

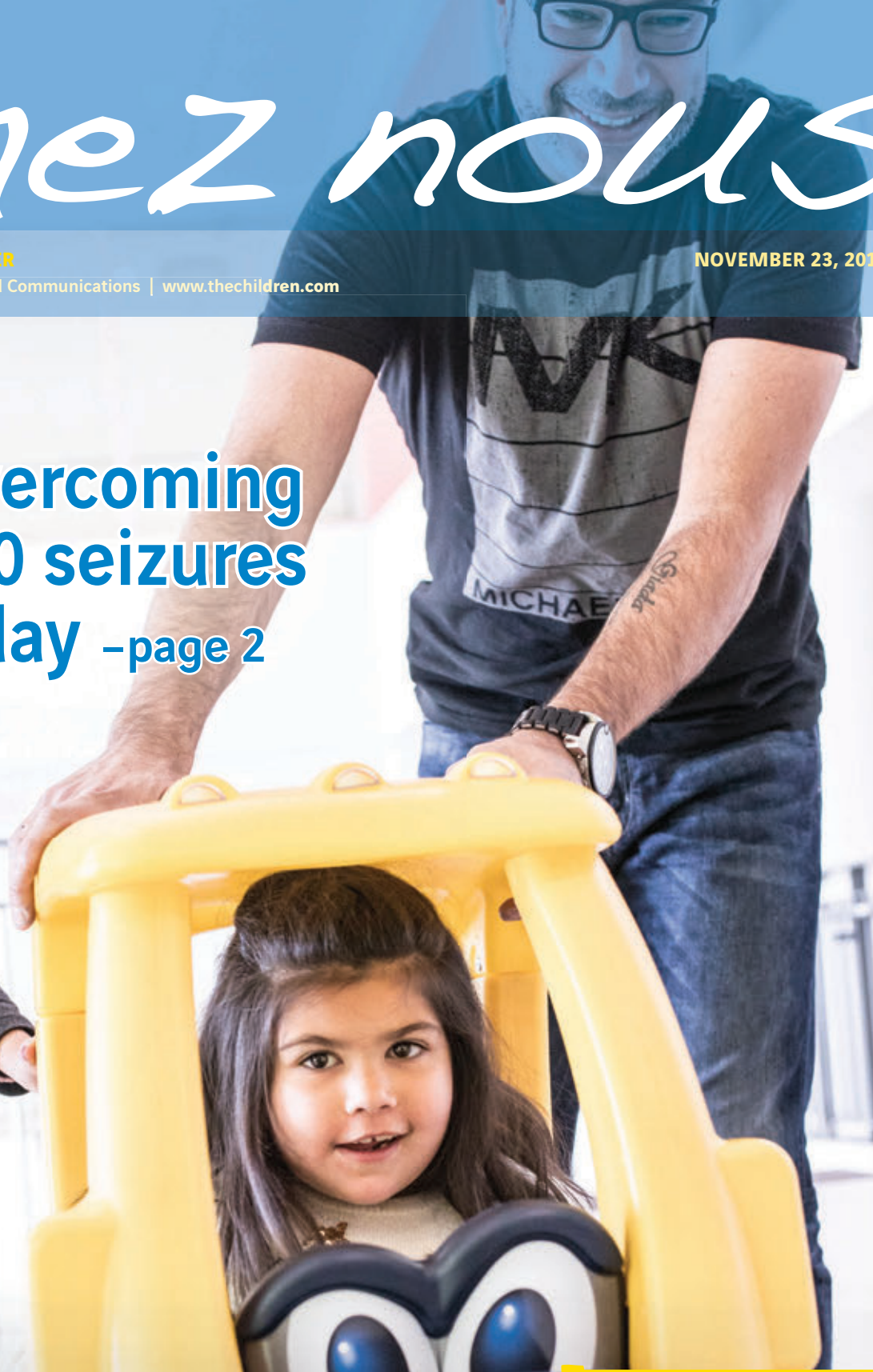
Chez nous

MCH EMPLOYEE NEWSLETTER

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Overcoming 500 seizures a day -page 2



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Montreal Children's
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High fat diet helps patient overcome 500 seizures a day

By Stephanie Tsirgiotis



► The Children’s Complex Care team checks Tiana’s bloodwork, vitals, as well as her height and weight on a monthly basis to make sure she’s growing and developing properly.

