This fall will mark 85 years since Dr. Wilder Penfield opened the doors of The Neuro - a significant milestone in the history of neuroscience made possible thanks to a visionary $1.2 million donation from the Rockefeller Foundation. More than eight decades later, philanthropy is still at the core of The Neuro. No matter the amount, no matter the source, it is these acts of generosity that have enabled us to continuously innovate and discover, advance research to enhance care, all for the benefit not only of the patients who cross our threshold each year, but far beyond.

The brain is the last frontier of medicine and one of the most significant unmet medical needs of society. More than 100 million North Americans are currently affected by a neurological disease and despite huge investments in research, it has been decades since a truly revolutionary new drug or treatment has emerged to alter the course of these terrible diseases.

In a groundbreaking move, The Neuro made the bold decision to change our way of doing science and become the first institution in the world to adopt open science as an operating principle. We are now at the very vanguard of the future of brain science: a transparent, fast and global flow of knowledge, where patients benefit from the most advanced research taking place around the world. And this was only possible through the power of philanthropy.

You will find within the pages of this report stories from our community. Stories of generosity, of impact from ensuring our patients' peace of mind and safety, to training the next generation of researchers, to ensuring we collaborate and explore new treatments for neurological diseases. Stories from volunteers, donors, ambassadors and friends, all critical partners committed to advancing neuroscience research and care.

With sincere gratitude,

Guy A. Rouleau, OQ, MD, PhD, FRCPC, FRSC
Director, The Montreal Neurological Institute and Hospital
Chair, Department of Neurology and Neurosurgery
Danielle Lepage
A volunteer in the trenches

On April 17, 2018, Her Excellency the Right Honourable Julie Payette, Governor General of Canada, presented long-time Neuro volunteer and community fundraiser Danielle Lepage with the Sovereign’s Medal for Volunteers. This prestigious honour recognizes the exceptional volunteer achievements of Canadians from across the country and pays tribute to the dedication and exemplary commitment of volunteers.

Danielle has been raising funds for research into sensory neuropathy since 2009. Her goal is to pave the way for a brighter future for youth who are diagnosed with this illness. Thanks to her motivation and devotion to this cause, she has raised more than $260,000 to support the research of The Neuro’s Dr. Bernard Brais into the disease.

Sensory Neuropathy, a rare neurological disease that disproportionately affects Quebeckers in the Lanaudière region, results in a dangerous lack of sensation in the extremities of the body, causing minor injuries to go unnoticed and become serious. In some cases, patients can even have limbs amputated. Danielle’s fundraising efforts over the past decade have been instrumental in helping our researchers to better understand the genetic mutation behind the disease, and a partnership with pain experts from Yale holds great promise for the development of a treatment.

OUR INSPIRATIONAL VOLUNTEERS

Volunteers are integral to The Neuro’s mission. Each year, we rely on hundreds of volunteers to help us collect donations, organize events, raise awareness and visit patients in the hospital. We are grateful to all our volunteers for their support and ambassadorship.
Nicolas Bertrand
226km for research - and for love

On August 19, 2018, more than 2,700 athletes took to Mont-Tremblant for the grueling Ironman Triathlon which challenge participants to a 226km swim, bicycle ride and marathon run. Among these participants was Nicolas Bertrand, who undertook the challenge not only for himself but to honour his wife, Laurie Dion, who is living with brain cancer. At the time of diagnosis, Laurie had been given a life expectancy of only 16 months. Over six years have since passed. Last summer, the couple embarked on a different type of challenge—Nicolas’ participation in the Ironman, which they used as an opportunity to raise awareness for the cause and fundraise for brain cancer research at The Neuro.

Nicolas & Laurie’s Story

As told by Nicolas Bertrand

For the past six years, I have been in a devoted relationship with a wonderful and inspiring woman. Unfortunately, 13 months after we began dating, our life together took a sudden turn. We discovered that Laurie had a cancerous mass in her brain—a Grade IV glioblastoma brain tumour.

This was a difficult year for us. We were forced to reconsider our outlook on life and our vision of our ideal future together. But it only served to increase the love that we felt for each other. We made a promise to each other that from there on out, we would live to the fullest. And so I thought—why put off until tomorrow what I can do today? We were soon engaged and married on April 11, 2015, a little more than a year following her diagnosis.

As I became more familiar with the realities of the cancer, I was driven by the need to do something for all those out there living with cancer, especially for my wife who is still living with it today. That is why I decided in 2018 to sign up for the Ironman. My goal was to take on a challenge that came as close as possible to what Laurie faces daily. To show her that I was willing to do what it takes to understand what she is going through and to help her one day overcome this cancer. Since her diagnosis, Laurie has tackled her cancer head on. I wanted to replicate this fight the best that I could.

In taking on the Ironman, I knew it would bring a higher credibility and importance to my cause. To most people, this type of triathlon is highly intimidating due to the physical challenge it entails. But it’s nothing when compared to what a person living with a brain tumour faces daily just to survive. That’s the message I want to get across.

