



Institut-Hôpital
neurologique de Montréal

Montreal Neurological
Institute-Hospital

Open Science at The Neuro | TOOLKIT

OPEN SCIENCE AT THE NEURO

CONTENTS

What is Open Science and why is The Neuro pursuing it?	3
What is The Neuro's Tanenbaum Open Science Institute?	6
What drives The Neuro's Open Science practices?	9
How is The Neuro putting Open Science in action?	11
Open Biobanking Platform	12
Open Early Drug Discovery	13
Open Neuro-informatics	13
Open Publishing Platform	14
Independent Evaluation and Monitoring Process	15
Generating Global Momentum	16
General questions and answers on Open Science	17
Website and Social Media	22
Contact	23

Open Science, to accelerate discovery and deliver cures.

Hundreds of millions of people worldwide are affected by a brain disorder. The numbers are increasing every year and represent one of the greatest unmet medical needs of our time.

To meet this global challenge today, we must do more – better and faster – to radically change our approach to brain science.

At The Neuro, we are driven to transform neurological research and care to improve lives.

Open Science is the concept of sharing data, information, tools and research results, and eliminating barriers to collaboration. And we believe it offers the most promising path towards patient-centred science – helping us to accelerate the scientific process towards solving the most persistent problems in neuroscience, to speed up discovery, and benefit millions of people affected by neurological disorders around the world.

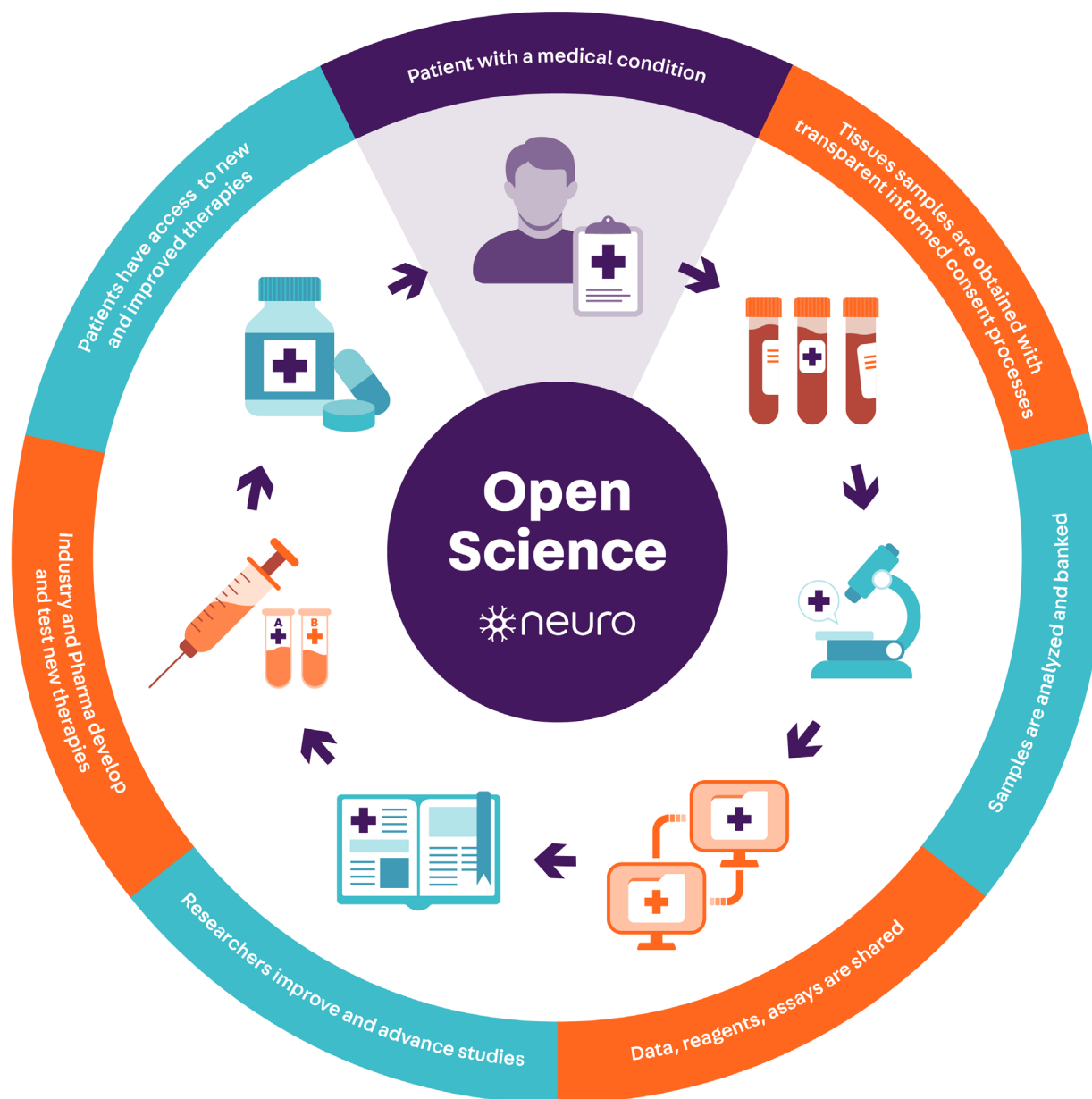
We're putting Open Science into action through The Neuro's Tanenbaum Open Science Institute and:

