

Chez nous

MCH EMPLOYEE NEWSLETTER

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Finding pain relief from an unexpected treatment

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Hôpital de Montréal
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Montreal Children's
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Finding pain relief from an unexpected treatment

MCH patient becomes first child in the world to use nitrous oxide at home to relieve pain

By Stephanie Tsirgiotis



► Skin care is a critical part of Evan’s everyday life. He uses nitrous oxide, more commonly known as ‘laughing gas’ to relieve pain while his mother, Yandy, cares for his blisters.

Last April, eight-year-old Evan Prescott trained for months with friends before running two 50-metre races in the Défi Sportif Altergo, a Quebec sporting event for children with special needs. Not only did he cross the finish line first, but he achieved a major milestone – he ran.

A RARE AND SHOCKING CONDITION

Evan was born with epidermolysis bullosa, a rare genetic condition that causes the skin to blister easily. “We knew something was wrong at birth, because he was missing skin on his palms and heels,” says his mother, Yandy Macabuag. Evan was immediately transferred to the Neonatal Intensive Care Unit (NICU) at the Montreal Children’s Hospital (MCH). Overnight, he started

to develop blisters all over his body; some were even as large as his hand.

One of the residents had treated a patient with similar symptoms during her training in Ireland, and Evan was diagnosed with a milder, yet severe version of the condition, called generalized severe simplex. But it wasn’t hereditary. “There was no genetic link to my husband and me,” says Yandy. “In Evan’s case, he was missing a protein called keratin 14.”

Epidermolysis bullosa can be fatal, especially during the first year of life, because of infection and failure to thrive. At one month old, Evan had a gastrostomy tube inserted to help with

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feeding because he wasn't latching properly. He would break out in blisters around his lips because of the friction from breastfeeding. "Evan has to eat even more calories than a normal child because his body is constantly healing," explains Yandy.

His body was also covered in open wounds and his parents had to keep him bandaged from head to toe. "Learning how to meet all of his needs was extremely challenging," recalls Yandy. "Every child with this condition responds differently to it." At six months old, Yandy and her husband Marc decided to stop bandaging Evan because his body wasn't responding well to humidity and it was leading to even more blisters.

LEARNING TO LIVE WITH THE DAILY ROUTINE

On any given day, Evan has a minimum of 10 blisters on his body, some smaller than others, but painful nonetheless. His hands and feet are prone to more blisters, because they are the most sensitive parts of his body. "At home, Evan moves around on his knees 75 percent of the time, because it's too painful to walk," explains Yandy. "For some reason, he doesn't blister on his knees and elbows. Those areas have developed callouses instead."

At school, Evan uses a wheelchair most of the time. He also writes with an iPad or works with a scribe, a teacher's assistant who writes for him. "But he's a stubborn eight year old so he wants to do everything himself," laughs his mom. He also prefers winter weather, because his skin is drier and blisters less, but the friction caused from wearing so many layers of winter clothes doesn't help his condition. "The fall going into winter is definitely the best period of time for him," says Yandy.



► At home, Evan moves around on his knees 75 percent of the time, because it's too painful to walk. At school, he uses a wheelchair most of the time.

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On the cover: Evan Prescott with his mother, Yandy Macabuag.

Cover photo: Owen Egan

Finding pain relief... (cont'd)

Skin care is also a critical part of Evan's everyday life. His parents clean, lance, and drain his blisters twice a day. If they notice an infection, Evan takes a bleach bath and rubs the open wound with antibiotic cream. He also takes a salt bath every second day to prevent infection by drying out the skin. "This is all part of our daily routine."



▶ Evan enjoys playing the piano in his spare time.

FINDING A WAY TO RELIEVE THE PAIN

Three years ago, Dr. Hema Patel, Director of Complex Care Services at the MCH, talked to Dr. Pablo Ingelmo, Director of the hospital's Chronic Pain Service. They were looking for ways to manage Evan's pain, especially during his skin care. Dr. Ingelmo created a special interdisciplinary team to deal specifically with Evan's case, made up of Dr. Yves Beaulieu (Psychology), Rachel Gauvin (Physiotherapy), Annie Guillemette (Pharmacy), Dr. Fatemeh Jafarian (Dermatology), and Christina Rosmus (Nursing). "We started off by treating Evan with all the standard treatment options available: opioids, anti-depressants, anticonvulsants and local anaesthetic creams," says Dr. Ingelmo. "Everything failed."

