Treating chronic pain: helping kids return to normal lives

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Eight thousand children in the Montreal and Laval area currently suffer from chronic pain. Unexplained chronic pain—that is, pain with symptoms that are not due to significant injury or disease—is commonly referred to as non-specific, idiopathic, or functional pain. The most prevalent functional pain syndromes in children are growing pains, non-migraine headaches, and recurrent abdominal pain. Children and adolescents are also at risk of migraine, neck and back pains, chronic widespread pain, and its subset fibromyalgia.

Since there is often no diagnosis, children can end up seeing several specialists, be given unnecessary medications that can have adverse effects, and miss school before they are treated for chronic pain. Dr. Pablo Ingelmo, Director of the Chronic Pain Service at the Montreal Children’s Hospital (MCH), joined the MCH in 2013 for his specialization in pediatric chronic pain. “Three out of four children with chronic pain will grow up to be adults with chronic pain, but that ratio drops to one in three when they receive proper treatment,” he says.

**Difficult to diagnose**

In March 2015 at the age of 12, Lorenzo Accurso was experiencing severe abdominal pain. The source of the pain was thought to be appendicitis among other possibilities, but no
definitive diagnosis could be made. Once all the possible causes had been explored, Dr. Ingelmo and the Chronic Pain Service team took Lorenzo into their care. “Lorenzo had Functional Abdominal Pain Syndrome (FAPS), which is a diagnosis by exclusion,” says Dr. Ingelmo. FAPS is a visceral pain that is sometimes unexplained, but if there has been repeated injury in the abdomen, nerve receptors can become overly sensitive and a painful experience can be experienced as more painful than before (even the normal digestive process can come to be perceived as painful). The Chronic Pain team applied different medical approaches during Lorenzo’s first, week-long hospital stay. Unfortunately, the medical treatment did not work and a month later, Lorenzo found himself readmitted for six weeks.
“The pain was unbearable and because of it, he was exhausted,” explains Alessandra Marani, Lorenzo’s mom. “Lorenzo was put on a lot of medication, but nothing seemed to work and at a certain point he had had enough,” she says. During the worst periods, Lorenzo would get four to five attacks per day and because he could sense they were coming, he would become stressed and start to panic. It was so taxing on Alessandra to see her son in such a state that she would have to step out of his hospital room during the attacks. “Chronic pain doesn’t only affect the patient, it necessarily affects the whole family too,” adds Dr. Ingelmo.

**Taking the lead**

“The most effective way to care for patients who suffer from chronic pain is through an interdisciplinary approach,” says Dr. Ingelmo. On the Chronic Pain team, someone other than the physician often takes the lead. In Lorenzo’s case, it was psychologist Dr. Yves Beaulieu. “The pain can often cause catastrophizing thoughts and anything that enhances the system, like stress, makes the pain worse,” he says. Dr. Beaulieu worked with Lorenzo in the moments of crisis to give him tools to cope with the panic and pain. “We teach patients how to calm themselves by using their brain in a way that they are not used to doing.”

Lorenzo admits that at first he was skeptical about the proposed exercise. “But at that point I had to give it a try,” he says. Dr. Beaulieu showed Lorenzo breathing techniques to deal with the bursts of pain. “Before this, I would pace back and forth when I experienced the pain, which made it worse,” he says. “Dr. Beaulieu told me to imagine myself in a place that I enjoy and focus on how it made me feel.” Although it took a lot of practice, the exercise eventually helped distract him from the pain. Understandably, after weeks in the hospital, Lorenzo just wanted to go home, and even though he was getting better at using the techniques to deal with the panic and pain, he would not be discharged until he felt no pain at all.

“Now, I am perfect!” says Lorenzo matter-of-factly. He is in secondary three and plays football and rugby and does winter fitness at his school. “I was eager to stop taking the medication but Dr. Ingelmo asked me to continue, so I slowly decreased the dosage and eventually stopped going to the clinic altogether.” Considering that taking a walk used to be a challenge for Lorenzo, he has come a long way.
The Chronic Pain Service team cares not just for the patients but for their families as well. As a parent, Alessandra never felt alone. “Chronic pain takes time to heal and the people in the Chronic Pain Service help you go through the tough moments,” she says. With the support of the Montreal Children’s Hospital Foundation, Dr. Ingelmo and his team are achieving meaningful results. “We are returning both patients and families to normalcy and to society as functional members.”