Moving forward, I will continue to push myself to do better each day in support of young people who are suffering from all forms of cancer, particularly glioblastoma. Above all else, I will continue to fight to honour my wife, who is still living with an incurable brain tumour.

Thank you to everyone who has supported me in this challenge. And thank you to The Neuro for continuing its important research into brain cancer and for offering the best services possible to families affected by this terrible disease.

Josie Arcobelli
Brain Matters

As told by Josie Arcobelli

I was diagnosed with a meningioma in November 2013, where I was immediately told that it would be mandatory for my tumour to be surgically removed. It was all very quick and so impersonal, that I just could not wait to get out of that doctor’s office and run back to my car so I can shed my tears in private. Unfortunately, the discovery of my tumour did not take place at The Neuro. As we searched for a second opinion and validation, we were blessed to encounter Dr. Kevin Petrecca. Dr. Petrecca studied my case diligently and then carefully followed up over time, as he kept my condition under a close eye. In October 2015, after my routine MRI, it was discovered that my meningioma had significantly grown in size and unfortunately surveillance was no longer a solution. Due to my tumour’s location, alongside Dr. Petrecca, we reconsidered the possible options. After multiple lengthy discussions, Dr. Petrecca recommended I begin radiation as the best alternative for positive results.

For a little over six weeks I was under the care of Dr. Abdulkarim, a splendid oncologist at The Neuro, as I made my way for daily treatments and weekly follow-ups. Those six weeks were not easy. Many tears were shed, and the anger and tiredness I felt along the way were inevitable. Undoubtedly, the team of doctors and nurses at The Neuro were paramount in helping me through this difficult time, as they always assisted my case with the greatest sincerity and care. More so, all throughout my treatments Dr. Petrecca was always there.

Despite the hundreds of patients that Dr. Petrecca treats daily (and I do mean hundreds for I have seen his office fill up like a concert hall), I always felt like a priority. Always available for any questions and concerns, being followed by Dr. Petrecca reassured me that I was in the best care possible.

Now, I stand here today still with a meningioma, yet a much smaller and definitely a less invasive one. No, I cannot say it is finally all over and done with, but I can say that I am grateful. I am grateful for where I am, where I was treated, the security and comfort I received, the results I have gotten, the people I’ve met along the way, and all the great difference they have made for me. I can proudly say that last year I began to start feeling like myself again. I don’t feel like I am completely out of the woods as there are still daily struggles. However I have become more accepting and at ease with life and the situations it throws our way.

Through this experience I have learned how important it is to have a strong, loving team that supports, guides, and paves the way for you even on the rainiest of days. My story here isn’t the only one - there are many more individuals, just like myself, who will inopportunely face these difficult situations. We all have the power to be someone’s ray of light and together we can be the team that helps so many out there!

As a token of my understanding and appreciation for this cause, I have tried to extend my gratitude by supporting Dr. Kevin Petrecca and his wonderful team, so that they may further their research and help all those that come their way. There are countless brain tumours diagnosed each day and unfortunately doctors and researchers cannot solve this negative wave on their own.

For that reason, my family and I created BRAIN Matters, which supports brain tumour research at The Neuro through regular fundraisers. All the proceeds from these events support Dr. Petrecca and his important work.
The Topor Family Fund
Supporting multiple sclerosis research & care

“To know that this microscope was bought and will directly help speed up the process to finding a cure is an amazing thing to see.”

Jordan Topor has raised over $500,000 for the MS Society and MS research in the lab of Dr. Jack Antel with his annual “Grip’N’Rip” golf tournaments, MS walks, poker tournaments and a 36-hour-Guinness World Record online hockey game. His volunteering helped pay for two high-powered microscopes that enhance our capacity to analyze the properties of myelin-producing cells under injury conditions in response to potential therapeutic agents.

Jordan and his family began fundraising for MS after his mother was diagnosed with the disease. During a visit to The Neuro, he was happy to see the physical devices that are now contributing to the cause about which he is so passionate.

“Most of the time when you raise money for charity you know that you are doing a great thing and that the money will go to great use. However, you rarely get to see exactly where your money went,” he says.

“To know that this microscope was bought and will directly help speed up the process to finding a cure is an amazing thing to see.”

“My mom is my hero and definitely the toughest person that I know. Her strength and determination are an inspiration to everyone who has had the pleasure to meet her and those that have the pleasure to call her a friend. My mom always says, ‘I may have MS, but MS doesn’t have me yet.’”

Jordan feels neurological disease does not get the attention it deserves. He is glad to help The Neuro research MS with the goal of finding better treatments and one day, a cure.

“Anyone that I have met that works for The Neuro has been great,” he says. “They are all kind-hearted and selfless human beings. I like to call these types of people ‘the good guys’.”

