PHILANTHROPY
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Impact of Giving: 2017-18

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Montreal Neurological Institute and Hospital

NEURO
Thank you for your generosity.
Welcome to the 2017-2018 impact report on philanthropy at the Montreal Neurological Institute and Hospital (The Neuro). The past year has seen The Neuro launch transformative new initiatives in areas from fundamental science to therapy-directed research to palliative care.

Our new Tanenbaum Open Science Institute (TOSI) brings The Neuro to the forefront of the open science movement, which is growing across the world. Thanks to TOSI, which encompasses the C-Big Repository and our advanced neuro-informatics, and drug discovery platform, The Neuro is being acknowledged as a world leader in creating entirely new ways to carry out scientific research. Open science further enhances our ability to collaborate with other partners, whether industrial or academic, sharing our expertise and learning from others to accelerate the development of fundamental knowledge and therapies, with the ultimate goal of benefitting patients.

We continue to make strides in brain cancer research thanks to your help. Since its 2015 launch, A Brilliant Night, a gala organized by the families of some of our patients, has raised nearly $3 million to support the Brain Tumour Research Centre’s neuro-oncology research. The gala has contributed to the opening of new directions for promising therapeutic approaches.

Thanks to your support, we are also launching programs that will have a more immediate impact on patient care. There are many promising treatments for amyotrophic lateral sclerosis (ALS) on the horizon, and our new ALS Phase One Clinical Trial Unit will enable us to be one of the very early adopters of these drugs, bringing these treatments, still in the experimental testing phase, to our patient population.

In addition, the Susan Cameron Cook Neuro-Palliative Care program will develop palliative approaches tailored to the specific and distinct needs of patients with neurodegenerative diseases. Our patients have conditions that often progress on a very different timeline from those of other palliative care patients, so traditional approaches are simply not appropriate. We aim to become a leader in developing palliative approaches designed to support people with neurodegenerative diseases.

We are in the process of completing our move into The Neuro’s new North Wing building, which is allowing for extended space for labs, equipment, and staff, while enabling our researchers to pursue projects unimaginable only a few short years ago.

In fall 2017, The Neuro was the recipient of a transformational gift from the Azrieli Foundation to create the Azrieli Centre for Autism Research.

As you can see, we have much to share with you in this report – and much to thank you for. None of these initiatives and accomplishments could have taken place without your visionary generosity. Together, we are truly transforming research and patient care!

Dr. Guy Rouleau OQ MD PhD FRCP(C) FRSC  
Director, Montreal Neurological Institute and Hospital
Open Science and Transforming the Research Landscape
Researchers around the globe are hunting for the answers to neurological questions, but have been hampered by traditional strategies for sharing information – or, often, not sharing it. In response to this issue, driven by a commitment to patient care and well-being, and supported by a very generous $20 million gift from the Lawrence and Judith Tanenbaum Family Foundation, in December 2016 The Neuro launched its new Tanenbaum Open Science Institute (TOSI).

“The Tanenbaum Open Science Institute represents a new way of doing science, and our decision to go this route has attracted a lot of attention in the media and among our peers around the world,” says Dr. Guy Rouleau, Director of The Neuro. “Five years ago it wouldn’t have been possible. Only now do we have the tools required to make information available and the capacity to generate enough data to share.”

In practical terms, the initiative means that The Neuro will share information from research via open science portals currently in development. The Neuro is also asking that its collaborators, those taking advantage of the shared information, also abide by the principles of open science and share their findings. TOSI itself is structured around three pillars: the Clinical, Biological, Imaging and Genetic (C-Big) Repository, Neuro Informatics, and a Drug Discovery Platform. While the C-Big Repository provides a huge databank of information, the Neuro Informatics initiative integrates this data for analysis and sharing with other researchers, and the Drug Discovery Platform provides patient-derived stem cells lines and assays so that scientists around the world can explore possible routes to new therapies. The ultimate goal: accelerating research and finding effective treatments for a wide range of neuropathologies.

