News

A young girl's face is stretched in innovative surgical procedure

MCH surgeons first to perform procedure in Quebec

By Lisa Dutton

ynthia Maldonato is 11 years old. She loves to sing in her church choir and her favourite subject in school is math. Instead of sporting the usual 'tween wardrobe of jeans and a hoodie, Cynthia dresses a little more elegantly. During a recent pre-surgical visit to The Montreal Children's Hospital of the McGill University Health Centre, she wore a skirt, blouse, jacket and black pumps. She also carried a dainty handbag.

Cynthia's dad, Galby Maldonato says his daughter is a like a magnet, people just naturally flock to her. He credits this to his daughter's kind, gentle and beautiful soul.

While the vast majority of people are kind and friendly, and even protective towards Cynthia, there are always a few who, unwittingly or not, make insensitive and hurtful comments about the way she looks. Cynthia was born with Crouzon Syndrome, a rare genetic disease which causes premature fusion of a baby's bones. As a result, Cynthia's skull is completely misshapen, her eye sockets are too shallow so her eyes bulge and constantly tear, and she can't close her eyes completely even when she sleeps. She has difficulty breathing through both



her nose and mouth; she has a significant underbite, which makes eating a challenge and eating hard foods such as apples impossible. Fluent in both French and Spanish, Cynthia also has a pronounced lisp.

"Her face is bowl shaped," says plastic surgeon Dr. Mirko Gilardino, one of two surgeons involved in Cynthia's care. "She has a very restrictive mid-face, it's almost caved in completely."

Diagnosed with Crouzon Syndrome at birth, Cynthia has already

undergone four surgeries including one to advance her forehead to allow her brain to grow.

On January 25, Cynthia underwent a newer type of surgery, the first of its kind to be done in Quebec. The surgery, performed by neurosurgeon Dr. Jose Montes and Dr. Gilardino, will essentially allow her mid-face, orbits and forehead to be stretched forward, as much as 21 millimetres.

During the challenging six-hour surgery, the surgeons peeled off her face after making an incision

(Continued on page 2)

from ear to ear. Then Dr. Montes used a special surgical saw, with a protector on one side to prevent injury to her brain, to remove her forehead exposing Cynthia's brain. At this point, Dr. Gilardino stepped in to continue the cutting. Using a surgical chisel and hammer, he cut the bone along both sides of her face and across the bridge of her nose so the whole face became mobile.

The next step was to fit Cynthia with what is called an external distractor halo. The semi-circular metal device looks like something out of a science-fiction movie. It was attached to the sides of her head with screws, just above and behind her ears. Dr. Gilardino also inserted four screws into Cynthia's face, two near her eyebrows and two on either side of her nose. Wires attach the screws to the halo.

The surgery went extremely well but due to the expected swelling, Cynthia was kept sedated and on a ventilator in the PICU for 48 hours. About a week after the surgery, Dr. Gilardino, with the assistance of Cynthia's parents, started the process of advancing her face, one millimetre per day. As the injured facial bones start to knit together both the bone and soft-tissues are "stretched" with the distractor to generate new tissue. The procedure is known as a monobloc distraction.

"Believe it or not, her parents are turning the four screws on Cynthia's face twice a day, morning and night," says Dr. Gilardino. "The stretching really doesn't hurt, but it will pull her face forward half a millimetre at a time over a period of three weeks." It works somewhat like braces on teeth.

As her face is stretched, her eyes will become less prominent as the orbits deepen, and her teeth will become more aligned. "I can adjust the alignment of Cynthia's face, pulling the bones of the face upwards, downwards, to the left or to the right. I can adjust it as we go," says Dr. Gilardino. "It is far from perfection, but it is a nice controlled gradual movement. During the distraction phase (stretching phase), I'm really focusing on her eyesif I overdo this, she'll end up with beady eyes. I want to make sure this doesn't happen."

In fact, Dr. Gilardino is planning to overstretch Cynthia's face in order to account for Cynthia's continued growth. This way she'll grow in to her new face.

Once the period of stretching is over, Cynthia will have to continue wearing the halo for about two months to allow her bones to set and harden. After that it is a simple procedure to remove the halo and screws. She might need another small surgery down the road to fine-tune her bite.