August 29, 2013, started off as a typical day for Linda Florio. She dropped off her two-and-a-half-year-old daughter Tiana at daycare and then made her way over to her other daughter’s new school. It was Giada’s first day of kindergarten. After the school drop-off was done, Linda headed to the dentist and was on her way home when she got a phone call that changed her life forever.

Tiana had fallen while being potty trained and hit her head. The daycare workers called Linda in a panic because she wasn’t responding. “She was rushed to the Emergency department at the Children’s because I thought she had a severe concussion,” explains Linda. But it wasn’t a concussion. It was something far worse.

FROM BAD TO WORSE

Once at the Montreal Children’s Hospital, the ED team ran a few tests and everything seemed normal at first. But then Tiana started seizing in the Trauma room and was sent up to the Pediatric Intensive Care Unit (PICU). “She developed a bad fever and they thought maybe she had meningitis,” recalls Linda. Yet as the day progressed, Tiana started showing other symptoms. She became very aggressive. She stopped walking and talking. She started having these abnormal movements around her mouth.

A few days later, her neurologist, Dr. Bradley Osterman, who was a neurology resident at the time, diagnosed her with Anti-NMDA receptor encephalitis, an acute and very rare

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autoimmune neurological disorder. On top of that, she had also developed a severe case of epilepsy, known as secondary refractory seizure disorder. "This type of encephalitis attacks the brain and stops you from developing normally," explains Dr. Osterman, now a pediatric neurologist and epilepsy specialist working at Centre hospitalier de l'Université Laval (CHUL) in Quebec City. "In Tiana's case, there was so much epilepsy in her brain that it just stopped functioning and she remained in a vegetative state."

The family stayed in the PICU on and off for over seven months while the neurology team at the Children's tried different treatments and medications. At first, she was being treated with steroids, and they seemed to be working, until she developed a bad case of pneumonia and they had to be stopped. "We couldn't put her back on steroids because of the pneumonia so we tried other options, but nothing worked," says Dr. Osterman. "This disease and these seizures can usually be controlled with medication, but not in Tiana's case. She has a very severe case."

THINKING OUTSIDE THE BOX




At this point, Tiana was still minimally conscious and was having up to 500 seizures a day. "She was in a world of her own. A bomb could have gone off and she wouldn't have known," says Linda. Dr. Osterman had never seen anything like this, especially in someone so young. Between January and March 2014, Tiana received three rounds of chemotherapy as Dr. Osterman tried

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► Tiana and her neurologist, Dr. Bradley Osterman, at a recent appointment in Quebec city. She visits him every six months for follow-up tests.

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*On the cover: Tiana with her sister, Giada, and her father, Jason.
Cover photo: Thibault Carron*

High fat diet... (cont'd)

destroying her t-cells in an attempt to wipe out the antibodies that were attacking her brain. “She started to walk again with a walker, but she was still seizing,” says her mom. “We were so tired of being in the hospital. I couldn’t stand the thought of spending another holiday or birthday there.”

Eventually her doctors were able to discharge her, but Tiana continued to visit the hospital on a monthly basis for chemotherapy and follow-up appointments with Dr. Osterman. He continued to monitor her seizures very closely. “She was still mute and wasn’t developing normally, so I decided to try something completely different.” As an epilepsy specialist, Dr. Osterman had occasionally suggested the Ketogenic diet as a form of treatment for children with hard to control epilepsy. “The diet isn’t for everybody, but it has helped a lot of my patients in the past,” he says. “It had never been used on a patient with Tiana’s autoimmune disorder, but it was time to think outside the box.” Linda and her husband, Jason, were hesitant at first, but they decided to try it because they had nothing to lose.