“The C-Big Repository is a tool for academic and industry researchers,” says Dr. Jason Karamchandani, the Repository’s director. “This is the first open science biorepository to include clinical information, so researchers will have information not only on a patient’s disease but also on how that patient is doing over time, how the disease is progressing and how the patient responds to therapy.” A key, of course, is patient participation. “We’re patient-centered and we want them to understand what they are doing by consenting to participate in this program,” says Dr. Karamchandani, who stresses that no information that might identify patients is shared. “This is truly a pioneering effort. Combining open science and biorepositories in one initiative is on the cutting edge.”

The Neuro has experience as a pioneer in sharing data. Twenty years ago Dr. Alan Evans, who is directing TOSI’s Neuro Informatics effort, led the development of LORIS, a platform for sharing brain-imaging information for a National Institutes of Health-funded study into normal brain development. Today, LORIS provides the foundation for TOSI’s Neuro Informatics platform, which will facilitate information sharing with researchers. “We have been expanding the database to accommodate lab information, tissue sample information, and other kinds of data it was not originally designed to share,” says Dr. Evans. “So it’s important to support people coding and building these platforms, so our researchers can upload data to a centralized repository, or get access to other peoples’ data in a form meaningful to them. These are not conceptually difficult things, but implementing them is not trivial.”

Evans is also the Principal Investigator of a Brain Canada grant concerning open science data sharing. “We have built a coalition of about 40 researchers from across Canada to create a single national platform, the Canadian Open Neuroscience Platform, and TOSI will play a lead role in this effort,” says Dr. Evans.
In the past 40 years, the model of drug discovery used by the pharmaceutical industry, while proving successful for some applications, has produced very little for neurodegenerative diseases. “Take Parkinson’s disease, for instance: there have been zero new disease-modifying medications developed in the last 40 years, despite hundreds of millions of dollars being invested in research,” says Dr. Edward Fon, whose lab focuses on molecular and cellular research into Parkinson’s disease. “We have to ask if there is a better way to find therapies that will modify the course of diseases, slowing or stopping them from progressing. While open science is not going to solve every problem, it will be a big part of the solution.”

The drug discovery initiative aims to support research by developing assays that investigate different aspects of target cells and sharing these assays with colleagues around the world. The main vehicle for sharing assays is The Neuro’s Induced Pluripotent Stem Cell (iPSC) platform, developed recently with seed money generously donated by Sebastian van Berkom and Ghislaine Saucier.

“We can provide industry-standard assays researchers can use to test compounds,” says Dr. Thomas Durcan, another Parkinson’s researcher who manages the iPSC platform. “In collaboration with researchers at Université Laval, we reprogram blood cells from patients with neurological diseases into stem cells, and then transform the stem cells into the type of neural cells most impacted in neuropathology.”

This gives researchers the ability to compare normal and diseased states of the cells within one patient, which has long been possible for some diseases but is a novel advance for neurological research. The Centre for Drug Research and Development, a Canadian non-profit organization that aims to speed the translation of discoveries into therapies, and the international Structural Genomics Consortium have both formed partnerships with the Tanenbaum Open Science Institute to use the iPSC platform.

“If we can identify potential compounds for targeting diseases such as Parkinson’s and share them so they can be screened and tested throughout the scientific community, we can accelerate the rate of discovery,” says Dr. Fon. “Other researchers can benefit from the resources we develop, and the chances of 100 laboratories finding something useful is much greater than that of one lab working alone. If we can come up with something leading to treatment for Parkinson’s disease, that would be an incredible payback.”
A Race Against Time: Making New Treatments for ALS Available as Early as Possible

Before promising new therapies can be approved for use in patients across the country, they must be tested in clinical trials. But patients with amyotrophic lateral sclerosis (ALS) face a tight timeline – usually an ALS diagnosis proves fatal within two to five years. So while researchers aim to develop treatments that can extend that time while also improving quality of life, the fruits of their efforts are remote to most clinical populations, reaching them only after years of trials.

However, thanks to a $1.5 million gift from the Reed Family and The Tenaquip Foundation, The Neuro is launching a new Phase One ALS Clinical Trial Facility, which will help move scientific and medical research discoveries to clinical practice quickly and efficiently, thus benefiting patients at The Neuro and beyond.