Dr. Gilardino is Director of the MCH Craniofacial and Cleft Surgery Team. He joined the MCH in 2008, along with Dr. Broula Jamal, the team's specialized craniofacial orthodontist. Cynthia is the first MCH patient and the first patient in Quebecto undergo this new "monobloc distraction" technique. The new technique has significant benefits in terms of post-operative infection. The traditional way of advancing a patient's face carries a nearly 50 per cent risk. With this new procedure, the risk of infection is reduced to virtually 0 per cent. Dr. Gilardino estimates he may do as many as four of these surgeries per year.

During an interview prior to the surgery with Gazette health reporter Charlie Fidelman, Cynthia confided she was very much looking forward to the surgery, because she wants her eyes to look normal, and her teeth to come together. And she wants to look like her brother and sister. She also told the reporter that she is eager for the surgery because she wants to look good for her 15th birthday celebration, the *Quinceañera*, an important celebration in the life of a teenager – like the Latin version of a Sweet 16.

The 2010 Awards of Excellence: Call for nominations ends February 26!

The Children's is truly distinguished by its people. In all areas of the Hospital, there are unsung heroes whose dedication and drive are responsible for earning The Children's its reputation of excellence in care. You can highlight their contributions by nominating one of your esteemed colleagues for an Award of Excellence. Nomination forms are available at thechildren.com. Don't delay! The deadline for submissions is February 26.

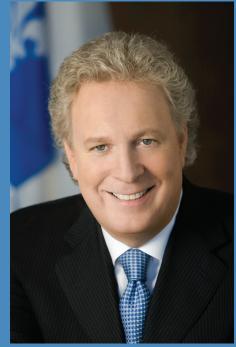
Correction

The previous issue of *Chez nous* included a photo of the members of the Council for Services to Children and Adolescents (CSCA). Several CSCA members were absent when the photo was taken. Their names are: Dr. Jean-Pierre Farmer (Surgeon-in-Chief), Dr. Warren Steiner (Interim Chief of Psychiatry), Ms. Jill Hugessen (representative from McGill University), Sen. W. David Angus (Chairman MUHC Board - exofficio member), Dr. Arthur T. Porter (CEO MUHC - ex-officio member), and Ms. Linda Léveillé (Council of non-professional staff).

Quebec Premier Jean Charest and his wife, Michèle Dionne, Patrons of Honour of the ABC Awards Ball for The Children's.

The MCH Foundation is proud to announce that Premier Jean Charest and his wife, Michèle Dionne, have generously agreed to be the Patrons of Honour of the 2010 ABC Awards Ball for The Children's, to be held on May 27, at Windsor Station.

In keeping with annual tradition, Marianna Simeone and Rémy Girard will return to host the Awards of Excellence ceremony that will highlight the accomplishments of ten outstanding individuals who have helped make The Children's an extraordinary hospital. The Children's official Ambassador, Nikki Yanofsky, will grace the stage. Guests will be dazzled and entertained, "Hollywood-style".





For information and tickets, contact Tatiana Aparicio at 514-934-4846, ext. 29229.

Vigilance and patient safety go hand in hand

Man was made at the end of the week's work, when God was tired.

- Notebook, 1903; Mark Twain, a Biography

By Lisa Dutton

"As human beings, we have the right to make mistakes but we cannot make the same mistakes twice," says Dr. Micheline Ste-Marie, Director of Professional Services at the MCH. "Health professionals need to be aware of their limitations as well as those of the healthcare system and put barriers up to prevent adverse events from happening."

For the last eight years, Dr. Ste-Marie has chaired the *Groupe vigilance pour la sécurité des soins*. Composed of experts in all fields of healthcare and safety and of patient representatives, the *Groupe vigilance* is a permanent consultative body to the Quebec Minister of Health and Social Services.

It was established in 2000, following a series of tragic adverse events in the province, by then Quebec Health and Social Services Minister Madame Pauline Marois. The group's role is to advise the Ministry on all aspects of patient safety including leadership, information to patients, research, management of healthcare facilities, risk management, accreditation and competency.

"Basically, our goal is to make patient safety a force within the ministry of health," says Dr. Ste-Marie. "In health care, there are a lot of people involved, it is a complex system. No one gets up in the morning deciding to do harm to their patient, but human error is unfortunately inevitable," says Dr. Ste-Marie. "So, before ordering any test, doing any procedure, ask yourself, 'is this in the best interest of this child?' Then ask yourself, 'if this were my child, would I do it?'"