Dr. Ingelmo then decided to think outside the box. "In our clinic we cannot give up," he says. He sat down with Evan's father, Marc, and asked him what his ideal pain management solution would be. "Marc was super clear. He said he needed Evan

not to cry when they lanced his blisters, he wanted something that would wear off quickly because he had to drop Evan off at school right after skin care and he also wanted something with no serious adverse effects," explains Dr. Ingelmo.

He concluded that the only treatment option available was nitrous oxide, more commonly known as 'laughing gas.' "In Italy, where I used to work, they use nitrous oxide inside and outside the OR on a daily basis for pediatric and adult patients," he says. "But it's not common practice here." Not only is it uncommon in North America, but nobody had ever suggested using the treatment at home. "Evan is the first child in the world to use nitrous oxide at home to help relieve the pain associated with his condition," says Dr. Ingelmo.

His parents were instantly on board with the idea, but Evan had to be convinced. He was scared of the mask used to breathe in the gas. "It took him four months to come around, but eventually he did," recalls Dr. Ingelmo. "Our team then jumped into action and they trained Evan's parents on how to use the device at home." The gas is stored in a small tank that houses a mix of 50 percent oxygen and 50 percent nitrous oxide and it limits the amount of gas Evan can inhale. "Evan uses it every time we do skin care. It relaxes him and relieves the pain," says Yandy. "It works within seconds."

CHANGE FOR THE BETTER

Yandy and Marc have noticed big changes in their son since he started using nitrous oxide. "He wants to try everything and he's less fearful of things because he knows that there's some comfort and relief at the end of the day if he needs it," says Yandy. Even with everything he goes through on a daily basis, Evan is still a smiling, energetic, happy-go-lucky kid, who just wants to be a kid. "Evan will have this condition for life. At the end of the day, everything causes a blister, so we can't stop him from pushing himself and trying new things. This is his life and we allow him to make choices. We don't put any limits on him." ■

The Chronic Pain Management program is generously funded by an anonymous donor.

A day in the life of ...two genetic counsellors!



Chez nous continues its series highlighting some of the less familiar professions in the healthcare industry. Sure, we've heard about them, but what do they actually do?

By Stephanie Tsirgiotis

The field of Genetics hasn't always been considered part of the mainstream. Not too long ago, it was seen as a consultative service specializing in only very rare diseases, but today, genetics is integrated into virtually every subspecialty of medicine. There are 10 genetic counsellors at the McGill University Health Centre (MUHC) specializing in many areas including general pediatrics, adult genetics, neurogenetics, prenatal diagnosis and oncogenetics.

Genetic counsellors help individuals or families who have just been diagnosed with or are at risk of a genetic condition. They interpret complex medical information, analyze inheritance patterns, assess risks of disease occurrence or recurrence, and help patients make informed decisions based on the available treatment options.

Chez nous sat down with two genetic counsellors to learn more about their profession.

Marilyn Richard:

Genetic counsellor in Prenatal Genetics



Marilyn Richard is one of two genetic counsellors specializing in prenatal genetics at the MUHC and has been working in the field for over a decade. Genetic counsellors are Masters-level health professionals with training and experience in medical genetics and counselling. "I get involved if an anomaly or fetal malformation is discovered during pregnancy," she says. "Usually this happens in the second trimester, but some genetic disorders can only be diagnosed after birth."

In some cases, Marilyn will also work with couples who are thinking about getting pregnant, but have a genetic condition in the family or who were previously pregnant with a child with anomalies. Once an anomaly is identified in the fetus, Marilyn will discuss the medical information with the medical geneticist. When a very complex anomaly is discovered, she discusses the findings with the hospital's Fetal Diagnosis and Treatment group, a team of specialists who provide prenatal diagnosis and treatment of fetal abnormalities. "We want to make sure we have a consistent message for the patient," she says. "This meeting ensures good communication between all of the care providers."

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A day in the life... (cont'd)

It is then Marilyn's responsibility to meet with the parents to review the findings and explain the potential significance for the child. At this point, she will present various options and will let the parents decide on the course of action. "Each couple makes a decision based on their values and past experiences," says Marilyn. "Some will choose to terminate the pregnancy, while others decide not to. Over the years, I have noticed that people's acceptance of anomalies is very different, as well as how they perceive disabilities, both physically and intellectually. Even 'simple' cases are complex."

If a family decides to move forward with the pregnancy, Marilyn will help coordinate meetings with other specialties, as well as plan the child's birth. She can also perform carrier testing, a type of genetic testing to determine whether or not someone is a carrier for a hereditary condition. This can be beneficial for parents who are thinking about having another child in order to clarify recurrence risks. If a family decides to terminate the



► Marilyn Richard is one of two genetic counsellors specializing in prenatal genetics at the MUHC.

pregnancy, she offers post-mortem counselling and will review the fetal pathology with the goal of learning more about the condition. "In these situations, we help families deal with a different kind of loss. It's about losing the hope of having a child."