The ceiling of The Neuro’s Art Deco foyer features the head of Aries the ram, the astrological symbol presiding over the brain. The four hieroglyphs are the first written symbols for the brain, which come from the Edwin Smith Egyptian papyrus dating to 3000 BC. The Greek quotation from the commentaries of Galen on the aphorisms of Hippocrates, can be translated, “But we have seen a wounded brain healed.”
You could say that The Neuro is part of Sherrill Rand Harrison’s extended family—and the family tree has deep roots. Several generations of her family have trained at The Neuro. “Dr. Eddie Archibald, a distant cousin of my grandfather was in part responsible for bringing Dr. Wilder Penfield to head up The Neuro where my mother, aunt, sister and mother-in-law did part of their RVH nursing training. My mother-in-law was, in fact, one of the operating room nurses for Dr. Wilder Penfield. My mother’s two brothers interned at The Neuro as part of their McGill medical degrees.”

In the decades since graduation, Rand Harrison has been an active volunteer for McGill. Most recently in the years since retiring to Nova Scotia, she has won the Alumni Event of the Year Award in 2008 and in 2018, the D. Lorne Gales Special Recognition Award from the McGill Alumni Association.

She first considered a commitment to The Neuro when she lost her husband to brain cancer at the age of 49. “Years later, I was inspired by a meeting with Dr. William Feindel, who gave me a tour of The Neuro and the Brain Tumour Research Centre. Through him, I met some remarkable doctors, such as Dr. Kevin Petrecca, and learned about their great research. It truly opened my eyes to the possibilities, hopefulness and specifically the importance of research into this form of cancer and the need to encourage and support scientists who dedicate themselves to this cause.”

For Rand Harrison, her bequest, therefore, is both a generous gesture and a very personal one. “The Neuro is a great research centre with a focus on patient care,” says Rand Harrison. “That’s why my bequest is to support research into brain cancer and contribute to progress in its diagnoses, causes, treatment and cure. The Neuro truly makes a difference.”

Legacy donors John F. and Nancy Gordon met at The Neuro in 1947. John was a patient of Dr. Wilder Penfield, and Nan was a nurse. Dr. Penfield would later escort Nan down the aisle when she wed John in 1948. Both felt a tremendous attachment to The Neuro and bequeathed half their estate to the institution. John died in 1960 and Nan in 2004, leaving a legacy of over $4 million to The Neuro.

“Dr. Eddie Archibald, a distant cousin of my grandfather was in part responsible for bringing Dr. Wilder Penfield to head up The Neuro where my mother, aunt, sister and mother-in-law did part of their RVH nursing training.”
When Brenda Milner was a young graduate student beginning her career at The Neuro in 1950, she received two pieces of advice: “make yourself as useful as you can” and “don’t get in anybody’s way”. After a stellar 65-year career, more than 20 honorary degrees, numerous academic awards, and an outstanding record of groundbreaking research, it’s safe to say that the world-renowned neuropsychologist has surpassed those original, modest benchmarks.

When Milner began working at The Neuro, it was at the threshold of a modern era of investigation into the complexities of the brain and nervous system. The Neuro was front and centre of these auspicious beginnings of neuroscience, pioneering a surgical procedure for patients suffering from epileptic seizures.

“Neuroscience is a great success story and The Neuro is part of that story,” says Milner.

Today, Milner is Dorothy J. Killam Professor at The Neuro and a Professor in the Department of Neurology and Neurosurgery at McGill University. She has contributed to enormous research advances and has helped countless patients through her discoveries about the brain and memory. Milner’s research has also had a profound influence on the development of tests to treat people with brain disorders resulting from traumatic injury, degenerative diseases, or psychiatric illness.

In honour of Milner’s 100th birthday, The Neuro hosted the Brenda Milner Centennial Symposium on September 6-7, 2018. Hundreds of people from around the world gathered to celebrate her legendary life and career, including: Nobel Prize laureate Eric Kandel; Her Excellency the Right Honourable Julie Payette, Governor General of Canada; Neuro Director, Dr. Guy Rouleau and McGill Principal and Vice-Chancellor, Suzanne Fortier.

At 100 years old (Milner attributes her longevity to good genes, a social network, a little exercise, and the benefits of bilingualism), she could easily rest - or retire – on her remarkable laurels, but laurel-resting does not suit Milner. She brings the same fervour to her work today as she did in 1950, when she first stepped through The Neuro’s front doors.

“It’s exciting to see the research evolve,” she says.

As one might expect, Milner brings the clinical rigour that characterizes her research to her legacy gift to The Neuro. Her bequest will support the Brenda Milner Fellowships in Cognitive Neuroscience and Neuropsychological Research. Milner knows that fellowships are a targeted need that will greatly benefit from donor support.

In recognition of her tireless commitment to the field of cognitive neuroscience and in appreciation of her generous philanthropy, The Neuro announced a matching fund of $1.5 million for Dr. Milner’s legacy gift at the Gala celebrating her 100th Birthday.
A New Lease on Life
Linda Kaplan’s story

For most people, January 18, 1979 was an unremarkable day in a cold Montreal winter; but that day changed the life of Linda Kaplan, a patient at The Neuro. “As a young woman, I had been having minor seizures which were undiagnosed for years,” says Kaplan, now an urban planner working for a not-for-profit housing organization in Chicago.