THE KETOGENIC DIET

In February 2016, Tiana was admitted to the hospital and put on the diet. “Whenever a patient is put on the Ketogenic diet, we admit them for four days, because it’s quite a shock to



► (l. to r.) Dr. Annie Sbrocchi, Tiana’s primary physician, meets with Tiana’s mom and dad, Linda and Jason, as well as her nutritionist, Marie-Josée Trempe, on a monthly basis.

the system,” says Marie-Josée Trempe, a nutritionist at the Montreal Children’s Hospital. “Their sugar levels can drop drastically.” The Ketogenic diet has been around since the 1920s and is predominantly used for patients with epilepsy who do not respond to medication. The diet is very high in fat, with little in the way of fruits and vegetables. “We supplement with a lot of vitamins to make sure the patient gets all the nutrients they need,” says Marie-Josée.

The human body usually uses glucose from carbohydrates to produce energy, but for children on the Ketogenic diet, their bodies use fat for energy. “Chemicals called ketones are produced when the body uses fat for energy. It gives the brain a different kind of fuel, which for some reason helps to reduce seizures for some people,” explains Marie-Josée. The patient eats enough protein to keep their muscles working, but sugars are severely limited because even an extra green bean can end up leading to an extra seizure.

Every diet is uniquely tailored for the patient and Marie-Josée works closely with the families to make sure they’re comfortable with the process. Everything the patient consumes

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► Nutritionist Marie-Josée Trempe works closely with each patient on the Ketogenic diet to make sure they’re getting all the nutrients they need.

needs to be measured and the ratio of fats versus protein versus carbohydrates needs to be exactly right. "It was a huge challenge at first, because she's on the strictest version of the diet," says Linda. Tiana needs to eat three meals a day, plus two snacks, and each meal must have a ratio of four grams of fat to one gram of protein/carbohydrates.

A typical meal is often made up of four foods: heavy whipping cream, protein about the size of a golf ball, a small serving of vegetables (about five green beans) or part of a piece of fruit (half a strawberry), and a large serving of butter. "Tiana's favourite meal is natural pork hotdogs dipped in sugar-free ketchup with a little side of vegetables, and lots of mayonnaise, olive oil and cream," says Linda. "She loves that for lunch!" Other parents whose children are on the Ketogenic diet often swap recipes, but Linda admits it's still challenging to make sure the ratios are just right. She refers to a website called ketodietcalculation.org to help calculate the ratios based on the grams she enters. "There are resources out there, but they are limited," she says.

Patients are also followed closely to make sure their bones, heart and kidneys are working properly, and they will only stop the diet once their seizures stop or become well-controlled. Most children are on the diet for two to three years, while some others can be on it for up to ten. Depending on what is causing the epilepsy, sometimes the patient can stop taking seizure medication and the seizures will stop indefinitely, but scientists are still not sure exactly why.

WALKING, TALKING AND SMILING AGAIN

Four weeks after being on the diet, Linda noticed a big change in Tiana. She became more alert, she stopped seizing and started to become herself again. "Even her skin and hair looked better," she says. "We were starting to get our little girl back." Dr. Osterman was shocked at how calm her brain looked in the EEG diagnostic tests. In the last year, Tiana has progressed rapidly. "She is developing like a normal child again," he says. "In the past 12 months, she has gained 12 months of development. I was hoping this diet was going to work, but I didn't expect it to work this well." Tiana is now



► Six-year-old Tiana is now walking, talking and smiling again.

walking, talking and smiling again. She has been seizure-free for over a year and her doctors think she could recover 75 to 100%. "She has the vocabulary of a three-year-old, but she's back to her baseline," says mom.