Dr. Ste-Marie says patient safety is something that must always be on our minds. "Patient safety needs to be part of our culture, part of our DNA from the Associate Executive Director all the way down."

Changing the way we care for kids

The MCH establishes the Brain-Development-Behavior Integrated Clinical Network.

By Lisa Dutton

As we prepare for the move to our new hospital, the MCH is looking at its operating structure, or the way we take care of children and their families, in order to find better and more efficient ways of taking care of patients. This process has led to the creation of "integrated clinical networks."

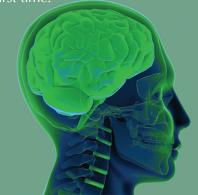
Why are we doing this?

Hospitals tend to 'work in silos'. This refers to each service doing its own thing, quite independent of other services. As a result, parents often find themselves going from one service to another, trying to figure out what type of care their child needs and how best to navigate the health care system. Take, as a hypothetical example, a young child who is having trouble acquiring language and social skills. The child is falling behind peers. A pediatrician refers the child to Neurology for an evaluation. The family waits for an appointment to discover that the child has an autistic spectrum disorder. The family goes back to the pediatrician who refers them to Psychiatry. They get on another waiting list only to discover there are also parenting and behavioral issues, requiring a subsequent referral to Child Development.

How will Integrated Clinical Networks make things better for our patients?

"The goal behind creating integrated clinical networks is to get services with natural alliances to work more closely together, cooperating, with a view to improving access to services, coordination of care, and internal

and external communications," says Dr. Eric Fombonne, Director of the Autism Spectrum Disorders Program. "Ultimately, the patient will get the right care, from the right service(s) at the right time, the first time."



Since October 2008, representatives from Psychiatry, Child Development and Neurology have been working together to create the Brain-Development-Behavior Integrated Clinical Network (BDB).

"Having these services work together allows for the coming together of the brain and the mind. They have many shared or overlapping patient populations," says Dr. Michael Shevell, Director of Pediatric Neurology. "It just makes good sense that by working together and developing joint protocols and processes, our patients will benefit from a team approach."

In fact, these services have worked quite closely for the last six years, but often on an ad hoc basis. The creation of the BDB Network is a way of formalizing this partnership and providing an organized, structured model of interaction.

"Parents will be relieved to know their children will be taken care of in the right way, even before they arrive for their first appointment, eliminating the frustrating hit-andmiss cycle. With integrated clinical networks, the care is seamless, eliminating duplication and delay of service and brings together specialty services for improved patient care delivery," says Dr. Emmett Francoeur, Director of Developmental Pediatrics. "This collaborative approach to dealing with complex cases opens the way to new methods and calls for the review of some of our practices, helping us build a framework to transform teaching programs and create new avenues for research", says Ms. Gratienne Lamarche, Clinical Manager, Pediatric Psychiatry.

Can these networks be established quickly?

Creating integrated clinical networks is not easy. It takes a lot of work to get services working side by side.

Among the BDB network's objectives is to create a "guichet unique" or central intake for patients with preschool developmental and behavioral issues. "These patients would ideally undergo a standardized triage by a BDB Network health professional," says Ms. Randy Robins, Administrative Head, Developmental and Behavioral Pediatric Services. "Based on an established protocol, the health professional would then decide on which service(s) must intervene as a priority and what type of tests and appointments need to be set up: a one-stop shopping approach to care."

While this sounds pretty straightforward, it actually isn't that simple. The network needs to: define the target patient population(s), implement process(es) to effectively and accurately pre-triage these patients, develop standardized evaluation tools, develop protocol(s) for post-evaluation, develop performance and outcome measures, identify resource needs, and ensure that the network fits seamlessly and effectively into an ever-evolving health care system.

What has BDB achieved to date?

Slightly more than a year into the process, much has been achieved. "The early months were spent getting to know each other, conducting research on the existence of other such models as well as trying to establish a shared direction," says Demetra Kafantaris, Senior Advisor Corporate Affairs and coordinator of the BDB project. "Since its inception, we have made tangible progress."

- 1) Waiting lists were cross-referenced to asses overlap/duplication; surprisingly few overlaps were found.
- 2) Joint BDB conferences were launched in October 2009. Six conferences will be held per year with each service alternating as host and organizer. The next conference is on March 1st.