Phase one clinical trials are the first step in evaluating newly developed drugs on a patient population. “This initiative will enable our researchers to get involved early in the drug discovery process so our patients can have access to new treatments as soon as they are available, potentially getting therapies that can change their disease course in its early stages. It will make a huge impact on what we are able to offer patients,” says Dr. Angela Genge, Director of The Neuro’s Clinical Research Unit. “Nowhere else in Canada is there a phase one clinic dedicated to ALS.”

Patients participating in phase one trials typically stay in the facility for at least 24 hours at a stretch, during which time they also require staff to assist them, so the new facility comes not only with the physical space and equipment needed but also with support for the necessary personnel, and has already begun running clinical trials. “The space allows us to be more proactive in participating in clinical tests, and less dependent on hospital availability, which can get really tight,” says Dr. Genge. When the facility is not being used for ALS clinical trials, it can also be used for trials of treatments for other neurodegenerative diseases. The initiative will also enable The Neuro’s graduate and post-doctoral students working in ALS to forge stronger connections with biotechnology and pharmaceutical companies, providing a useful network for those wishing to bring their expertise to industry research labs.

The Phase One ALS Clinical Trial Facility is the first step in the ambitious global centre of excellence in ALS The Neuro aims to develop, and represents one of five major aspects of this initiative. The others include an expansion of the current ALS multi-disciplinary clinic to incorporate a focus on dementia, along with components focusing on imaging data, genetic information and a biobank repository.
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Brain cancers can be difficult to treat because everyone’s cancer is unique. But at The Neuro’s Brain Tumour Research Centre, researchers have identified a protein that seems to be a common factor in the development of the cancers. “This molecule plays fundamental roles in normal neural development as well as in the development of brain cancer – the mechanism that allows stem cells to transition into differentiated cells or cancer cells is the same,” says Dr. Kevin Petrecca, Director of the Centre. “And that’s a major finding that opens a new spectrum of targets for therapy, because it means that at the early stages of the cancer, everyone is quite similar – unlike at the later stages. So we are now trying to identify some fundamental pathways that can be targeted in all patients with brain cancer.”

Dr. Petrecca’s research has benefited from A Brilliant Night, a gala that enjoyed its third edition on October 18, 2017, and has in its short time raised nearly $3 million for the Brain Tumour Research Centre. “With the support of A Brilliant Night, we have enhanced our understanding of brain cancer and how it develops, and have discovered opportunities for developing new therapeutic approaches, which will hopefully lead to useful drugs,” says Dr. Petrecca. “We’ve gone from the discovery of a molecule involved in the development of brain cancer, to learning how this molecule works in the greatest detail, to presenting this research at conferences. Companies have approached us and now we’re testing drugs in therapeutic models of the disease here in our lab. We have come a long way, and hopefully will soon have a new drug to test in patients.”

“I cannot stress enough the importance of A Brilliant Night,” says Dr. Petrecca. “Government funding is not sufficient to drive therapeutics development, and pharma and biotech companies do not do this kind of expensive and laborious fundamental research. Without our donors, we would have a difficult time doing this kind of work.”

Probing for Cancer

Dr. Kevin Petrecca’s clinical and research activities have merged in the development of a new technology, the Raman probe, that can identify cancerous cells as the surgeon is actively excising them from the patient’s brain. The device hardware, completed almost two years ago, was portrayed in the 2016 edition of The Neuro’s Impact Report, the past year has witnessed the further development of the software dataset for machine learning, building up the library of data to allow the software to determine with greater precision if a cell is cancerous or not.

Most recently the research team has been invited by the Food and Drug Administration, the United States’ approval body for medical devices, to participate in an expedited access program to get regulatory approval. The research team has now begun clinical trials, with surgeons using the probe to help decide where to make incisions.