At the time, Kaplan’s family was living in Washington, D.C. Their quest for answers led Kaplan’s parents to seek help from many neurologists in the U.S. – without success.

The breakthrough came when doctors finally managed to trace the origin of her seizures to the left side of the brain at the temporal lobe. The good news was that the condition could be treated surgically. However, the undisputed leader in the procedure was a hospital in Montreal, Canada: The Neuro.

When Kaplan arrived at The Neuro in January 1979, she underwent a battery of tests to ensure she was a suitable candidate for surgery. She was discharged four weeks after a successful operation.

“I’ve basically been seizure free ever since,” says Kaplan. “I’m very indebted to The Neuro because of this. It lifted so many weights from my life and let me pursue things I’d never done before.”

Less than two years after the surgery, Kaplan was able to pursue a full-time career with no seizures, no speech impediments, and no problems.

She still has vivid memories of her time at The Neuro, particularly her camaraderie with other patients and the dedication of physicians like Dr. Brenda Milner and Dr. Theodore Rasmussen.

“It was inspiring to see their genuine love and interest in the field,” she recalls.

Kaplan’s bequest stems not just from her own experience at The Neuro but from a sincere desire to help patients in the future. “My gift is going to research,” she says. “I want researchers to find ways of controlling this. I don’t want people to go through what I went through.”

IMPACT ON RESEARCH

Through their transformational generosity, these donors are supporting scientific breakthroughs by funding innovative research programs and enriching the training environment for our students and fellows who make up the next generation of neuroscientists.
Twelve trainees from across Montreal made up the inaugural cohort of the Quebec Autism Research training program. The Transforming Autism Care Consortium (TACC) is a multi-organization research network that connects and mobilizes Quebec’s strengths in autism research to improve the quality of life of people with autism and their families. TACC seeks to accelerate scientific discovery by funding innovative research, providing training opportunities to graduate students and fellows, and integrating research with clinical care. TACC is a Québec-wide initiative, bringing together researchers from The Neuro, McGill University, University du Québec à Montréal, CHU Ste-Justine, Université de Sherbrooke, Université de Montréal, Université du Québec en Outaouais, and the École de technologie supérieure.

An important component of TACC is the creation of the Quebec Autism Research Training program, which aims to attract and train outstanding graduate students and fellows and support their career development and training in autism research. Twelve graduate students and fellows from the participating institutions were selected as the first cohort of the training program in 2018. They attended a week-long summer school in August, which was led by mentors from across Quebec. More than 20 experts (researchers, professionals, people with autism and their families) contributed to training activities ranging from lectures to interactive skill development sessions.

Launched in 2017, TACC has since raised over $10 million in funding from both governmental and philanthropic sources. This initiative would not be possible without the drive of our scientific community and without the generosity of TACC donors, including La Fondation Marcelle et Jean Coutu, Fondation François Bourgeois, The Birks Family Foundation, The Azrieli Foundation, The Mike and Valeria Rosenbloom Foundation and the MacDonald Stewart Foundation.
Fondation des Jumelles Coudé
Advancing research into rare disease

After their twin daughters Valérie and Alexandra were diagnosed with Andermann syndrome in 1991, Louise Gagné and Alain Coudé were faced with the difficult realization that this rare neurodegenerative genetic disease had no treatment. Worse yet, research at the time had not even been able to identify the cause of this disorder, which damages peripheral nerves related to sensation.

In face of this difficult diagnosis, the family decided to create La Fondation des Jumelles Coudé in 1993. Their goal was to give hope to the increasing number of children with the disease by fundraising for research, which has since succeeded in bringing some clarity to this rare disorder.

Since its creation, the foundation has distributed over one million dollars in donations to support the research of Dr. Guy Rouleau. Dr. Rouleau and his team managed to locate the gene responsible for Andermann syndrome in 1996, which was identified in 2002. This breakthrough allows individuals to be tested for carrier status to control the propagation of the disease.

The foundation’s latest donation of $300,000 established Le Fonds dédié des jumelles Alexandra et Valérie Coudé at The Neuro. This endowment will support in perpetuity the work of a graduate student researching a neurodevelopmental or neurodegenerative disease that appears during infancy, in particular sensorimotor polyneuropathy with or without agenesis of the corpus callosum.

Rachel de Barros Oliveira is the first recipient of an endowed studentship funded by La Fondation des Jumelles Coudé.

Rachel de Barros Oliveira describes the impact this funding will have on her research:

“This support from La Fondation des Jumelles Coudé will give me the opportunity to expand my horizons by contributing to research in Hereditary Motor and Sensory Neuropathy/Agenesis of the Corpus Callosum and Restless Leg Syndrome. My goal is to help other neuroscientists to understand this huge puzzle that is the human brain and hopefully discover new treatments to improve quality of life for patients. By awarding me this funding, I will be able not only to learn new techniques but to continue with my studies in one of the best neuroscience programs in the world. This act of generosity has inspired me to never give up on my dream of helping people.”
Gary Armstrong
Tiny fish could be the key to an ALS breakthrough

“It’s a tiny fish that’s been used in research for a long time because researchers can manipulate their genome in precise ways,” says Armstrong, who joined The Neuro in 2017 as an assistant professor in McGill University’s Department of Neurology and Neurosurgery. “As a genetic model for testing drugs, they’re fantastic. I can make the same genetic mutations in these fish that cause ALS. Moreover, with the new equipment that I have, I can test drugs on hundreds of fish at a time, which creates a wonderful drug-screening platform.”