- 3) Organization of joint teaching and research opportunities is ongoing.
- **4)** Mechanisms to improve communication of clinical information between services are under review.
- 5) Establishment of the "guichet unique" is entering a pilot project phase.
- **6)** A joint vision will be developed for the Glen site.

Is anyone else doing this?

To date, there are few examples of this kind of integrated model of care but some new potential partnerships within Quebec and North America are emerging.

Will the MCH develop other Integrated Clinical Networks?

The hope is that as we prepare for our transition to a new hospital, other similar networks will be developed within the MCH to streamline processes, improve access to and coordination of patient care, optimize utilization of resources, and improve teaching and research opportunities. MCH Senior Management is working on identifying the next set of priorities. Stay tuned.

Anthony and Alexia Calvillo bring Grey Cup to Sarah's Floor at the MCH

Alouettes quarterback Anthony Calvillo and wife Alexia made a heartwarming and inspirational visit to Sarah's Floor for Pediatric Oncology at the Children's, on January 24. Much to the surprise of patients and their families, the celebrated Grey Cup winner and CFL 2010 most outstanding player brought the Grey Cup along with him.

On January 21, Alexia Calvillo (I.) and Anthony Calvillo (r.) met some of our patients including Erika Cheng-Tarantino and her parents. Calvillo, quarterback with the Montreal Alouettes, brought the Grey Cup along for the visit!



Please note that **Monday**, **February 22**, will be a **statutory holiday** for employees of the MCH, as well as other hospitals of the MUHC. On this date, the hospital will function on a weekend schedule with only essential services maintained. Make sure to advise all patients who are being referred to clinics and diagnostic services without appointments.

The Therapeutic Nursing Plan is in place!

Starting in April 2009, l'Ordre des infirmières et infirmiers du Québec (OIIO), introduced a new Professional Standard: The Therapeutic Nursing Plan (TNP) or Plan thérapeutique infirmier (PTI). This documentation tool, legally acknowledges nurses' responsibility competence and regarding their clinical assessment. The nurse determines and records a Therapeutic Nursing Plan along with any subsequent adjustments she or he makes based on the client's clinical course and the effectiveness of the care and treatment.

Preparation for the implementation of the TNP started in June 2008. After initial discussions, it was decided to roll out the implementation unit by unit, to ensure the maximum of support, and also for the fine tuning of the implementation process.

The units that piloted the implementation were our oncology/hematology unit and our technology dependency unit. These units have small patient groups, with a longer length of stay thus allowing nurses to create and update the plans as their care evolved. The units identified 'resource 'nurses who would receive the initial theory of the PTI and then act as support nurses for their teams.



Discussions took place with all inpatient and out-patient leadership groups to find the best approach for that unit in regards to practice change. Our goal was to promote PTI as a tool to improve communication if used properly and try to integrate it with existing documentation to avoid duplication.

Our team offers ongoing guidance/ mentoring with the leadership and the nursing group from different areas via email, phone or group discussion. We receive ongoing support from our MUCH PTI leader (Emma Monaco), our ADON (Barbara Izzard) and our Staff Development Practice Consultant (Eren Alexander).

On December 1, 2009, a chart audit was conducted on several in-patient units to determine the presence and the accuracy of the Plan thérapeutique infirmier (PTI).

The results were very encouraging with 90-100% of patients having a PTI. Those patients who did not have a PTI had been admitted to hospital less than 12 hours.

Implementation will occur in the Emergency Department in early 2010. Congratulations to all the nursing teams for their hard work.

Margaret Ruddy, Nursing Supervisor Anne Choquette, CNS, Hematology-Oncology Marlene Cairns, Nursing Supervisor



Memorial service at the MCH

A memorial service is being organized to remember the children who have died recently at the MCH. We shall also be commemorating children who have died of SIDS. All staff members are warmly invited to attend this service.

Tuesday February 16 2 p.m. Amphitheatre (D-182)

Auxiliary Sales

- Wednesday, February 17: Videos
- Wednesday, February 24: Hand-knitted items
- Wednesday, March 3: Miscellaneous
- Tuesday, March 9: Baked goods and savouries
- Wednesday, March 10: Books

All sales take place on 2B



MCH Staff @ work



Martine Nagy,

Telehealth 19 years at th<u>e MCH</u>

Tell us something about yourself: I like to cook when I have the time. I redid the landscaping in front of my house. I also like to crochet, can preserves, knit and I really enjoy getting outdoors to walk, snowshoe, cycle, etc.

