

Chez nous

MCH EMPLOYEE NEWSLETTER

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Karl's story: a promising discovery, a promising outcome

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Hôpital de Montréal
pour enfants
Centre universitaire
de santé McGill



Montreal Children's
Hospital
McGill University
Health Centre



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Twelve-year-old manages full life despite chronic disease — Page 6

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Putting research into practice

Children's patient benefits from surprising discovery

By Maureen McCarthy



Two years ago, Dr. Nada Jabado, hemato-oncologist at the Montreal Children's Hospital, and researcher in the Child Health and Human Development Program at the Research Institute of the McGill University Health Centre (RI-MUHC), approached Dr. Jean-Pierre Farmer, neurosurgeon and Chief of Surgery at the MCH, about a promising discovery for treating brain tumours. She explained that a mutation—known as

BRAF V600E—found in a certain type of melanoma was the same mutation found in a subset of brain tumours known as gangliogliomas. What's more, drug treatments using targeted inhibitors with proven clinical success in treating melanoma were available. Dr. Jabado suggested that these same treatments could be used to target gangliogliomas that carried the specific mutation.



► Dr. Jean-Pierre Farmer and Karl.

The first patients in Quebec to take one of these drugs were a young girl and a teenage boy, who both had tumours that could not be completely removed by surgery. They had failed several therapies, including radiation therapy, but within a month of starting the targeted treatment, their tumours shrank. The positive outcome from their treatment paved the way for another young patient this past fall.

A sore arm reveals a more serious problem

Seven-year-old Karl is a bright young boy with a huge smile and a mischievous sense of humour. Last August, on a short trip with his parents Marc and Josée to visit family in the Laurentians, he began feeling pain in his arm. He'd been playing on swings in the park so his parents thought he might have pulled a muscle. Karl didn't sleep well that night, but the following day he was ok. The next night, he slept poorly again. His parents took him to the local hospital, and received a referral to Orthopedics at the Montreal Children's Hospital for a possible brachial plexus injury. A magnetic resonance imaging (MRI) scan of Karl's plexus was started but it rapidly revealed the presence of a

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► Ana Lereu takes a blood sample from Karl during a recent check-up at the Children's.

tumour. Within a few hours, Karl was seen by Dr. Farmer who explained to Marc and Josée that Karl's tumour was in his brainstem and cervical spinal cord.

Confirming the diagnosis

Dr. Farmer suspected that Karl's tumour was a ganglioglioma but the only way to confirm a diagnosis is by biopsy. Gangliogliomas are low-grade tumours which occur most frequently in the brain. As the tumour grows, it can lead to symptoms such as seizures, fatigue, or weakness on one side of the body.

The treatment process often involves surgery to remove the tumour, but complete removal is not always possible if the tumour is close to important functional areas of the brain. However, if the tumour is not completely removed, it will continue to grow. Even after surgery, the tumour can grow back. "The surgery would have required an extensive incision that might have destabilized Karl's cervical vertebral column," says Dr. Farmer, "and the chances of a complete resection were slim because of the tumour's location in the brainstem and cervical spinal cord. We always have to think of what's best for the patient. In Karl's case, performing a biopsy to confirm the diagnosis and mutation was preferable. However, if the biopsy did not confirm the mutation, Karl and his family would have had to face a more extensive surgery a few weeks later. As it turned out, Karl was an ideal candidate for the drug treatment."

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Did you know you're reading an award-winning magazine?

Chez nous came in second for best internal health care newsletter in Canada! The award was given by the Health Care Public Relations Association of Canada.

On the cover: Karl with his parents Josée and Marc

Cover photo: Owen Egan

Putting research ... (cont'd)



► Dr. Geneviève Legault, pediatric neurologist, talks to Karl during his check-up.