The Chronic Pain Service approach encompasses the family as well as the child. From l. to r.: Dr. Yves Beaulieu, Alessandra Marani, Lorenzo Accurso, and Dr. Pablo Ingelmo.

MCH Town Hall

All staff and physicians are encouraged to attend the next MCH Town Hall being held on Wednesday, February 1, 2017, in the RI Auditorium (ES1.1129) from 12 to 1 pm.

Memorial service

All staff members are warmly invited to attend a memorial service on Friday, February 10, at 2 p.m. in the RI Auditorium (ES1.1129) to remember the children who have died recently at the MCH. Children who have lost their lives to SIDS will also be commemorated.
Happy New Year!

Everyone at the MCH should look back at 2016 with satisfaction and look forward to 2017 with excitement. Last year was a period of stabilization, collaboration and hard work at its best, as we got used to our new environment and identified our pediatric priorities. Building the Future of Excellence in Academic Child Care (BFEACC) was a consultation process that asked us to look at ourselves and see how we could elevate our practices and services as well as define where we want the MCH to be in five years. On a practical level, undertaking BFEACC prepared us for the MSSS- and MUHC-mandated consultation processes allowing us to be clear about where the MCH stands in the process. The exercise would not have been possible without your participation and input.

Although the MSSS and MUHC consultations have yet to be concluded, we can say for sure that four pillars have emerged from BFEACC that will inform every decision we make moving forward:

1. Developing patient, family and community partnerships
2. Moving research, teaching and innovation forward
3. Continuously improving quality, safety and efficiency
4. Building and sustaining human and financial resources

Keeping the four pillars in mind when making a decision, whether big or small, will keep us aligned internally, within the MCH and with the MCH Foundation, as well as with the MUHC and MSSS.

In 2017, we’ll begin preparations for the 2018 Accreditation Canada process, the first accreditation since the move. A new feature is a focus on patient involvement, which when considering how successfully we have adopted the Patient- and Family-Centered Care (PFCC) philosophy, places us in an advantageous position for favourable results on that front. Also this year, the annual Canadian Association of Paediatric Health Centres (CAPHC) conference will be held in Montreal and the MCH will play a big role and have a strong presence.

Key to developing and maintaining alignment are participation and communication. In 2017, we encourage you to share important memos with your teams and colleagues, encourage each other to attend town halls, meetings, and events, sign up for LEAN trainings, share ideas on how to involve patients and families and community partners, foster innovation, and improve quality, safety and efficiency.

We are sure that 2017 will continue to present challenges, but with clear objectives and tools we can align ourselves and move forward together without leaving anyone behind. Thank you for your passion, determination, and for always making patient care our number one priority. Here’s to making 2017 a year of great advancements!

Sincerely,

The Executive Committee (EXCO) of the Montreal Children’s Hospital

Dr. Lila Amirali
Dr. Robert Barnes
Frédéric De Civita
Dr. Jean-Pierre Farmer
Dr. Pierre Fiset
Dr. Annie Marleau
Randy Robins
Dr. Michael Shevell
Chantal Souligny
A team of surveyors from Accreditation Canada will visit the McGill University Health Centre (MUHC) from March 18 to 23, 2018. The goal of Accreditation Canada’s QMENTUM process is to encourage general participation from MUHC teams in our continuous quality and safety improvement endeavours.

The MUHC will undergo a series of phases in order to prepare for the visit. The first phase is called “Self-assessment” and will take place from January 9 to February 17, 2017. Staff and physicians, as well as patients and/or their families, will be invited to complete surveys that assess our conformity to quality and patient safety standards.

Accreditation Canada has recently revised their standards to reflect a shift in focus on increased patient involvement at all levels of the organization. Consequently, for the first time this year, patients and/or their families will be invited to participate in the MUHC’s self-assessment process by completing a short questionnaire regarding their care experience.

Your contribution is essential to the success of the Accreditation process. We thank you in advance for your participation.

**QUESTIONS & ANSWERS**

1. **What is QMENTUM?**
   In preparation for the Accreditation Canada visit, the QMENTUM process enables us to review our current practices and to identify areas where improvements could be made. In addition, the process evaluates our compliance with the Required Organizational Practices (ROPs).

2. **What are Required Organizational Practices (ROPs)?**
   ROPs are essential practices that minimize risk and improve patient safety. The MUHC must comply with 31 ROPs. A few examples include medication reconciliation, reporting and disclosure of incidents/accidents, staff education on hand hygiene, and the prevention of falls.