Armstrong’s activity falls into the category of translational biomedical research, which aims to refine laboratory discoveries in a short time period and at low cost before the discoveries undergo lengthy, costly clinical trials. A key advantage of zebrafish is their small size. Adult zebrafish can be bred by the dozens each week and experiments can be performed on the thousands of juvenile fish at little expense. Test drug compounds are simply added to the water in which the fish are living.

Purchased with money from a generous private donor, the zebrafish motion tracker system called DanioVision developed by Noldus is small enough to fit on a desk. It is capable of monitoring the movement of huge numbers of fish so that a researcher can spot signs of ALS. Drug compounds can be tested on these fish to see whether the symptoms can be stopped. Rather than having the researcher test drugs by hand one chemical at a time, the motion tracker can screen thousands of potential chemicals rapidly and in an unbiased way.

“I have different ALS models because we know at this point of about 35 different genes that are involved in ALS, causing different defects at the cellular level. Although ALS manifests symptoms similarly among patients, the cellular defects can be very different from one patient to the next. So in our models, our test drugs target different things.”

ALS remains a relentlessly progressive and devastating disease. But considerable advances have been made and these discoveries have opened the door to innovative approaches to the study of cellular defects that arise in ALS. This gives us hope.”

The Djavad Mowafaghian Foundation
Donation to open science powers innovation in drug discovery for autism spectrum disorder

Autism spectrum disorder (ASD) affects a growing number of Canadians. A generous donation from the Djavad Mowafaghian Foundation will create a new partnership between researchers at The Neuro and the University of British Columbia, who will collaborate to advance drug discovery in ASD in an open science framework. The aim of the donation is to help scientists generate ASD research data that will be shared globally.

Inspired by the promise of the global open science movement and leadership role of The Neuro, the Djavad Mowafaghian Foundation Autism Spectrum Disorder Drug Discovery Fund will support the development of new expertise in autism research in The Neuro’s Open Drug Discovery Platform. Researchers in the platform have proven expertise in working with induced pluripotent stem cells (iPSCs) and developing assays to screen for promising targets for drug therapies. Now this promising new avenue of discovery will be applied to autism spectrum disorders.

As part of The Neuro’s open science policy, data produced by The Neuro and UBC scientists through this partnership will be shared so that the worldwide community of researchers can use the data to develop therapies for ASD. This will ensure this work has the maximum chance of leading to concrete breakthroughs in the treatment of ASD.

Autism research is a major priority for The Neuro. Scientists have a lot to learn about what causes autism, specifically what role genes and environment play in the development of the disorder. Effective treatments for its often-debilitating effects are lacking. This donation will strengthen our knowledge of autism, helping autistic people lead better lives.

“I first became aware of the seriousness of ASD when a good friend’s daughter was given the painful diagnosis of severe autism more than 20 years ago,” says Hamid Eshghi, President of the Djavad Mowafaghian Foundation. “Since that time, I have learned of many similar stories and, have come to learn that, while many more children are being diagnosed with ASD in recent years than in the past, there remains little understanding of the disorder, its causes, and effective treatments.”

“We are proud of our relationship with McGill and The Neuro, and it pleases us to announce this first significant gift outside the province of British Columbia. It is also very satisfying to know that the research carried out at The Neuro will be shared with the scientists at the University of British Columbia.”

“The support of the Djavad Mowafaghian Foundation is pivotal, with an impact far beyond The Neuro. It is the beginning of a new partnership in open science,” says Dr. Guy Rouleau, Director of The Neuro. “Thanks to this donation, we will be better equipped to harness important insights and increase the pace of drug discovery for the benefit of millions of people around the world living with ASD—as well as their families.”

Members of the Djavad Mowafaghian Foundation are pictured with Neuro researchers and McGill Principal and Vice-Chancellor Suzanne Fortier during a visit to The Neuro to celebrate their $1 million donation to autism research and the open drug discovery platform.
Every year, The Neuro is supported by a community that is more than 4,500 strong. Together, we are building a better life for those living with a neurological disorder.

**BY THE NUMBERS**

Donations statistics are for the 2019 fiscal year.

- **4,000+** Donors
- **1,800+** Surgeries
- **42,000+** Ambulatory visits
- **100+** New and ongoing clinical trials
- **2,100+** Admissions
- **$14.6 M+** Total raised
- **$1M+** Raised for patient care
- **$750K+** Financial support for trainees
- **$13M+** Raised for research

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**PHILANTHROPY CHANGES LIVES**
A Brilliant Night 2018 raised over $1M for The Neuro’s Brain Tumour Research Program. Since its inaugural event in 2015, the annual gala has donated more than $3.5M for the fight against brain cancer. It is with thanks to these funds that researchers at The Neuro have made incredible scientific breakthroughs, changing the course of brain cancer research worldwide.