Laura Palma:

Genetic counsellor in Oncogenetics



"Our field goes beyond the psychosocial aspect," says Laura Palma, one of two genetic counsellors in oncogenetics at the MUHC. "We are risk estimators." Laura has been working at the MUHC for over 13 years. She works mostly with adult patients at the Cedars Cancer Centre, but also sees patients from the Hematology-Oncology and Gastroenterology units at the Montreal Children's Hospital.

Her small team receives 35 referrals a week. "Our service introduced referral criteria in 2013 to address the increased demand for oncogenetics. A patient is only referred to us if their physician thinks their cancer or their family history might be hereditary." Approximately 5-10% of cancers are hereditary, though this figure strongly correlates with the type of cancer and the age of diagnosis. Hereditary cancers tend to surface in younger patients with a strong family history of cancer. "Just last week I met with a teenager who had a cancer that is often only seen in elderly patients," she says. "Very often, these unusual cases are hereditary."

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Once a cancer is flagged as genetic, a patient's treatment decisions or surgical options might differ. The results of genetic testing can be used to plan for surgeries such as mastectomies and/or preventative oophorectomies, the surgical removal of the ovaries, or even to select appropriate related donors for a stem cell transplant in a patient with an inherited hematological disease. "This knowledge can help guide the patient in making an informed decision based on all the treatment and screening options available," she says.

Laura also does a lot of risk assessment. "We look at the risk of future cancers or the risk of cancer in the family," she says. "We don't estimate the risk of a recurrence of the same cancer in different parts of the body, but rather the risk of a new cancer in another organ, linked to the same underlying genetic cause." If a cancer is confirmed to be hereditary, Laura writes a letter that outlines the risk to the family and refers the extended family members to different health facilities. Thanks to Telehealth, Laura has also been able to reach more people by offering oncogenetics counselling to patients in the Abitibi-Témiscamingue and Amos regions of Quebec. "Demand for this type of genetic counselling is very high," she says. "There are a lot of people these days who are interested in finding answers." ■



► Laura Palma and her colleague, Evan Weber, receive 35 referrals a week.



► Laura reviews a patient's family history.

Lean Six Sigma Yellow Belt 2018: SIGN UP NOW!

The MCH's *Bureau de la Qualité et de l'amélioration continue* (BQAC) invites you to sign up for the upcoming 2018 Montreal Children's Hospital Continuous Quality Improvement Approach: a Lean Six Sigma Yellow Belt training session.

The one-day training offered by BQAC aims at introducing MCH staff to the basic concepts of this technique for continuous quality improvement. To date, 372 employees and physicians have participated in this training in the less than two years since it's been offered.

The course dates are **February 2, February 23, March 16, April 27** and **May 1 from 8:00 a.m. to 4:00 p.m.**

To reserve a spot please contact Gabrielle C. Allard at gabrielle.cunningham@muhc.mcgill.ca or **37285**. ■



Harini Sinnakili, PFCC Star of the Month

By Maureen McCarthy



When Lina’s parents Wahid and Amira were asked to nominate a staff member for this month’s PFCC Star award they didn’t hesitate a minute. “Harini was the first person who came to mind,” says Wahid. “We felt very lucky to have her looking after our daughter.” Wahid and Amira say that beyond carrying out her nursing duties, Harini did so much more for them in terms of moral and emotional support. She’d also call them regularly at home to let them know how Lina was doing. “When we knew Harini was working, we were very calm, because it was like leaving our daughter with a sister or a mother. She’s exceptional on every level.”

Harini started her nursing career working in emergency in the adult sector, but she eventually applied to the Children’s. “Even though I’d always been interested in pediatrics I had never really imagined working in the NICU. Obviously, it was really different to what I’d done before,” she says.

From the perspective of patient and family-centered care, Harini says that coming to the Children’s provided the new challenge of caring for the family, not just the patient. “When I got here, I told myself if I’m looking at the patient as a whole, then that ‘whole’ includes the parents. They play a huge role in their baby’s life,” she says. “And as I mastered my nursing skills I was able to go beyond my nursing tasks and really focus on the psychosocial aspects of care too.” Harini, who is a graduate of Vanier College, is currently doing her bachelor’s degree online. “A class on family nursing is part of the program, so I think that also helped me in my journey here in the NICU.”