3. **How will the Required Organizational Practices be evaluated?**
   Proof of compliance with the ROPs will be evaluated with the use of:
   - Documentation such as policies and procedures, presentations, information extracted from reports, records and logs;
   - Compliance based on audits, which may include direct observation, consultation of relevant data, file review and interviews.

4. **How do staff and physicians participate in QMENTUM?**
   In the first phase, Self-assessment, many of you will be asked to complete at least one questionnaire. Staff will be given the questionnaire that best suits their work responsibilities.

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How much time does completing a QMENTUM questionnaire take?
Depending on the questionnaire, it will take 15 to 30 minutes.

If I work in more than one service, how should I respond?
You should answer based on the service in which you spend most of your time.

What happens to the QMENTUM questionnaires once completed?
Each MUHC interdisciplinary team will receive results of the questionnaires in the form of a Roadmap, highlighted with red, yellow or green flags. The red and yellow flags identify areas that need improvement. Each team will decide where to focus its improvement efforts, create an action plan, and begin to make necessary changes.

What happens during the Accreditation Visit?
During the visit, the surveyors will use the Tracer method to gather information. This means they will tour all the MUHC hospitals, talking to many different employees, physicians, patients and/or their families, reviewing documents, and observing a variety of activities to evaluate quality and safety of care.

What is Patient and Family Centered Care?
Patient and Family Centered Care is an approach to the planning, delivery and evaluation of healthcare where patients and families are partners in their own care and also within the organization. Involvement in the organization also includes quality improvement, management, research and teaching.

How will patients and/or their families participate in the QMENTUM process?
During the accreditation preparation phase:
• Patients and families will be invited to share their experience with us as part of the MUHC self-evaluation process. Their feedback, combined with results from other patient experience surveys, will be used to foster discussions among the interdisciplinary teams.
• Family partners will be integrated into MCH interdisciplinary teams. They will participate in the process of identifying areas for improvement and contribute to the development of action plans.

During the Accreditation Canada visit:
• A team of surveyors will meet with admitted patients and families to evaluate compliance with clinical tracers.
• Family partners will participate in planned meetings with the surveyors to evaluate compliance with administrative tracers.

Our goal is to make quality improvement an ongoing part of the MUHC’s daily operations and culture. The QMENTUM Self-assessments, Roadmaps, Audits and Visit will help us do just that, by asking all members of the MUHC community—including patients and their families—to participate. Share your ideas, help put your ideas into practice, and contribute to better patient care!

For more information on the QMENTUM 2018 Accreditation process, please consult the QMENTUM section of the MUHC intranet or contact Anne-Elyse Deguire by email at anne-elyse.deguire@muhc.mcgill.ca or by telephone at 514-934-1934, ext. 35662.

For more information on the MCH Patient and Family Centered Care component, please contact Alexandra Black by email at alexandra.black@muhc.mcgill.ca or by telephone at 514-412-4400, ext. 23991. 
PfCC Star of the Month: Paule Comtois, Nurse Clinician, Nephrology

By Maureen McCarthy

Marika Edvi, December’s PfCC Star, nominated her colleague Paule Comtois for this month’s award. “Paule worked for a time in Urology and that’s when I first got to know her,” says Marika. “Some of our patients are followed in both Urology and Nephrology so we often work together with the same families. She connects so easily with patients of all ages, and she advocates on behalf of families with everyone on her team. She is really knowledgeable and families know they can depend on her for guidance and support.”

When Paule started at the Children’s, she worked on the hospital’s medical unit but eventually moved to the Nephrology clinic. “I really like working here,” she says. “It’s an interesting field which covers a lot of issues and different problems. The families need a lot of support and that’s where I feel comfortable.”

Most of Paule’s patients have chronic kidney disease and many will eventually need dialysis and transplant. Paule’s role in the department is in a pre-dialysis context, which for any individual patient can span a period of months or many years. She also follows patients with glomerulonephritis.

For Paule, practicing patient and family-centered care means starting with the family. “When I first started in the clinic, I’d be so eager to give families all the info I wanted them to know,” she says, “but I’d sometimes notice they were lost in their thoughts.” She soon realized that it was more important to assess their needs first, an approach that she takes with each new family she meets.

Paule sees the family as the centre of the team, and in Nephrology, the multi-disciplinary approach is always evident. “We work with many people whether it’s a social worker, nutritionist, nurse or physician. My goal is always to support the family and help them take charge of their child’s disease, and be ready for dialysis and transplant when the time comes.”

