 26 kilograms. It was touch and go a few times.

(Continued from page 1)

Then Vincent started to make slow and steady gains. Today, he has put on a good 20 kilos. He walks around the hospital and lifts weights in the physiotherapy room. His trusty mechanical heart is always in tow. It is the size of a small shopping cart.

He's had some famous visitors including members of his favourite band Simple Plan, a bunch of players from the Montreal Canadiens and Anthony Calvillo of the Montreal Alouettes.

Rumour has it that the MCH teachers used to go easy on him, but not any more. He even has homework. He keeps in touch with his friends via Facebook and a few drop in to keep him company. He's even gone outside a few times to see his dog Max, a Doberman.

The goal is to get him as healthy as possible for when his new, slightly used heart arrives. "The medical challenges are less now, says Dr. Samara Zavalkoff, a PICU physician and one of Vincent's primary caregivers. "We're just waiting". "What is most crucial at this time is to keep Vincent's mood elevated and keep him motivated. He's bored. Who can blame him? His only outing is to other floors in the hospital. No matter how much he likes the team in the PICU and we like him, we're not his friends. His friends are at school. It isn't a normal life for a 15 vear old."

Looking forward to the day when the new heart arrives, Vincent admits, "It will be weird when the mechanical heart is removed. I plan to keep it as a souvenir."

Dr. Zavalkoff looks forward to that day too. "I often think about the moment when his heart arrives. I've gone over in my head how we'll tell him and his parents. I figure the moment I walk in to his room, they'll see it on my face right away."

You can help!

Sign your Medicare Card to become an organ donor

Want to help Vincent and kids just like him? Then please sign the Consent to Organ and Tissu Donation Form from the Régie de l'assurance maladie du Québec or sign the sticker on the back of your Medicare card, available through RAMQ. Talk to your family about your decision. "I know this is a very hard decision to make, but you'll be giving people like my son another chance at life," says Lyne Chabot, Vincent's mum.

GIVING YOUR CONSENT

If you would like to donate organs or tissue, there are three ways of making your wishes known:

- Sign the Régie de l'assurance maladie du Québec Consent to Organ and Tissue Donation form.
- Sign the sticker and put it on the back of your health insurance card
- Have your decision recorded in the Registre des consentements au don d'organes et de tissus of the Chambre des notaires du Québec.

According to data published by the Canadian Institute for Health Information (CIHI), 2,103 solid organ transplants were performed in Canada in 2010 (11 more than 2009) thanks to 1,022 organ donors (living and deceased). There were 135 Canadians awaiting a heart transplant in 2010. Unfortunately, 22 people died while waiting.

It takes a team!

"Just about every department and service at the MCH has been involved in Vincent's care," says Dr. Samara Zavalkoff, PICU intensivist and one of Vincent's primary caregivers. "From the PICU to cardiology, and cardiac surgery and the perfusionists. There is also nutrition, social services, psychology, occupational therapy, physiotherapy, education services, child life, music therapy, nephrology, ophthalmology and the clowns. There's a reason I'm not leaving anyone out. Every single member of that team is crucial including, most important, Vincent and his parents. Today, the most important person is the nutritionist, tomorrow it might be social services. Take away any one member and Vincent would not be where he is today."

Drawing on imagination

It started with an idea, which led to a stroke of a marker, which resulted in a masterpiece on a board in the Montreal Children's Hospital Oncology Unit. In the fall of 2010, nurses Valérie Lamarche and Dalia Parvin gathered some markers and started to draw a picture on the white eraser board in front of the reception area on 8D. The simple image stopped children, families and staff in their tracks. Many a smile erupted on the faces of the admirers.

Realizing she was onto something, the next month Valérie drew another image, and every month since that board has been dressed in the Dior of drawings. Toy Story, Winnie the Pooh, The Lion King, Happy Feet, Disney Princess and Aristocats are among the collection, which unlike a museum, don't stay around longer than a month but like a museum, are adored by all. Children on 8D are now submitting ideas and other staff—including the

doctors—are contributing to the drawing and colouring. Lately, the characters are taking on the names of the children, which has been a huge hit! This image shown here is for the month of April.



to: Claudio Calli

Brand new veins for the Glen Site!