Harini met Lina and her parents within their first couple of days on the unit. “Amira and Wahid asked me to be Lina’s primary nurse,” says Harini. “To see how Lina has grown and developed, and how much her parents did along the way is wonderful. They were here with Lina every day and very involved in her care.”

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Many families in the NICU go through a lengthy and often steep learning curve. "Every day, they're being given new information," says Harini. "As a nurse, you work with them to make sure they understand the info, what needs to be done and of course, reassure them as much as possible." She says it's rewarding to see how families eventually become more at ease with everything. "Sometimes during morning rounds, Amira would do the talking and I wouldn't have to say a thing!"

When Harini first started in the NICU, she didn't expect she'd grow to love it so much. As Lina was getting ready to go home with her parents, Harini reflected on why that is. "You don't always realize it on a day-to-day basis but then you see the end results, and see how both baby and parents are doing. The NICU is so much about teamwork, and it's such a good feeling to know you've contributed to something." ■



Our PFCC Stars are featured on the Children's Facebook page and Instagram. Here's what people had to say about our previous award recipient, Dr. David Mitchell.

Gail Lamica

David you are an amazing doctor, leader and most of all the most down to earth and humble doc I know! Congratulations!!

Darla Johnstone

An amazing doctor with an amazing team. Thank you Dr. Mitchell for all you have done for Tyler and our family.

Dominique Aubre

Dr. Mitchell, I would give you a thousand stars!!!! You are an amazing doctor and an even better person. Thank you for the great work. We will always be grateful. ❤️

Steven Croucher

One of my best doctors to ever care for me!!

Ministry starts new vaccination promotion program

Did you know that 35% of parents have hesitated about having their child vaccinated?

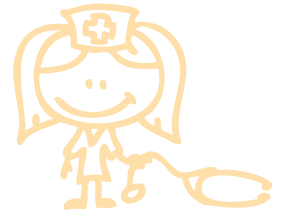
The *Ministère de la Santé et des Services sociaux* (MSSS) has started a new vaccination promotion program in 13 hospitals across Quebec, called *Entretien motivationnel en maternité pour l'immunisation des enfants* (EMMIE). At the maternity ward of the Royal Victoria Hospital of the MUHC and in the Neonatal Intensive Care Unit of the Montreal Children's Hospital, vaccination counselors have already begun meeting with new



parents to explore their views on vaccination. The 20-minute session is voluntary and takes place in the patient's room on an individual basis. The goal of this Ministry-funded program is to promote the importance of vaccination and to inform parents about the vaccination schedule. To learn more, visit msss.gouv.qc.ca. ■

On-the-spot communication coaching:

10-minute sessions help staff with difficult conversations



By Stephanie Tsirgiotis



Are you about to have a difficult conversation with a patient, family or colleague and don't know what to say or how to say it? Patient and family-centered care coordinator Marie-Claude Proulx is now

offering on-the-spot coaching for staff who need extra support before embarking on a difficult conversation. "When I meet with someone, I tell them how I would say it, but my goal is for them to find words they're comfortable with," she says. "My main objective is to coach and empower staff in less than 10 minutes."

To date, she has received calls from nurse managers, physicians, as well as staff in clinics and on the wards. Marie-Claude emphasizes that every approach is different depending on the person and the situation. "People often get stuck and don't know what to say because they care and want to do a good job," she says. Her rapid coaching session is based on communication tools she's adapted from the Mutual Learning model, as well as other communication tips she has learned along the way.

This fall, Marie-Claude was contacted by Rebecca Pitt, a nurse clinician with over 21 years of experience. She recently started working in the Chronic Pain Service after years on the surgical unit. "I now work with a whole new patient population. Most of our patients are between 14 and 17 years old and I often have to take them aside to have private conversations with them. I was struggling with how to explain this to parents without making them feel unvalued or somehow betrayed in the process," she says. "Marie-Claude's insights helped me to feel more confident approaching these situations. She offered things to say, but also encouraged me to put it in my own words."

In Marie-Claude's experience, it's often the first couple of sentences that get people into trouble. "The whole situation might



► Marie-Claude Proulx

escalate if you get those wrong. Asking permission before diving into a difficult conversation is very important," she says. "I suggest beginning a conversation with, 'I'd like to talk about [...], is this a good time?' This shows that you care about resolving this issue and are respectful of the person's busy schedule and state of mind. If you show that you care, the conversation will likely go well. It's the first step to de-escalating any conflict."

The service is now being offered to administrative and clinical staff. Whenever her schedule allows, Marie-Claude responds to requests immediately. You can reach her by paging her through locating at [ext. 23333](#). ■