Starting treatment

Two weeks after Karl's biopsy, he and his parents met Dr. Jabado, who sees patients at the Children's in addition to her work at the Research Institute. "Dr. Jabado explained how the drug treatment had the potential to shrink Karl's tumour," says Josée. "At first I was worried about giving Karl the medication at home, but once we got through the first day I saw that Karl was going to tolerate it well."

"The BRAF mutation that is common to both melanoma and a subset of gangliogliomas opened the door to consider the drug treatment for children with these types of gangliogliomas," says Dr. Jabado. "For Karl, as for any child who is a good candidate for the treatment, providing an option that is this effective with minimal side effects is very promising."

A successful outcome

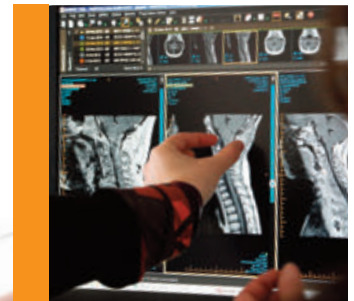
Karl's tumour has responded well to treatment. Three weeks after he started the therapy, his tumour shrank by 50 per cent

and he regained use of his right hand. By the time he had his third MRI in November, the size of his tumour had decreased by 75 per cent. He and his parents now come to the Children's every month for check-ups. The tumour is stable and hasn't moved so he'll continue on the drug treatment for the foreseeable future.

The decision to try the drug treatment meant a much quicker recovery for Karl and the possibility of saving his right hand. Any other therapy would have taken more time to be effective, if at all. "The rapid response in the two other patients we had treated, and results for a few other children treated in the US, drove us to offer this therapeutic option," says Dr. Jabado. "It also meant a better quality of life for Karl since it's a pill taken orally that does not require infusion or a hospital stay."

"There was a huge change in just a few weeks," says Josée. "Karl's recovery was fast, and he was able to go back to school very quickly. We're very grateful that the treatment was an option for him. And we're more than grateful to have Dr. Jabado and Dr. Farmer looking after him." ■

► Dr. Legault, Marc and Karl look at results from his MRI scans.



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A team from the Research Institute of the McGill University Health Centre (RI-MUHC) led by Dr. Nada Jabado was selected as one of the top Canadian teams to attack brain cancers in children and adults. This New Cancer Stem Cell Dream Team led by The Hospital for Sick Children (SickKids) in Toronto, received \$11.7 million in funding for four years to focus on the cancer stem cells that drive the growth of tumours. The announcement was made on *World Cancer Day*, February 4.

► Dr. Nada Jabado

Nouvelle capsule vidéo! On dit que la vérité sort de la bouche des enfants.

Voyons voir ce qu'ils pensent de la communication à l'Hôpital de Montréal pour enfants dans cette capsule vidéo de la campagne Parlons-en. Rendez-vous au parlonsen-hme.com pour voir la capsule vidéo.

New video! Children are often wiser than we think.

Let's see what kids think about communication at the Montreal Children's Hospital in this clip from the We Should Talk campaign. Watch the video at weshouldtalk-mch.com.



School, sports and fundraising

Twelve-year-old manages full life despite chronic disease

By Maureen McCarthy

Jack is an enthusiastic fundraiser for the Arthritis Society of Quebec. For the Scotiabank Charity Challenge on April 24, he'll be captain of a "Green Team" of runners raising money for juvenile arthritis. Last year, he ran the 5K and he plans on doing the same this year. It's quite a feat for any twelve-year-old, but what makes it even more remarkable is that Jack himself has juvenile idiopathic arthritis.

When Jack was seven years old, one of his big toes became enlarged. It soon spread to the other big toe and his ankles. An avid soccer player, he went from being the most active kid on the field to not being able to run at all. His parents Rosina and Jim took him to several different doctors but it was a chance meeting with a resident working at a local clinic that led them to the MCH division of Rheumatology. In late 2010, they met pediatric rheumatologist, Dr. Gaëlle Chédeville, and nurse Gillian Taylor, who recently retired.