The Glen Site will be a cutting-edge academic health centre filled with the latest and most modern equipment to improve both work flow and the delivery of care to patients. Among these innovative pieces - and probably the largest one of all - is the pneumatic tube system.

Hidden behind the walls of the Glen, the pneumatic tubes will be the veins of the Glen Site. With an estimated 5,000 transactions per day, they will carry blood, medication and emergency medical items to our medical professionals. According to Terrence Meehan, Director of Logistics, "Since the Glen is so large, materials will sometimes have to travel distances of 1,000 feet and many stories up or down. Pneumatic tubes will help deliver critical items, medicine and even blood quickly, which is extremely important in a tertiary and quaternary care institution."

Users can also program the pneumatic tube system to prioritize certain capsules that need to be received or analyzed quickly; the system can then slow the progress of all other deliveries to prioritize a specific one. Only authorized personnel will be able to use the pneumatic tube system.

"Together with our hard-working porters, the pneumatic tubes will help ensure that patient care is delivered quickly and that workflow, from the lab to the emergency department to the patient's bedside is as efficient as possible," concludes Mr. Meehan.

Interesting facts about the Pneumatic Tube System

- A capsule in the pneumatic tube system can travel 20 feet per second which is a little over 20km/h.
- The size of a capsule is similar to that of a 2L plastic bottle.
- Personnel will be able to track a capsule's progress at all times. Carriers can also be returned automatically to their sending stations after delivery.



Wellness Challenge Program

In September 2011, the MUHC Wellness Challenge Program (pedometer/nutrition program) was launched. A total of 310 employees registered for the Program, which consisted of wearing a pedometer for eight weeks, tracking physical activity behavior and daily fruit and vegetable consumption. Follow-up emails, as well as weekly health tips and challenge updates were sent to participants on a regular basis. Before starting the program and at the end, participants were screened for baseline data (blood test and cardio-metabolic risk assessment) and were asked to fill out a questionnaire (general health status, weight, food habits, physical activity, tobacco use, the workplace psychosocial environment, stress, and demographics).

During the intervention, over 90% of participants entered their progress online. At the end of the program all seven MUHC teams had crossed the finish line and

accumulated a total of 207,211,613 steps - equivalent to walking 157,936 km or 3.9410 times around the world!

Preliminary results from individual interviews highlight that participants felt healthier after the intervention and highly motivated. Participants also felt more conscious of healthy eating habits and perceived walking at the workplace as an enjoyable, effective and feasible physical activity. In addition, results show a significant improvement in stress, fatigue and insomnia scores, as well as blood pressure and overall health status.

This program conducted by Dr. Charles Sounan, Dr. Mélanie Lavoie-Tremblay, and Kara Martin, supports the widely recognized asset of health promoting workplaces as the key to raising the bar for employee health, quality of care and organizational performance.

The Caring for Kids Radiothon: a chance for your patients to share their stories

The Caring for Kids Radiothon is coming up on May 24, less than two months away! The Radiothon is an amazing opportunity to let everyone know about the wonderful work done by you, the staff at the MCH, and to raise some urgently-need funds for the hospital. Once again, the MCH Foundation needs your help. We're looking for patients and their families to share their stories with Montrealers. If you know of someone who would like to help the hospital and perhaps get to meet their favourite radio personalities, please contact Kim Fraser (kfra@mchf.com) or Luke Quin (lqui@mchf.com) at the MCH Foundation.



Our Kilimanjaro climbers are back!



After nine grueling days of trekking, each member of the expedition safely arrived on the summit of the tallest peak in Africa, an astonishing 5,895 meters above sea level (by comparison, Mont Tremblant is only 875 meters high!) To date, this group of 12 amateur climbers has managed to raise over \$117,000 towards the new MCH. Their perseverance, hard work, and enthusiasm for our cause is truly inspiring! A special thank you to The North Face, official sponsor of the climb.