Six-year-old Tiana is still followed regularly by her primary physician Dr. Annie Sbrocchi, a pediatric endocrinologist in Complex Care Service at the Children's and she and her parents go to see Dr. Osterman in Quebec City every six months. Her healthcare team at the Children's checks her bloodwork, vitals, as well as her height and weight on a monthly basis to make sure she's growing and developing properly. "She's a completely different girl. She used to never make eye contact, or speak or point, and now she giggles, answers you and gives lots of hugs," says Dr. Sbrocchi. "It's unbelievable how far she's come." ■



A day in the life of a...cast technician!

By Stephanie Tsirgiotis

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?



► Reg Kennedy is one of seven PAB cast technicians at the Children's. There is also Pierre Beauduy, Richard Zeliger, Mohamed Hitake, Nick Raspa, Eddy Gouveia and Nunzio Mancini.

Reg Kennedy has been working with broken bones for 32 years. He is one of seven cast technicians at the Montreal Children's Hospital. "I started my career as a PAB at the Children's, but they needed people who could put on casts, so I applied and was trained by George Kafalis, another cast technician with 40 years of experience," he says.

A typical day starts at 7:00 a.m. and begins with Reg checking in with the Emergency department to determine how many patients need a cast. "Some days I have nobody, while other days I put on casts back to back all day," he explains.

On average, Reg applies five casts per day and each application can take between five minutes to an hour depending on the situation. On slower days, he still works as a PAB for various departments in the hospital. "I definitely do not have a regular schedule," he says. "I work in different areas in the ED and occasionally visit the orthopedic clinic on the second floor."

THE ART OF APPLYING CASTS

Besides being trained as a PAB, Reg also graduated with a Degree in Fine Arts and he still uses these creative skills, but in a different way. "Working in a hospital means you often have to think outside the box," he says. "Being creative definitely helps." Like most healthcare workers can attest, every case he comes across is different. "I need to determine the right product, for the right situation, for the right patient," he explains.

Synthetic casts are the new rage because they come in a variety of colours and patterns, but they don't work for every situation. These particular casts dry in two minutes and work best with older patients who can sit still while the cast is applied. "I choose which cast to use depending on the fracture and the patient. For example, I wouldn't choose a synthetic cast for an autistic child because it would be too difficult to apply."

In these situations, his go-to cast is the traditional plaster cast. A plaster cast is easier to apply because Reg can control how fast it dries. The cast dries when warm water is applied, so if Reg needs more time to get a cast just right he applies cold water to extend the drying period. "Plaster casts are also non-toxic and very flexible. Heck, they've been around since the Romans!"

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DEALING WITH DIFFICULT SITUATIONS

Reg works predominantly in the Emergency department and sees all kinds of patients. In very painful situations, a nurse will have to be called in to put the patient on an IV, while an orthopedic surgeon helps Reg put the bone back into place. "During the cast application process I ensure that the bone doesn't move after the swelling has gone down and the muscles get smaller. If the bone needs placing, we use traction to align the bones and then we cast and use imaging to confirm everything is in the right place," he says. In some difficult cases, an x-ray needs to be taken before and after the cast is applied to make sure the bone didn't move during the application. "We only do this in severe cases and only if necessary because we don't want to overexpose patients to radiation."

Some of these more challenging situations can be anything from applying a hip spica, a body cast that immobilizes the child's hip and/or humerus, or when a patient needs a cast, but also has lacerations that need to be cleaned. "In these cases, I need to cut out a little window in the cast so that I can disinfect the wound," he explains. "This is challenging because the patient is already in a lot of pain and I have to

use a vibrating saw to cut a hole in the cast." He has also experienced having to put a cast on a very violent patient in handcuffs. "I've seen a lot in my career!"