Shortly after their first visit, Dr. Chédeville confirmed that Jack had juvenile arthritis. "He didn't want to hear anything about it at first but Dr. Chédeville found a way to connect with him," says his mom. "She and Gillian really helped us understand what Jack was going through. Before long, whenever he'd walk into the clinic room, he had a smile for them, even if he was in pain."

You can't see pain

For children with arthritis, mornings can be difficult. After waking up, Jack would often have to be carried downstairs. He'd go to school on crutches but by lunchtime, he could move better so he'd put the crutches aside. A lot of his classmates thought he was faking, so Jack decided to help them understand arthritis better.



► Jack is captain of his level B hockey team.

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As a class assignment, he wrote a blog entry on the disease. He then did a report on a book about arthritis he'd asked his mother to buy. "He knows that people can't see pain, but he wanted to help them understand that it's real," says his mom. Rosina says both the students and the staff have been great. "They created a space for Jack in the principal's office where he can stretch during the day, and his teacher did the same in his class."

Finding the right medication

When Jack was first diagnosed, he started taking medications to control the pain, as many as 40 pills a week. On Dr. Chédeville's advice, he eventually started methotrexate injections. "Jack really resisted having the injections but after six months he realized the medication was working," says Rosina. "He was able to play soccer again. Since running was

still an issue he decided to be a goalie. And it turns out he's a great goalie!"

Although he had made progress on methotrexate, Dr. Chédeville felt he could improve even more with the help of an injected medication called Enbrel. Within two to three weeks, they could see the results and Jack has now been pain-free for two years.

Don't ever lose hope

Living without pain has helped Jack be active again. He continues to play soccer and also took up hockey, a dream that gave him hope when he was in pain. He's now captain of his level B hockey team. He's also the Arthritis Society spokesperson for Childhood Arthritis Month this March.

As Jack prepares for the Scotiabank 5K, he hopes to raise even more money than last year since the proceeds will help some of his friends spend the week at Camp Articulation, a one-week camp for children with juvenile arthritis.

"Jack is always an optimist," says his mom. "He tells us he wants to play in the NHL someday. When we remind him it's a long shot for any young player, he says, 'Don't ever lose hope, Mom.' Those are words to live by!" ■



► Jack at the *Marche contre la douleur / Walk to Fight Arthritis* last June.

Join the campaign to create a more respectful work environment



► Don't miss the drama with the MUHC's fictional cast of characters — Fatima, Yan and their boss Josée. The video is available in English and French.

The McGill University Health Centre (MUHC) has adopted a new policy on respect and civility to help resolve workplace problems and prevent or stop incidents of violence and harassment. To launch the policy the MUHC invites you to a special video screening! Free *Bad Monkey* popcorn will be handed out.

Friday, April 1
Research Institute Auditorium (Bloc E S1.1129)

ENGLISH VIDEO:

> 8:30, 9:30, 10:30 and 11:30 a.m., 12:30, 1:30 and 2:30 p.m.

FRENCH VIDEO:

> 9:00, 10:00 and 11:00 a.m., 12:00, 1:00, 2:00 and 3:00 p.m.

Victor Goldbloom, 1923-2016



Dr. Victor Goldbloom passed away on February 16 at the age of 92. A man who dedicated most of his career to public service—first as an MNA in Quebec's National Assembly, followed by several important positions including Canada's commissioner of official languages in the 1990s—Dr. Goldbloom began his career as a pediatrician in 1950. He was on staff at the Montreal Children's Hospital and as a member of McGill's Department of Pediatrics, taught in the faculty of Medicine.

Dr. Nicholas Steinmetz, former Associate Executive Director of the Montreal Children's Hospital and Chairman Emeritus

of the MCH Foundation Board of Directors, remembers Dr. Goldbloom from his time as a medical student at McGill. "Dr. Goldbloom worked very closely with all of us, both students and residents. Under his guidance, we learned so much more than just medicine. He taught us ethics, how to talk to families, and how to see their point of view. Dr. Goldbloom was someone who instructed us in both the science and the art of medicine. He was a superb teacher."