Dr. Petrecca and his team have created a company in collaboration with Dr. Frédéric Leblond of Polytechnique Montréal, ODS Medical, to commercialize the probe, and have completed seed money fundraising. While the device has been developed without donor funding, post-doctoral researchers funded by philanthropic support have made critical contributions to creating the probe’s software, and the insights Dr. Petrecca has gained from donor-supported research have indirectly nourished the growth of the Raman probe.

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NEURO FACTS

4,278 donors
$16.3M raised

*Statistics are for the 2017 Fiscal Year

$1M
brain cancer research

$1M
new equipment

$800K
Multiple sclerosis research

$750K
nursing and patient care

$600K
Parkinson’s Disease research

$500K
rare disease research

More than $750,000 distributed to students and post-doctoral fellows through donor-funded awards!

NEURO MEDIA REACH

2,689 web articles published

8,743 Facebook followers

4,219 Twitter followers
Founder and first Director of the The Neuro, Dr. Wilder Penfield was featured in a Google Doodle on January 26, 2018 – the day of his 127th birthday!

The Clinical Research Unit, led by Dr. Angela Genge, at The Neuro is the top recruiter for clinical trials in Canada.

World-renowned pioneering neuropsychologist Dr. Brenda Milner can count these prestigious awards among her lifetime achievements: Order of Québec, Order of Canada, Royal Society of Canada, Canadian Medical Hall of Fame, Kavli Prize, Balzan Prize, and the Gairdner Foundation International Award in Health Research. Milner will celebrate her 100th Birthday in 2018.

Current Director of The Neuro, Dr. Guy Rouleau has contributed to the identification of more than 20 disease-causing genes!

Creating a New Approach to Neuro-Palliative Care

People think palliative care is just for those who are dying,” says neuro-palliative care nurse Justine Gauthier. “But that’s not the case. Conventional palliative care programs are built for patients with clear end-of-life prognoses, such as with cancer patients in advanced stages of the disease. But patients with neurological diseases like Parkinson’s disease, ALS, or even brain tumours are different. Some will live with a life-limiting illness for a long time, and they also tend to be younger than most palliative care patients. So they need a different kind of support.”

In January 2017, Gauthier was named the neuro-palliative care nurse at The Neuro’s new Susan Cameron Cook Neuro-Palliative Care Program. She has worked closely with the director of the program, Dr. Jeffery Hall, a neuro-surgeon who recently completed a fellowship in neuro-palliative care, to design the program. This initiative is the first of its kind in Canada. “We want to be involved with patients early in their disease when we can help them more,” she says. “And of course we also work with patients near the end of their lives.”

While the latter group fits within the traditional model of hospital- or hospice-based palliative care, the former group requires innovative approaches. “We can help them by linking them to various resources in the community that will enable them to stay at home as long as possible,” says Gauthier, who follows up with these patients through regular conversations.

“And in the case of diagnoses that will eventually be fatal, we will address medical directives with patients, exploring what they want instead of waiting until the last minute to consider those questions. Patient autonomy is very important to us, and we want to ensure that people are able to make their own decisions,” she adds.

The program was launched formally in October 2016, thanks to critical seed funding from the family of Susan Cameron Cook. In addition to being the first centre in Canada to provide palliative care for patients with neurodegenerative conditions, the Susan Cameron Cook Neuro-Palliative Care Program is further supported by an education and training fund established in 2017, thanks to a generous donation from the Rossy Family Foundation. Dr. Hall and Justine Gauthier have already provided workshops and webinars, developing the educational aspect of the new program.

“Palliative care is not about death, it’s about what you do beforehand,” says Gauthier. “The program will involve an ongoing partnership with the patients, to ensure a high quality of life for patients, their family members, and their caregivers.”

“Palliative care is not about death, it’s about what you do beforehand.”

– Justine Gauthier, Neuro-palliative care nurse
Assessing Alzheimer’s
Currently over half-a-million Canadians are living with dementia, according to Alzheimer Society Canada, and the future does not look encouraging: the Society predicts that number will rise to over 900,000 in 15 years. Detection and treatment are thus critical to extending the health and lifespan of people with Alzheimer’s disease. Thanks to a gift from Joanne and André B. Charron, Dr. Louis Collins’s NeuroImaging and Surgical Technologies Lab has been able to support a team of doctoral students leading research projects into different aspects of Alzheimer’s and dementia.