What do you like about working at the MCH? I like the diversity of the people I've met – and continue to meet – in the various positions I've held at the MCH.

Louise Martin,

Ambulatory Services 19 years at the MCH

Tell us something about yourself: Something about myself... (I feel like I'm signing up for on-line dating ... okay just kidding!) I like to read and I scrapbook a little. Spending time with my friends and family is very important to me.

What do you like about working at the MCH? I love my co-workers; we are like a big family. This has been said before, but it just proves that it's true.

Continuing Education

Pediatric Grand Rounds

8:00 a.m. Amphitheatre

Feb. 17

Universal Newborn Hearing Screening Anne Marie Hurteau, M.O.A., Audiologist, Professional Coordinator of MCH Audiology, Department Clinical teacher at University of Montreal, Member of the Advisory Committee on UNHS at the MSSS

Feb. 25

Pediatric Jeopardy
Dr. Pamela Valentino
Dr. Tanya Di Genova
Chief Pediatric Medical Residents
The Montreal Children's Hospital – MUHC

Research Institute Seminars

Monday, 12:00 noon C-417

C-41/

February 15

mRNA Export, Signalling, Cancer and Patients: A Day in the Life of the Oncogene elF4E Dr. Katherine Borden Institute for Research in Immunology and Cancer Université de Montréal

March 4

Segmenting the Urinary Tract: Which Way Is Out? Dr. Doris Herzlinger Department of Physiology and Biophysics Weill Medical College of Cornell University New York, New York

Our People

Lucy Caron

Creativity and team work key to meeting hospital's challenges

By Lisa Dutton

As I walk in to Lucy Caron's office, she looks at me and says "Today is a good day, today is a good, good day." She isn't parodying the Black Eyed Peas, she's reveling in a small victory: a nurse who was lukewarm about continuing to work at the MCH had just come to see her to report that he loves his new assignment and its challenges. The MCH nursing team kept this experienced pediatric nurse in the department and thus it was a "good, good day".

As the newly appointed Nursing Administrative Manager, Lucy is responsible for nursing services on the wards and for patient flow (patients going from the ER to the ward; moving from the PICU to the ward). The job has its challenges.

"In the past five years, patient acuity (how sick children are) has increased significantly. The children are sicker and their care is much more complex. Patient acuity has revolutionized nursing at the MCH because nurses on the wards now take care of children who might previously have been treated in intensive care," she says.

Two other challenges: retirement of senior, highly experienced nurses and the influx of young nurses who need to learn a lot very quickly. But Lucy is undaunted. "No one has all the answers," she says. "Working together as an interdisciplinary team we can meet the needs of our patients and we can make sure our nurses are challenged and respected and that they enjoy a good work environment."

Growing up, Lucy envisioned becoming a nutritionist, not a nurse.

When she voiced her concern that her chosen career might not give her the amount of patient contact she was looking for, a counsellor suggested nursing. The rest, as they say, is history.



Lucy started at the Royal Victoria Hospital 33 years ago. She wanted to work in pediatrics but at the time peds nurses had to have extensive experience in adult care. Over the years, Lucy has become known as a creative thinker. "I think outside of the box," she says.

Asked to give an example of her creative thinking, she immediately recalls a little boy she cared for in the 1980s. She was working on the MCH's oncology ward. The child's mum had one item on the Christmas wish list – she wanted her terminally ill son to be home for the holidays. At the time, the hospital didn't offer today's well-entrenched ambulatory services. This request was unprecedented: the doctors were skeptical, and pain

control was a major issue. "We moved mountains to grant this mum's wish," says Lucy. "It required a mammoth amount of organization."

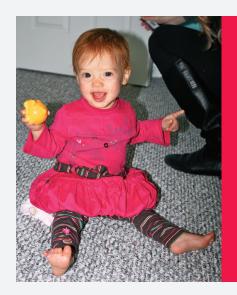
On Christmas day, the little boy was at home surrounded by family. He returned to the hospital the next day and passed away on December 30.