Dr. Goldbloom's father, Dr. Alton Goldbloom, was a founding chairman of McGill's Department of Pediatrics, and played an instrumental role in the development of the MCH. ■

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ighlighting our trusted medication experts



March marks *Pharmacist Awareness Month*

By *Pamela Toman*



ALAIN DESROCHES
Pharmacist, Montreal Children's Hospital



We therefore need to pay particular attention to how medication is administered and ensure that we have all the information we need."

Thanks to his wealth of experience working in various hospital departments over the course of his career, Alain says his relationships with hospital staff members brings a richness to his job that he thrives on. "Because I know many of the physicians and nurses on the floors, I can easily collaborate with them to find solutions to

With over 24 years of experience working in the Pharmacy Department at the Montreal Children's Hospital, pharmacist Alain Desroches has seen the impact of advances in drug therapy firsthand. "I remember when I first started working in the Hematology-Oncology Department, the medications we had were limited to one very small room. Today, things have changed. We're part of a very big department and we have access to highly developed and specialized tools."

Alain currently works in the central pharmacy located in the ground-floor atrium of the Glen site. His role is to fill and check prescriptions that will be sent to inpatient floors to be administered to patients, and to liaise with clinicians when there are questions about a given prescription or medication dose. Given the vast fluctuation in each pediatric patient's weight and height, accuracy and attention to detail is key. "We see patients who range from newborns to teens who are 18 years old and can be given adult doses of medications.

sometimes complex problems. I take it upon myself sometimes to fix technical problems or system issues to help improve work flows and make this easier. It's something I really enjoy doing."

But what makes his job the most rewarding, says Alain, is the combination of being able to learn from his fellow pharmacists and colleagues and to come to work every day and contribute to something concrete. "I like that my day starts even before I get to work, with prescriptions coming in overnight. I feel really satisfied when I'm able to help ensure we deliver everything that's needed in the time frame requested. The day passes by incredibly fast and I get to see the results firsthand."

Join us in thanking our team of dedicated hospital pharmacists for the expert care and counsel they provide, day in and day out. ■

Restoring hope: The power of social work

March is *National Social Work Month*

By Pamela Toman

At the Children's, our social workers are committed to supporting the well-being of our patients and their families. Their role is to assess patients' psychosocial needs to get a better understanding of their overall health. They work with families, multidisciplinary teams and commu-

nity partners to mobilize resources to assist the patient in achieving goals, both big and small. Join us in thanking all of our social workers for the amazing work they do to support our patients, families and fellow health professionals every day.



LAURA JOHNSTON
Social Worker, Montreal Children's Hospital



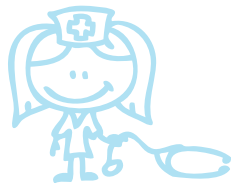
Laura Johnston has worked at the Montreal Children's Hospital since 2001, and for the past five years has been with the Neurosurgery and Hematology/Oncology teams providing support to families facing acute or chronic illnesses.

"My work is primarily with children who are being treated for brain tumours, or who have sickle cell anemia," she explains. "We support patients and families at diagnosis—a time of crisis for the whole family—and throughout their treatment. We can help provide strategies for parenting a sick child, facilitate communication between the family and their health care team, assist with financial challenges, and link people with hospital, community, and governmental resources to support them."

Laura says she developed an interest in working with children and families early on in her social work career. Her interest in healthcare is something that seems to run in her family, with three generations of nurses. Her work at the Children's is both a challenge and a source of inspiration, she explains. "I really like the interdisciplinary nature of pediatric social work. On any given day I work with multiple specialties to help families find solutions to their unique and often difficult situations."

When asked about the most rewarding part of her work, Laura is quick to reply. "I am always touched by the bravery I see in patients and their families. I often meet them at such a vulnerable time; it's incredible to witness how resilient people can be."