Prenatal and Childhood Origins of Disease program gives blueprint for research at the Glen

By Alison Burch

Every child deserves the best possible chance to grow into a healthy adult. Detecting disease early is the best way to prevent or decrease lifelong illness and suffering, and this is the strategy for building research strengths at The Montreal Children's Hospital (MCH), according to Dr. Jacquetta Trasler, Scientific Director for Child Health Research at MUHC. "To deliver better health care," she says, "we must first discover and better understand the causes of birth defects, developmental disorders and diseases in children."

Strengths in these areas are the backbone of the Prenatal and Childhood Origins of Disease program, a blueprint for child health research as the MUHC research community regroups for the move to new facilities within a few years. A concentration of expertise is emerging around each of the three themes in this program, shown below.

"The Prenatal and Childhood Origins of Disease program is one of the great strengths of the Research Institute of the MUHC and McGill," says Gretta Chambers, Chair of the Advisory Group on Research to the Council for Services to Children and Adolescents. "And MCH investigators excel in each of the three main research themes. All have direct bearing on lifelong health care."

MCH investigators' advances in these key areas are in step with new research priorities identified by the federal and provincial governments, Dr. Trasler notes, and also with priorities of the Canadian Institutes of Health Research (CIHR). Moreover, the Prenatal and



Photo: Ow

Childhood Origins of Disease program is enriched by its placement on the continuum of Translational Research and Intervention Across the Lifespan, a concept that won the Research Institute of the MUHC the \$100 million grant from the Canada Foundation for Innovation to build a cutting-edge research centre on the Glen Campus.

In the next stretch of the road to the Glen, adds Dr. Trasler, "we will be strengthening our themes through targeted recruitment and funding applications for our research teams."

Themes of the Prenatal and Childhood Origins of Disease program

- Genetics and Genomics of Rare Disease, Common Disease and Cancer
 Some studies in progress at MCH: research into birth defects, diabetes, brain tumours
- Prenatal and Childhood Environmental Origins of Disease
 Some studies in progress at MCH: research in the fields of reproductive/perinatal epidemiology, environmental contaminants, childhood asthma and allergies, assisted reproduction, effects of prescription drugs, high-risk children
- Brain, Behaviour and Development
 Some studies in progress at MCH: studies in autism, prenatal asphyxia, attention deficit disorder

Making Headlines

Dr. Nada Jabado, hematologist-oncologist at The Montreal Children's Hospital and a researcher in medical genetics and genomics at the RI-MUHC, was recently interviewed on RDI Santé. Visit www.radio-canada.ca/rdi/sante/ to see her interview.

Dr. Claire LeBlanc is chair of the Canadian Paediatric Society (CPS) Healthy Active Living and Sports Medicine Committee and co-author of a new CPS position statement on physical activity, which was featured in The Montreal Gazette: www.montrealgazette.com/health/Yo ung+children+need+exercise/6367939/story.html. Dr. LeBlanc was also interviewed on CTV Montreal: www.ctv.ca/CTVNews/Health/20120327/toddlers-children-exercise-fitness-guidelines-120327/.

MCH Mini-Med sessions available on Canal savoir

From **April 16** to **July 15, 2012**, Canal Savoir (UHF29, Cable 26–47) is broadcasting presentations from season 2 of the MCH Mini-Med series. All of the hour-long talks are presented by MCH specialists. Rebroadcasts will run several times a week through mid-July. Check your local listings or visit canalsavoir.tv/emission.php?id=10169 to find dates and times.

Hwards and Nominations

Dr. Thérèse Perreault has been appointed the Director of the MUHC's Division of Neonatology, effective April 1, 2012. As the Director of the MUHC's Division of Neonatology (MCH/RVH NICU), Dr. Perreault will play a leading role in the establishment of this 52-bed unit that will be a major force in the new hospital featuring well integrated links with activities in obstetrics, maternal-fetal medicine and every pediatric medical and surgical service.

The Montreal Children's Hospital Foundation is pleased to announce the appointment of **Kim Fraser** as Senior Director of Communications, beginning March 26.

With 13 years' experience in broadcasting, Ms. Fraser brings a wealth of media and public relations expertise to her new role. As producer, executive producer and show host, she is responsible for creating dozens of awardwinning news and public affairs shows. In addition to hosting *Lunch With Kim, The Kim Fraser Show* and

Saturday and Sunday in Montreal, Ms. Fraser was a regular commentator on CTV.