WhiskyFête 2018, held by the St. Andrew’s Society of Montreal, raised $40,000 for the Preston Robb Day Centre at The Neuro. The Centre is used by patients that are undergoing a day surgery for intravenous medical treatments. The funds raised will enhance the Centre’s space and improve its overall service to provide patients and their families with the most positive experience possible. Proceeds from WhiskyFête 2019 will fund a research partnership between The Neuro and the University of Edinburgh.

The Topor family’s annual Grip ‘N’ Rip golf tournament, in honour of matriarch Joanne Topor, raised a total of $86,000 this year for The Neuro’s Multiple Sclerosis Greatest Needs Fund. Now in its fifth year, the tournament’s supporters have contributed significantly to the purchase of equipment dedicated to MS research.

On October 13, 2018, the Église Missione dell’Annunziata held an inspiring fundraiser that raised $22,000 for research at The Neuro, where many of their parish members have been treated. The funds will go toward brain cancer and multiple sclerosis research.

The Associazione Siculiana held their first annual gala fundraising dinner, Heading for a Cure, on May 5, 2018, at Le Chateau Classique to raise money for brain cancer research at The Neuro. Altogether, the gala raised over $17,000 for the cause.

The Neuro was well represented at the 2018 annual Scotiabank Charity Challenge held in April, with four teams and a total of 67 participants aged 2 to 68! Congratulations to all of our runners, and thanks to everyone who participated! Thanks to you, we surpassed our $25K goal and raised $31,429 for research and patient care at The Neuro.

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Philanthropic dollars go a long way in improving the physical and mental well-being of our patients and families. The following stories demonstrate how our donors continue to support the quality of care by purchasing much-needed equipment and funding patient-centred programs.

Manon’s Story
Living with young onset's Parkinson’s disease

As told by Manon Day

My first neurological symptoms appeared at age 17. Although I have stuttered since childhood, my disorder subsequently got worse to the point where I was slurring my words. I consulted several neurologists but none were able to diagnose my disease. For the next decade I was left with uncertainty and no answers or treatment.

In 2011, I had the chance to be referred to The Neuro’s Movement Disorder Clinic, where I met Dr. Ron Postuma. He reviewed my family history, ran a detailed physical examination, ordered some laboratory and imaging tests and prescribed levodopa.

A few weeks later when I went for my next appointment, I felt a lot better! What a difference it made in my life. The medication helped me tremendously. Dr. Postuma diagnosed me with Young Onset Parkinson’s, a rare form of the disease. Usually, Parkinson’s affects people age 60 and up. I finally knew definitely what was afflicting me for so many years.

Dr. Postuma was the only neurologist who was able to unravel my medical mystery.

Although I was only 27 years old at the time, a few years later, following genetic tests, it was confirmed that I had the PARK2 gene, which has been linked to Parkinson’s disease. I must say that I will be forever grateful to Dr. Postuma because he saved my life.

At The Neuro, I receive a full range of services such as physical, occupational, and speech therapy, as well as patient education to help me with the management of Parkinson’s disease. I also have access to a nurse clinician who I can reach anytime.

I strongly recommend The Neuro because the Movement Disorder Clinic team offers excellent medical care. It really makes all the difference in someone’s life to be treated with humanity.

"At The Neuro, I receive a full range of services such as physical, occupational, and speech therapy, as well as patient education to help me with the management of Parkinson’s disease.”
Sophie’s Story
Seizure free thanks to surgery

As told by Sophie Jodouin

I was a young teenager and in perfect health, when suddenly I started having absence seizures at school. Undiagnosed as such, I would often tell my mother how I got lost in the classroom or even in my room.

On Christmas Eve of 1997, I woke up to find two paramedics standing over me. My body felt like it had been through a massive marathon. I was rushed to the hospital not once but twice that day. I had experienced two tonic-clonic seizures. It was official: I was diagnosed as being epileptic.

Throughout the years, my epilepsy and seizures were never easy to control, and my neurologists in Ottawa were baffled by the reason behind the seizures.

Four years ago, after a burnout from stress and being over tired at work, I seized non-stop for 140 hours and since then my life has never been the same. I was released from the hospital but started having seizures on the left side of my body three to four times a night and they were never able to stop or control them. My neurologist referred me to The Neuro.

In May 2017, I was invited to take part in two weeks of EEG monitoring at The Neuro in the hopes of finding some answers. This was a chance of a lifetime! I met Dr. Martin Veilleux who was, at the time, the neurologist on staff on 3 North.

All the amazing nurses and staff cared for me very well. They provided support and knew exactly how to care for the special needs of each patient. It is a one-of-a-kind place, and I felt very lucky to be there.

During my stay, I had the pleasure of meeting who I consider the Dream Team: Dr. Andrea Bernasconi and Dr. Neda Ladbon-Bernasconi, who were able to find the cause of my seizures through an MRI where they reconstructed my brain layer by layer, in 3D. They discovered a lesion that I have had since birth. This was the moment that changed everything.