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SUE MYLONOPOULOS
Social Worker, Montreal Children's Hospital



"Being a social worker has been transformative and humbling ...It is a privilege to assist families who are dealing with a child's illness. Fostering resilience and restoring a patient's and family's sense of hope in the face of adversity, pain, and fear are essential to our work."

Sue Mylonopoulos says she was always drawn to working with teens, and a career in social work has been a great way to blend her interest in humanitarianism, mental health and pediatrics. Since late 2001, Sue has guided and counseled patients and their families in the Eating Disorders Program at the Montreal Children's Hospital, conducting psychosocial assessments and leading family-based interventions.

"Eating Disorders can have complex, multilayered manifestations. My goal is to get a comprehensive understanding of a patient's strengths, cultural, social and school background, family dynamics, key stressors, and past as well as current health concerns in order to guide therapeutic interventions."

Given that eating disorders are acute and potentially chronic illnesses, Sue explains that working with patients who are diagnosed with anorexia nervosa can be challenging. "I support families who are dealing with one of the most distressing periods of their lives. To help empower and mobilize the teen and family to achieve their goals, and to move beyond being hostage to this illness, however, is very rewarding."

"I believe in the human capacity for change and growth and most notably the strength and resiliency of children and youth – even in the most difficult circumstances," says Sue. "It's most fulfilling when I am able to help a teen and their family find internal and external resources to improve their well-being and to bear witness to them re-establishing a sense of hope and normalcy in their lives." ■

Food that makes you smile

Boulangerie & Cie owner fulfills long-term dream by opening restaurant at the Glen

By Sandra Sciangula



► (l. to r.) Chef Giuseppe Sacchetti and Boulangerie & Cie co-owner Andy Aboushaybeh proudly stand by their new restaurant near the front entrance of the Montreal Children's Hospital.

The businesses setting up shop in the Glen's commercial spaces are adding charm to the new building. Among the recent additions is Boulangerie & Cie, known for its fresh food, which opened an express counter near the cafeteria on CS1. For a more relaxed atmosphere, there's a restaurant with eight tables and ten stools for customers in the spacious Larry and Cookie Rossy Promenade at B 01.0037 by the Children's main entrance.

This eatery is the brain child of Andy Aboushaybeh, a Montreal restaurateur with 33 years of experience in the business. When Andy was hospitalized thirteen years ago, his family brought him meals from home. The fresh bread, fruits

and vegetables caught the attention of the other patients in his room. "It was my pleasure to share my meals with them! The homemade meals made them smile. It was as if the good food made them happy even if only for a few moments in the day," says Andy.

This experience was the catalyst for Boulangerie & Cie. "My time in the hospital made me realize I wanted to do something health-related," but it would be years before his dream came to fruition. Andy had to step away from the demanding reality of the restaurant business to care for his health, but his passion for it couldn't keep him away forever. With a lot of encouragement and support from his wife Cinthia, and good timing, Andy jumped on the opportunity to open up a restaurant at the Glen.

Chef Giuseppe Sacchetti was brought on board to create a menu meant to provide savoury and healthy food. The team takes pride in the freshness and quality of the food they offer: they bake their own muffins, grill their own vegetables and get fresh bread from some of the top bakeries in Montreal, including *Hof Kelsten* and *Boulangerie Guillaume*. "It's about feeling fulfilled, not filled," says Giuseppe.

The menu also caters to customers who have special dietary needs, and includes options like gluten-free, vegetarian and vegan meals. Opening Boulangerie & Cie at the Glen was not an easy feat. Andy admits, "Building a restaurant according to hospital code was a challenge, however this was a passion project and we really wanted to offer people wholesome, flavourful food that makes them smile even if only for a moment in the day."

As for what's coming up next, Andy is diligently working on an app that will allow clients to pre-order their meal so that they can skip the lunch hour line-up. ■