Ms. Fraser joins the foundation after playing a key role in the broadcast of the Foundation's annual Caring for Kids Radiothon. She has been involved since the Radiothon's inception in 2004 and has a great passion for the cause.

Events

QLW raffle

In celebration of Mother's Day, the MCH Quality of Life at Work Committee will hold a draw of three baskets (Regal and Mary Kay products) on May 11. Each basket is valued at approximately \$100. The tickets are \$2 each, and will be available from April 10 to May 9. Contact Johanne, ext. 23478, or Christiane, ext. 22514 to purchase your tickets.

 \sim 25 per cent of proceeds will be donated to the MCH Quality of Life at Work Committee for employee activities at the hospital.



Golf tournament to benefit the MCH Auditory Sciences Laboratory

Saturday, June 2

Club de Golf Hemmingford Golf Club 313 route 219, Hemmingford, Quebec For registration and donations, contact: **Martine Lestage** at 514-412-4400, ext. 23685 or (pager) 514-406-2382, or **Chantal Lefrançois** at 514-412-4498

Teen Road Safety = No Accident

Did you know that motor vehicle collisions are the number 1 cause of death in teenagers in Canada? Young drivers make up only 10% of road users, but are involved in 24% of crashes causing injury in Quebec.

On April 26, 2012, members of MCH Trauma, as well as representatives from Mothers against Drunk Driving and the Société de l'assurance automobile du Québec will be answering questions regarding road safety for young drivers in the 2B clinic area from 9:00 a.m. to 2:00 p.m. We will distribute our new educational materials and provide lifesaving tips on how to ensure that you and your teen are safe on the road. Participants will have an opportunity to try out Beer Goggles and will have the chance to win exciting prizes. Come join us for an informative and innovative day.

For more information please contact:

Liane Fransblow

MCH Trauma

Ext. 23422 or liane.fransblow@muhc.mcgill.ca

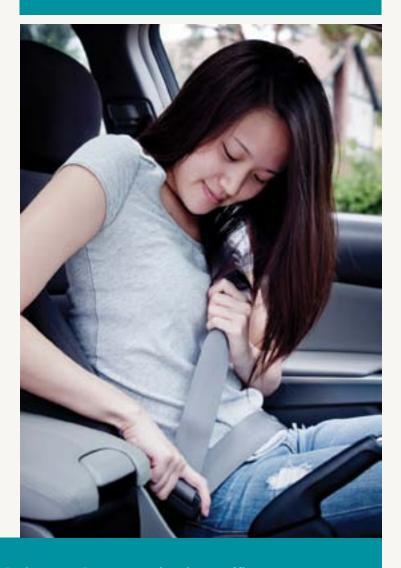
MCH Auxiliary activities

All sales take place on 2B

Wednesday, April 11 Videos, books and toys

Wednesday, April 18 Knits

Wednesday, **April 25** Miscellaneous



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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.







Volunteers @ work

Celebrating National Volunteer Week: April 15 to 21, 2012

In March of this year, the results from the most recent Canada Survey of Giving, Volunteering and Participating were released and the news was very positive: over 13 million Canadians take part in volunteer work, an increase of almost one million over the previous year. What's more, young Canadians are volunteering in ever increasing numbers. Ann Hébert, head of Volunteer Services at The Montreal Children's Hospital, says that's good news for everyone. "We're lucky enough to have almost 400 people volunteering at the MCH on a regular basis," she says. "Our volunteers have so many amazing skills and talents to offer us, and every day, throughout the hospital, you can see these people in action."

A couple of weeks ago, we stopped in to a few places around the hospital to see what some of our volunteers were up to. Here are some of the people we met:



In celebration of National Volunteer Week 2012, we thank all of the dedicated individuals who give their time to the Montreal Children's Hospital. Every day, you help us go that extra mile to provide the best care possible to our patients and their families.



Surgery can be scary

MCH Child Life Specialist helps kids cope

By Lisa Dutton

ny visit to the hospital can be a frightening experience. Surgery in particular can be scary because it is a new unknown experience. That's where Child Life Specialist Sabrina Drudi comes in. She makes having surgery, particularly day surgery, more palatable by using everything from guided imagery to music and games to help kids and teens have a more positive experience.