Later on in October, I had an appointment where I met Dr. Jeffery Hall and a couple of residents from out of the country. The plan was to have a surgery called deep electrode implantation. This is a procedure where they put electrodes directly on your brain to get more precise information to help target the cause or location of the seizures. I wasn’t nervous and I was more than ready.

In May, I went for a second surgery called thermocoagulation. This is the process of putting electrodes directly in my lesion and burning it. What a fantastic experience and one I will never forget. Since the procedure I have been seizure free and I truly feel I won the lottery.

I cannot thank these doctors enough for their determination, expertise and their compassion. They gave me the best gift of all, they gave me my life back after 21 years. This was a long journey for me but it ended well.

Private Donation Makes Patient Transport Van a Reality

The new vehicle will reduce stress of intra-site transports for patients and their families

Mario Di Carlo knows the frustration that often comes with moving between medical facilities. He has been a patient of the post-polio clinic at The Neuro for the past 20 years, and has had to be transferred from one facility to another to receive care.

There is a special something about Dr. Hall that puts you at ease, and having been there before, I knew I was in great hands. This was the right choice for me.

A year after I first walked into The Neuro I went in for my surgery, excited and ready for more answers. The team was amazing! Dr. Hall knew precisely where to put the electrodes to get the best results as the doctors had carefully mapped out my surgery beforehand.

If there is one thing I’ve learned about my visits and stays at The Neuro, it is that everything is done as a team and cases are never looked at by one independent doctor. As a patient there, I was privileged to have numerous doctors examine the results of my tests and talk about them collaboratively. The solution was found because of their teamwork and their combined skills.

After implantation, I had the pleasure of being a patient of Dr. Birgit Frauscher’s. I have met many neurologists on this journey, but none as enthusiastic about their job or results as Dr. Frauscher. She is one of a kind and has been a gem throughout this process. Her passion for her work and her drive for success is exemplary and being under her care, I knew I was going to get the right results.

“We have the best doctors in the world. They will go above and beyond to make sure that you’re taken care of, and you might be in pain,” says Di Carlo, who is also a patient advocate, and former co-chair of The Neuro’s Patients’ Committee. “You may have nobody to turn to. You are just in limbo. A long wait could definitely exacerbate your pain level and your negative perception of what’s going on with your health.”

That is why Di Carlo was happy to hear that the McGill University Health Centre (MUHC) now has a vehicle dedicated to patient transport, a first of its kind for the organization and for Quebec. The van was purchased thanks to a donation from a private family foundation. It first hit the road in early 2018.

The Ford Transit 250 can carry one patient at a time, with room for a stretcher, oxygen, a nurse, and up to three family members. It is specially modified with LED lighting and tinted windows to reduce glare and give the patient privacy. The van is used to transport chronically-ill patients who need close medical supervision at all times. A nurse rides with the patient to ensure safety during the trip between facilities. The van runs during peak hours

“Since it first hit the road in 2018, this transport vehicle has completed over 450 trips between hospital sites.”
between The Neuro, the Glen Site, the Lachine Hospital, and the Montreal General Hospital. It is also used to transport pediatric patients.

The addition of this transport van has already made a huge difference in the lives of patients. They can be picked-up and dropped off immediately, whereas before a patient might spend the entire day waiting for a ride to a brief appointment. A more efficient transport service has also meant fewer cancelled appointments and therefore less anxiety and frustration for patients.

### The Neuro-CareAxis Partnership

Relieving spine pain and reducing surgical wait times for patients across Quebec

Spine surgeons have long wait lists, but the majority of these people don’t need to see us,” says Carlo Santaguida, a neurosurgeon who directs The Neuro’s Spine Program. “When a family doctor refers a patient to a spine surgeon because they believe that patient requires surgery, they’re right only 15% of the time.”

As a consequence, patients who do need spinal surgery are caught in a long waiting line, while those who don’t undergo needless tests and could have their condition treated more quickly and efficiently. “We need to completely refocus how we care for these patients,” says Santaguida. “That’s why we created the CareAxis network.”

CareAxis, a non-profit organization formed to address the problem of long wait-times for surgical assessments, has recruited and trained a team of physiotherapists who can identify appropriate candidates for surgery with a high degree of accuracy— and without imaging examinations.

“Rather than go through diagnostic tests and wait for an appointment they don’t need with a spine surgeon, patients can be treated more quickly and effectively by a physiotherapist,” says Santaguida. “And those patients who do require surgery can be identified by the physiotherapists and flow through the system more quickly.”

Santaguida, CareAxis’s Chief Medical Director, co-founded the network with his brother Paul, its CEO, whose background in program management includes implementing a similar program in Ontario. Since incorporating in 2015, CareAxis has linked with six clinics around Montreal; in spring 2019 it expanded its network to thirteen clinics, including sites in Val d’Or and Gatineau. “Eventually we want to be able to serve all Quebec,” says Carlo.