"This meant so much to the family and to the little boy," says Lucy. "The nurses and doctors had enough confidence in each other and the family to meet the needs of the patient."

Lucy is confident the MCH's 'can do' attitude will help us meet and surpass today's challenges. "All it takes is a little creativity, teamwork and a willingness to get the job done."

Lucy's creativity spills over in to her private life. She does needlepoint and recently took up scrapbooking. As well, Mike Holmes, Canada's Mr. Fix-it, had better watch out because Lucy knows her way around a tool box. Painting walls – no problem. Sewing curtains – no problem. Laying a hardwood floor – no problem. Plumbing – okay a little problem. Lucy recounts how she tackled fixing her broken dishwasher. She only made one tiny mistake. She forgot to turn the water off. Oops.

In her new job, Lucy expects a mistake or two will be made along the way, but she's set a very lofty objective. "I want to make sure the nurses at the MCH are the best they can be." No small order, but one Lucy is confident can be realized.



Our Heroes

Zoe's story: strength and hope in the face of a rare disease Baby girl inspires her parents to launch MCH fundraiser

By Denisse Campos

Tammy Nemes Saskin's pregnancy had gone very smoothly but not long before her due date, an ultrasound revealed that there was something wrong with one of her baby's lungs. The doctors were not sure what it was so Tammy and her husband Adam were sent to the Montreal Children's Hospital to meet with surgeon Dr. Pramod Puligandla. One week later, Tammy underwent another ultrasound which showed that it was actually a mass in the baby's lung and it had doubled in size. Tammy was sent for an emergency C-section at the Jewish General Hospital so that her baby could be treated right away.

Within moments of being born, baby Zoe was transferred to the MCH. Adam went with her while Tammy stayed at the Jewish General for the next three days--a very difficult moment for a mother who hadn't even seen her little infant before she was transferred. At the Children's, an ultrasound showed that the mass in Zoe's lung had exploded and blood had filled her chest. Dr. Jean-Martin Laberge and Dr. Puligandla performed surgery to remove the tumour and to stop the bleeding. During the surgery, Zoe lost so much blood that the doctors thought she wasn't going to make it, but as Tammy will tell you, "They are the most incredible doctors, they saved her life." Zoe's lower left lung and part of a rib were removed.

Zoe spent two weeks in the Neonatal Intensive Care Unit (NICU) at the MCH. "We were amazed at the dedication, compassion and skill of all the doctors and nurses," says Tammy. Once Zoe got stronger, she was moved to the surgical ward for a week and then was finally able to go home.

At only three weeks old, Zoe had met more doctors than most people will meet in a lifetime. Her tumour was extremely rare; many experts were consulted but nobody was able to provide a diagnosis. Zoe's oncologist, Dr. Sharon Abish, made the decision to monitor Zoe with MRIs every three months and ultrasounds every three weeks followed by check-ups with her surgeons.

Unfortunately, one of these MRIs showed that another tumour was present. "She had to undergo surgery again," says Tammy. "It was fast--two hours after the surgery she was home, but unfortunately the doctors still saw positive cells inside her chest." Since then Zoe has continued to return to the hospital for MRIs and ultrasounds regularly; for six months everything has been stable.

Doctors are still following Zoe regularly and her diagnosis is uncertain but they now think it could be infantile fibrosarcoma. If the tumour grows again, Zoe will need to

have another surgery and probably have to undergo chemotherapy.

Zoe's parents say she's doing well and seems so healthy. "When you see her, you wouldn't be able to tell that she has gone through all this," says her mom proudly. And Zoe can also be proud of her parents. Tammy and Adam faced this challenge with strength and hope and in the midst of everything they were going through, they looked for a way to give back to the Hospital, to show their gratitude for the treatment Zoe received at the MCH.

Last year, Tammy and Adam organized a ski-a-thon called 'Ski for The Children's'. A total of 60 skiers participated, each of whom called on their own network for donations. The support was incredible and they surpassed their target of \$50,000 by raising \$80,000 for a Giraffe incubator for the NICU. This developmentallyadvanced and supportive microenvironment is designed to minimize the effects of external factors such as light, sound and touch on a baby.

Plans are currently under way for this year's 'Ski for the Children's', on March 20 in Stowe, Vermont. This year's goal is to raise \$100,000 for the MCH. Visit www.skiforthechildrens. com for more information.