Even though many of Paule’s patients transition to dialysis and are then under the care of another nurse, she continues to communicate with them about what’s happening in their lives. The nephrology team members also keep each other up-to-date on their patients. “We have great communication in our department,” she says. “Everyone in our group brings their knowledge to the table so that we always try to get what’s best for every patient and their family.”

Our PfCC Stars are featured on the Children’s Facebook page each month. Here’s what people had to say about Marika.

Julie Côté
Marika is the nurse who looks after my daughter in Urology. It’s great to feel like someone is listening to us, and she always takes her time with us.

Tracey Mulholland
Way to go Marika! You deserve the recognition! Merci Marika!

Andrea Nagy
Fantastic! Way to go Marika!
Six-year-old Matis was born with esophageal atresia. He had his first surgery only six hours after he was born, and since then, has undergone more than 10 procedures. His parents Mélanie and Stéphane say the surgeries Matis had as a baby didn’t take a big toll on him but as he got older, his awareness of what would take place caused a great deal of anxiety not only for him but for his mom and dad too. A special program at the Montreal Children’s Hospital (MCH) however, has made a world of difference to the family. Unique in Quebec, the Children’s Parental Presence at Induction (PPI) program is led by Child Life Specialist Sabrina Drudi, who works in collaboration with the Anesthesia department to help ease the stress that comes with surgery for the patients and families involved.

Preparing the child, reducing anxiety
Sabrina has worked at the Children’s for 10 years, and since 2011, has been developing the PPI program in partnership with the OR staff. In her first year, she saw several dozen patients. Today, thanks to support from the MCH Foundation and one of their generous donors, Sabrina sees approximately 600 patients and their families every year. The day of Matis’s surgery was the third time Sabrina prepared him and his family for surgery. Sabrina tailors each session according to the patient’s age, stage of development, level of anxiety, and previous hospital experience. Since the program involves one of the child’s parents accompanying them into the operating room, Sabrina also works closely with the parents to answer their questions and help prepare them for what to expect. She continued >>>

▶ Mélanie holds Matis as Dr. Pierre Fiset speaks quietly to him while administering anesthesia. According to Dr. Fiset, the PPI program has meant that many children need fewer medications to calm them down before going into the OR.

A family affair
Parental presence at induction helps ease stress for both generations

By Maureen McCarthy
uses everything from guided imagery to music and games to help children and teens have a more positive experience.

Sabrina’s session with Matis and his parents lasted about 45 minutes. In a typical day, Sabrina sees five to seven patients in the Surgical Day Centre. She uses medical play to prepare the child for surgery. “The child doesn’t have a choice about surgery but we give them other choices,” says Sabrina. “Together, we decide what scent will be added to their mask, the comforting item that will accompany them into the OR, as well as the comforting strategy they will use while falling asleep. With Matis, we created a story about going deep sea diving. We even played with an anesthesia mask to help him be as calm as possible when having anesthesia.”

**Peace of mind for parents**

Mélanie and Stéphane are very happy the PPI program exists. “Being able to go into the OR with him and stay there while he falls asleep gives us a lot of comfort,” says Mélanie. “And telling him that we’ll be there when he wakes up reassures him too.” Mélanie acknowledges that it’s not always easy to see your child receive an anesthetic but being with them until they’re asleep actually helps reduce the stress of waiting for the procedure to be done. “It’s a really great program, and we’ve seen how it helps him and us both physically and psychologically.”

Matis has had problems with recurrent pneumonia as a result of his atresia. His most recent procedure at the Children’s was done to see if the problems he was experiencing were getting better. Dr. Dominique Lévesque, Matis’s gastroenterologist, says the PPI program has helped their work tremendously. “The operation was a success and Mélanie accompanying Matis into the OR helped things go smoothly,” she says. There will be more procedures in Matis’s future, but he’s less anxious than he used to be and as a result, Mélanie and Stéphane are less anxious too. “I think we’re often more stressed than he is but to see him go into the OR with a smile on his face really helps,” says Stéphane. “It’s such a positive change for all of us.”
Which of your coworkers personifies excellence?

Administrative and Clinical Support Staff
Professional Staff
Research
Medical
Nursing
Teamwork

Tell us before February 20th!

Nomination forms available now at the Children’s Foundation office (BRC.0010) or online at childrenfoundation.com

Awards ceremony sponsored by: Pfizer