“The idea of using physiotherapists is not innovative, but how we are implementing the care model is,” explains Paul. “One major challenge involves applying this model across a region as vast as the McGill health network in a cost-effective way. So instead of building brick and mortar clinics, we recruit top physiotherapists from independent clinics across the province to form an affiliate network.”

These physiotherapists then receive advanced training and accreditation by The Neuro’s surgeons and are given access to a shared technology platform managed by CareAxis, enabling them to provide surgical assessments consistently across the network. They are also able to refer patients for further treatment at The Neuro when clinically indicated. CareAxis and The Neuro have developed performance measurements to track the initiative’s impact on health outcomes, patient satisfaction, wait times, and treatment costs.

Further, as part of its partnership with The Neuro, CareAxis introduced The Neuro-CareAxis Spine Program for Seniors, which aims to improve surgical assessment wait-times for patients 65 years or older. As part of this program, eligible patients receive access to CareAxis services at no cost, including an assessment by a local physiotherapist and expedited referral to a surgeon at The Neuro for surgical candidates.

Since its launch, CareAxis has been able to grow its scope thanks to the generosity of donors, specifically the Mirella and Lino Saputo Foundation. A recent commitment from the foundation allowed the network to expand the number of clinics served throughout the province, and therefore the number of patients reached. With this funding, the feasibility of the CareAxis model will be further tested and function as a proof of concept for additional growth that, if successful, has the potential to radically change a patient’s journey from initial symptoms to treatment.

“The support from the Mirella and Lino Saputo Foundation means we’ll be able to divert over 1000 patients over the next 14 months from needlessly waiting for appointments with surgeons, so those who require consultation will be seen faster, and those who don’t will be given the resources to manage spine pain without having to set foot in a hospital,” say the Santaguida brothers. “The support of donors means the world to us. It is helping us transform how spine patients are cared for within our health care system.”

### The Neuro Cares Fund

Supporting patients beyond the bedside

A hospital is often a difficult place to find hope. It’s hard enough to overcome the physical and health challenges that come with the diagnosis of a neurological illness or injury. For many of the more than 2,300 patients admitted to The Neuro each year, this challenge is further worsened by the financial difficulties that come as a direct result of their diagnosis.

Thankfully, The Neuro Cares Fund is here to help. Created in 2012 and overseen by The Neuro’s Social Services team, this fund provides financial support to those in need.

The Neuro’s Social Services team oversees The Neuro Cares Fund, supporting patients in need.
“As social workers, we witness firsthand how financial pressure and uncertainty can overwhelm a patient’s ability to cope and worsen the impact of their diagnosis. Through The Neuro Cares Fund, we can help alleviate some of this stress for our neediest patients.”

By providing assistance to cover expenses such as groceries, medication, utilities, transportation, medical equipment, and more, the Fund helps relieve stress and allows patients to concentrate on what matters most - their health and their family.

“As social workers, we witness firsthand how financial pressure and uncertainty can overwhelm a patient’s ability to cope and worsen the impact of their diagnosis. Through The Neuro Cares Fund, we can help alleviate some of this stress for our neediest patients,” explains Mia Lanno, Clinical Coordinator.

The program also funds initiatives that aim to improve hospital stay for patients, such as the distribution of welcome kits (which include toiletries, sanitary products and entertainment like Sudoku books or crossword puzzles), television rentals, and the delivery of holiday baskets for patients and their families.

Private donations are the lifeblood of The Neuro Cares Fund as the program is entirely donor-funded. This important service continues to exist only thanks to the generosity of donors who make annual or monthly gifts, as well as staff who contribute through regular payroll pledges.

The Neuro Cares Fund has also benefitted from the support of foundations and corporations such as The Friends of The Neuro and DRW Montreal, who selected the program as a beneficiary of their 2018 Holiday Giving Challenge. Together, they raised more than $5,000 this past holiday season for the program.

“The Neuro Cares Fund is special because every dollar that goes into the fund directly helps a patient in need,” says Lanno. “The degree to which we have been able to assist our patients and their families would never have been possible otherwise. For that we are truly grateful.”
While reading this report, we hope you were inspired by the stories that demonstrate the philanthropic strength of our community and its enduring generosity to the cause of finding new and more effective treatments for neurological diseases. Above all else, we express our profound gratitude to you - our donors, volunteers and ambassadors - for the impact you have on the lives of so many within the walls of The Neuro and beyond.

Your dedication is an inspiration for all of us. You are part of the fabric of The Neuro. The power of philanthropy knows no bounds and together, we will build a better future for people living with neurological diseases, pushing research beyond current limits and bringing innovation and new treatments to our patients.

We look forward to continuing to share our progress and discoveries with you.

On behalf of all of us at The Neuro, thank you for believing in us and for embarking on this journey that promises a new era of scientific and clinical innovation.

“By supporting The Neuro, you are driving innovation, fuelling discovery and bringing hope to patients at The Neuro and around the world living with a neurological disease or injury. Thank you for your generosity.”

Anièle Lecoq
Executive Director, Philanthropy
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