Medial temporal lobes – structures in the centre of the brain that are involved in memory – shrink in different dementias, including Alzheimer’s, and normally the faster the shrinkage, the worse the dementia will be. But assessing shrinkage is no easy task, so PhD student Azar Zandifar has developed techniques to use magnetic resonance imaging to segment the brain, accurately identify the medial temporal lobe, and estimate its volume. “Being able to characterize this precisely provides a good tool for early diagnosis and prognosis,” says Dr. Collins. “It would also be very useful in a clinical trial, to determine if a new pharmaceutical drug might actually slow down, stop or even reverse the rate of atrophy in the structure.” The techniques Zandifar has developed may even be applied to early diagnosis, identifying shrinkage before other objective testable symptoms of Alzheimer’s disease present themselves.

A second PhD candidate, Mahsa Dadar, uses magnetic resonance images to focus on white matter hyper-intensities, lesions caused by small blood vessel diseases in the brain. While almost everybody has some small lesions, they are inconsequential in small numbers; however, studies have shown that after a certain point the number of these lesions is inversely related to cognitive ability. “By characterizing the impact on cognition being caused by small vessel disease, we can separate it from cognition loss caused by Alzheimer’s, which is important because these vascular dementias are treatable,” says Dr. Collins. “With the techniques being developed by Mahsa, we can assess how much dementia might be due to vascular disease as opposed to Alzheimer’s; then we can treat that problem and the patient can recover.”

Dr. Collins’ lab has several other projects exploring the use of imaging technologies to assess and characterize Alzheimer’s disease, with the shared objective of being able to improve diagnosis and prognosis. “A number of tools are available for diagnosis, from tests of cerebral-spinal fluid to neuro-psychology tests, but there is very little at present that can be used for prognosis,” he says. “But when patients receive the diagnosis, the first things they ask are ‘What will my life look like? Will this stay stable or get worse? How long do I have?’ So, with support from donors, we’ve been developing a combination of prognostic tools to help answer these questions.”

The result is that in a cohort of about 400 subjects with mild cognitive impairment, his team can predict with about 74% accuracy who will progress to Alzheimer’s disease and who will stay stable over a three-year period. The team is now working to be able to make that prognosis earlier, which could be particularly useful in clinical drug trials. Trials can be limited by the difficulties of identifying people in the earliest stages of Alzheimer’s disease. “If you enrich your study group with people likely to develop Alzheimer’s, you can increase the statistical power of your trial, thereby testing therapies more efficiently,” Dr. Collins notes.
Your support is critical in helping students at The Neuro to excel – and that benefits everyone! The three articles that follow show some of the many ways in which promising doctoral and post-doctoral researchers are bolstered by private support.

Understanding Pain Reception

“The prefrontal cortex is the area of the brain involved in the emotional processing of pain experience,” explains Maria Zamfir, who works in the lab of Dr. Philippe Séguéla. “But we don’t know much about how the receptors work.” Her work focuses on pain processed by mu opioid receptors (MOR) and the effect of opioid analgesics. “My project specifically investigates the anterior cingulate cortex, part of the prefrontal cortex, to better understand how these mu opioid receptors function when patients are taking analgesics to diminish pain,” she says. “We hope this fundamental research will eventually help in developing drugs.”

Zamfir is the 2017 recipient of the Albert Gombay Neuroscience Travel Award, which enabled her to attend the 38th annual scientific meeting of the Canadian Pain Society in Halifax. “The keynote lecture was by a professor who was also investigating opioids in the cortex, so I was able to meet with him and discuss our shared research interests,” she says. She also met with other prominent researchers in her field, making the conference experience a very productive way to establish a professional research network. “I’m still in touch with these researchers, which keeps the door open for future collaborations,” she says.

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– Maria Zamfir
Searching for a Cure

Chanshuai Han joined the neurodegenerative disease research lab of Dr. Peter McPherson on a Jeanne Timmins Costello Fellowship after completing her doctorate in China, and began research into DENND5A, a protein about which very little was known. “We learned that it is especially implicated in neural developmental,” Han says.