Sabrina began working as a Child Life Specialist in the ER in 2006. "Play is the child's language and a natural part of everyday life. In the hospital, playing becomes a therapeutic tool helping the child communicate and problem-solve in his own way. Playing prior to surgery, helps diminish patient and parental anxiety by focusing on a pleasant and comforting experience." Since 2009, Sabrina has been working with children and families arriving for day surgery. "I love being able to prepare and empower children to have the most positive OR experience possible," says Sabrina.

Age-appropriate preparation

Sabrina's work with a patient and family begins in the Day Surgery Waiting Area. Meeting the patient and family and building a trusting relationship are crucial steps to enabling a positive hospital experience. Sabrina then prepares children for their surgery using audio-visual materials, Benny the Bear and a medical play kit. These tools help familiarize the child with the upcoming procedure. During this preparation, coping strategies for the induction process are also reviewed and rehearsed with the patient.

Many children can become anxious at the moment they have to change into a hospital gown. Letting go of their clothes is a symbol of the loss of control and security they may feel. So Sabrina makes a point of calling these gowns "hospital pyjamas". Children also receive hospital pyjamas for their stuffed animal. These child-friendly pyjamas are generously sewn and donated by volunteers.



Innovative project on the rise

Particularly anxiety inducing for children can be the separation from parents at the OR doors. Many North American pediatric hospitals allow some parents to accompany their children during the induction process. Studies show that allowing a calm parent to be present relieves anxiety for the child and increases the family's overall satisfaction.

In February 2011, a partnership between the Anesthesia Department and Child Life Services began. This partnership has given Sabrina the opportunity to accompany 38 patients into the OR. This initiative is a stepping stone towards Parental Presence during Anesthesia Induction (PPI).

(Continued from page 9)

At times, children may be identified by surgeons and pre-op nurses as particularly anxious about their pending surgery. Sabrina is then consulted to accompany the patient during anaesthesia induction. She meets with the child and family prior to the big day in order to provide age-appropriate preparation, well as to help the child develop coping techniques such as guided imagery for the induction process. Using the anesthesia mask as a jumping-off point, Sabrina and the child will weave a tale led by the child's imagination. These stories could be about deep sea diving, swimming with dolphins or a trip to outer space. Sabrina encourages them to rehearse the story in the days leading up to the surgery.

On the day of surgery, Sabrina will review with the child and family, the preparation for surgery as well as the coping strategy chosen. To ease the process further, Sabrina also changes into scrubs while the patient changes into their hospital gown. Then, along with the nurse, Sabrina holds the patient's hand and accompanies him into the OR. Since hearing is the last sense to "go to sleep" during anaesthesia induction, music and an ocean drum are also used to enhance the guided imagery experience. "When a child tells me, after his surgery, "J'ai réussi ma chirurgerie," I know I helped play a part in improving the child's surgical experience" says Sabrina. She also admits, that parents see the benefits that the hospital's 15 Child Life Specialists provide, and often ask why adult hospitals don't offer a similar service.

When it comes time for Sabrina to relax, she hits the dance floor with her fiancé, dancing the Tango or the Puerto Rican dance called the Bachata. "It's fun and it helps me de-stress after work," says Sabrina. "I am so lucky, my fiancé loves to dance; it's a passion we share." The two will tie the knot on June 30th.

The Family Advisory Forum recently presented Sabrina Drudi with the Patient and Family-Centered Care Award. Sabrina's work as a child life specialist is remarkable. She helps patients build confidence before surgery and follows them through post-op while making their families feel comfortable at a time when they feel helpless. Her efforts play an important role in creating successful outcomes for patients and their families.



Practicing Patient and Family Centred Care

Involving patients and families as partners and advisors will...

- Bring important perspectives about the experience of care
- Teach how systems really work
- Inspire and energize staff
- Keep staff grounded in reality
- Provide timely feedback and ideas
- Lessen the burden on staff to fix the problems... staff don't have to have all the answers
- Bring connections with the community
- Offer an opportunity for patients and families to "give back"

(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.