Reg is also responsible for determining which way the arm or leg should be positioned in order to ensure a proper healing process and spends time teaching parents how to care for the cast. "I also show them the x-ray of the broken bone, because the kids like to take pictures of it for their Facebook pages," he laughs. Reg even follows up with Orthopedics to make sure the patient's broken bone is healing properly after their one-week check-up. "I like the feedback because I'm constantly looking to improve and get better at what I do," he says. "I do everything I can to make sure they don't need a repeat visit."

Even though a child's experience in the casting room can sometimes be difficult, Reg does his best to help them get through it. "I always tell them this is short-term pain for a long-term gain."

Wise words from a cast technician who has applied more than 35,200 casts in his career. ■



Passing the test

MRI simulator helps decrease the need for sedation in young children



By Maureen McCarthy



► The MRI simulator has a display screen on the outside, and a camera inside the tunnel. Once the child lies down on the table and moves through the tunnel, the results of their movement appear on the screen.

Asking a typical five-year-old not to move for 30 minutes might seem like a tall order, but a new protocol in the Children's Medical Imaging department is helping young patients succeed at the task, and providing real clinical benefits in the process.

Pediatric Radiologist Dr. Christine Saint-Martin and Chief Technologist Johanne L'Écuyer are leading a project to reduce the rate of anesthesia in children undergoing magnetic resonance imaging (MRI) exams. Children under the age of six normally need sedation for an MRI to ensure they don't move during the exam, but the hospital's acquisition of an MRI simulator—the first hospital in North America to do so—has meant fewer children need to be sedated.

Johanne learned about the MRI simulator while attending the Radiological Society of North America (RSNA) annual convention. "The machine produces the same noises at the same volume as a diagnostic MRI so it's very useful in preparing the patient for the real exam," she says.

MINIMAL MOVEMENT MEANS MAXIMUM SUCCESS

The MRI simulator has a display screen on the outside, and a camera inside the tunnel. A key determinant of whether the child can go without sedation is how much they move during the exam. Once the child lies down on the table and moves through the tunnel, the results of their movement appear on the screen as coloured boxes, similar to a bar chart. "Green boxes mean the child stayed still for a specific length of time, but yellow and red boxes indicate that they were moving too much to get accurate readings," says Dr. Saint-Martin. "The technologist shows the patient the results and says, 'You were doing great here, but then you moved a bit, so let's try it again', and once they can stay still long enough, we know they're a good candidate to do the real MRI without anesthesia," says Johanne.

During the test period between May and August this year, of the 31 patients who did the test in the MRI simulator, 70% succeeded and were able to forego anesthesia. "We go through the requisitions ahead of time to identify children who are potential candidates," says Dr. Saint-Martin. "When they arrive, we talk to their parents and if they agree, we proceed to the simulation."

The MRI simulator is helping to improve both patient care as well as the MRI waiting list. "When a patient successfully completes the MRI simulation test, they can go straight away for the real exam, and because there's no need for anesthesia or recovery, they can go home sooner," says

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Dr. Saint-Martin. She also points out that because less time is required, the Medical Imaging department is able to fit some patients in earlier than anticipated which frees up more time and resources for children who must have anesthesia.

Johanne says one of the factors contributing to its success is having the same technologist conduct the simulation exam as the real test. "Our technologists take a very personalized approach with our patients, and they're very experienced at helping young children feel at ease," she says.

Dr. Saint-Martin presented the team's findings at the Canadian Association of Pediatric Health Centres (CAPHC) annual meeting held in Montreal last month; the project received the Innovation in Clinical Practice award.



▶ Johanne L'Écuyer and Dr. Christine Saint-Martin

The Medical Imaging department acquired the MRI simulator thanks to support from the Sabrina and Camillo D'Alesio Foundation. ■

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Dr. Elizabeth Hailu, PFCC Star of the Month

By Maureen McCarthy



When Anissa Abdelaal talks about her son Milo, she marvels at his strength and determination. She and her husband have seen the extraordinary gains Milo has made so far in his life, one that started much earlier than expected when Anissa gave birth at 25 weeks. Milo weighed only 600 grams, just a little over one pound, when he was born. “To see him today at five pounds is extraordinary,” says Anissa.