Her research led to a Lewis Reford Fellows Travel Award to attend the annual conference of the International Society for Developmental Neuroscience, where she presented a poster and met researchers from the University of Toronto and SickKids Hospital who worked with children suffering from a mutation of this same protein. DENND5A causes a severe form of epileptic encephalopathy in which the patients are all very young children.

“Since that conference I set up my new research target: finding a way to help the children who are suffering from this mutation,” she says. Han is now leading international collaborations, using cells taken from these young patients and transformed into stem cells, and then into target neurons for analysis; a first paper on this research was published in November 2016.

“I hope this will lead to powerful tools to help patients. The travel award pulled everything together,” Han adds. “If I had not been presenting at the conference, this collaboration, and all the research that has grown out of it, would have waited until after I published my paper on fundamental research – if it happened at all. But being able to participate in the conference made everything happen much faster.” 📢
Augmenting Surgical Reality

Simon Drouin first joined Dr. Louis Collins’s NeuroImaging and Surgical Technologies lab in 2002 as a technician lured from the gaming giant UbiSoft to create IBIS, the interactive brain imaging system. IBIS aimed to correct a problem pervasive in image-guided programs used by neurosurgeons in the operating room. Before going under the scalpel, patients would be scanned under an MRI, providing a map of the brain that could be used to guide the surgeon—except that, once opened, the brain would swell and shift, thus quickly rendering the MRI useless. IBIS addresses this issue by using ultrasound scans performed regularly during the operation. The ultrasound images are less precise than MRI images but can be laid over them, enabling the program to adjust the “brain map” to more accurately show where the surgeon was directing the blade.

After developing the initial IBIS system (which over the years has been added to and refined by other researchers), Drouin left Dr. Collins’ lab to pursue a master’s degree and other employment, but returned in 2010 and soon after began his PhD, focusing on introducing augmented reality into the IBIS system. “Commercial systems force the surgeon to move their centre of attention between the patient and the computer screen, which is often quite distant, so our goal now is to bring all the navigation information into the view of the surgeon,” explains Drouin.

Working with neurovascular surgeons who use a surgical microscope to guide their dissection of very small blood vessels in the brain, Drouin is developing a way to use the surgical microscope to display the navigation information. His research explores how to capture the image from the microscope, augment it with navigation information, mostly derived from a scan of tissues under the surface, and then reinject the image into the microscope in a way that is perceptually correct. “The surgeon will then see the regular microscope image, as well as augmented reality showing the underlying tissue, which could be a brain tumour or blood vessels,” he explains. While Drouin’s work is not directly supported by philanthropy, donor support for Dr. Collins’s lab has indirectly benefited his research.
I sincerely hope that you enjoy reading this 2017-2018 Neuro Donor Impact Report which serves to illustrate how you are critical partners in our research, training, and patient care.

Before starting as Executive Director, Philanthropy at The Neuro, I was awestruck by the stories that I had heard about this illustrious place. When speaking of The Neuro, former patients and their family members were often emotional in their expressions of gratitude. This was one of the primary reasons that I decided to embrace philanthropy at The Neuro. And, I wasn’t disappointed. At the heart of The Neuro’s pioneering firsts and many successes are the people who make it all possible. Every student, researcher, and medical professional, as well as every patient, has a unique story. I feel a responsibility to share these stories with the local, national, and international community in our continued search for funding, which is increasingly imperative.

I am pleased that there is an abundance of good news to share with you in the pages of this report. Stories that provide inspiration and hope for the future. Our work however, is far from complete. We know that as the population ages, the incidence of diseases of the brain exponentially increases. The reality is that most of us will be directly or indirectly touched by these often-devastating conditions.

Please do not hesitate to connect with me, as I am happy to help you get to know The Neuro and the incredible work that goes on here every day. It would also be my pleasure to learn what your aspirations are for The Neuro.

Thank you for being a vital member of The Neuro community and for supporting its avant-garde global neuroscience initiatives!

Anièle Lecoq
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