Milo’s progress has been steady but he has faced some serious challenges along the way. One Sunday towards the end of September, Milo hit his lowest point. He had developed serious complications with his breathing, and was

deteriorating rapidly. Dr. Elizabeth Hailu was on service that day. “Dr. Hailu stayed by Milo’s bedside for five and a half hours,” says Anissa. “Throughout the afternoon, she was extremely focused on him—she knew the signs before they started happening—but she still did everything she could to keep me involved, showing me results of his x-rays and explaining what was happening.”

The next couple of days were harrowing but by Tuesday—when the antibiotics he was given began to take effect—Milo started to improve. “I had known Dr. Hailu before this happened but that day really sticks out for me,” says Anissa.

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"I felt like she was very in control of the situation, and I saw what an amazing doctor she is." And that's why Anissa, on behalf of Milo, nominated Dr. Hailu for the PFCC Star award.

Dr. Hailu joined the Children's NICU team in 2013 but years before, when she was still in medical school in her native Ethiopia, she had an idea that neonatology would be her career path. "In Ethiopia, the medical training is different to here in that you get to do an internship before you finish medical school." She came to North America to pursue graduate studies, first at McMaster University in Hamilton, and then Columbia Presbyterian in New York where she did her residency in pediatrics and fellowship in Neonatology.

When she first came to Montreal, Dr. Hailu was struck by the generous maternity leave available in Canada—something she sees as a privilege in terms of health policy. She also feels it's a privilege to work in an environment that offers single-patient rooms to babies and their families, providing a more encouraging environment for parents to develop bonds with their baby. "In neonatology, it's very important to have parents involved at bedside, and it should be part of what we do. Those of us in the medical community really need to understand what parents go through."

Dr. Hailu has seen what it means for parents to be part of the process from the first moments. "The more you work in the



► (l. to r.) Anissa Abdelaal, Milo, and Dr. Elizabeth Hailu.

field, the more you see that what we do medically is just part of it," she says. "When parents can tell us about how their baby is doing, as well as bond with them, hold them, read to them, talk to them—all these things can make a big difference to their baby's outcome." ■



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

tamski1

A true star! Cared for my daughter as if she were her own child.

Sharon Cheong

Congrats Samara!!! Well deserved! Keep up the amazing work!!

Helen Seremetis

From resident to fellow to staff, always amazing! Congrats Samara! ❤️

Robert Bloom

Congratulations, very well deserved!!!

Like Comment Share

Video game created for MCH patient

Magic Rumble + Teknoboy was designed for Loïc Bydal

By Stephanie Tsirgiotis

Like most teenage boys, 14-year-old MCH patient Loïc Bydal spends countless hours playing video games. So when he approached the Children's Wish Foundation, he had a very specific wish in mind. He wanted them to create a video game based on a fictional character he created, Teknoboy. "I've been creating this character in my mind since my first year of hospitalization," says Loïc. "He does not really have powers—his ally is technology."

A group of students from the School of Digital Arts, Animation and Design (NAD), along with professor Pierre Tousignant, were assigned to the project and they worked very closely with Loïc to make sure they got everything just right.

They decided to use an already existing game called Magic Rumble as the base, and inserted Teknoboy into the story-line, hence the creation of Magic Rumble + Teknoboy. The racing and strategy game exceeded Loïc's expectations and he was very happy to see the final product.

"I enjoy playing video games because they transport me to another world," says Loïc. "A world very different from being in the hospital." ■



► Annie-Claude Nadon, a coordinator at the Children's Wish Foundation, recently delivered a Magic Rumble + Teknoboy poster to Loïc. His mother, Anik, is working on getting it signed by all the students who helped design it.



► The programmers are looking into getting Magic Rumble + Teknoboy on the market. This would definitely take the game to the next level!



► Loïc plays two to three hours of video games a day.