- establishing best practices and developing tools and infrastructure to support sharing at The Neuro
- expanding and measuring its impact
- encouraging the global scientific community to embrace this new way of doing research.

Join us in adopting our model and together, we can open science to the world, once and for all.

WHAT IS OPEN SCIENCE AND WHY IS THE NEURO PURSUING IT?

Open Science at The Neuro, patients at the heart



Open Science is the concept of sharing data, information, tools and research results, and eliminating barriers to collaboration around the world.

More than 100 million people in the US alone are affected by a brain disorder. This number is increasing every year and represents one of the greatest unmet medical needs of our time.

To meet this global challenge today, we must do more – better and faster – to radically transform our approach to brain science. From its inception, The Neuro’s mission has been to advance medicine through patient-centred science. Open Science offers the most promising path to implement this, helping to expand our research impact and speed up innovations in neuroscience that will benefit people affected by neurological disorders.

Related resources:

- More about Open Science at The Neuro: [About Open Science at The Neuro](#)
- The latest on Open Science at The Neuro: [Open Science stories](#)
- Meet the people behind The Tanenbaum Open Science Institute (TOSI): [Open Science ambassadors](#)
- News surrounding the launch of TOSI: [Open Science in the press](#)
- [The Neuro’s mission, vision and values](#)
- [A patient’s perspective: Open Science is empowering](#)

¹Including amyotrophic lateral sclerosis, brain tumours, epilepsy, multiple sclerosis, rare disorders, Parkinson’s disease, autism spectrum disorders, and other neurodevelopmental disorders and neurological conditions.

WHAT IS THE NEURO'S TANENBAUM
OPEN SCIENCE INSTITUTE?

Thanks to a generous donation of \$20 million from the Larry and Judy Tanenbaum Family Foundation, The Neuro created the Tanenbaum Open Science Institute (TOSI) in 2016.

TOSI establishes The Neuro as a leader and living lab for Open Science, with the goal of:

- establishing best practices and developing tools and infrastructure to support sharing at The Neuro
- expanding and measuring its impact
- encouraging the global scientific community to embrace this new way of doing research.

Larry Tanenbaum and Heather Munroe-Blum lead the TOSI Founders Group, building relationships and gathering resources and support to advance The Neuro's Open Science mission.

TOSI also consists of a twelve-member [Leaders Council](#) who advise, evaluate and serve as ambassadors; as well as an Executive Team made up of Guy Rouleau and Annabel Seyller who plan and manage the implementation of Open Science at The Neuro.

TOSI's Open Science Grassroots Initiatives Committee encourages and promotes Open Science grassroots initiatives and research practices at The Neuro and beyond for the advancement of knowledge and clinical care, and the welfare of the community.

Related resources:

- [A Generous Donation: McGill University announces a transformative \\$20 million donation to The Neuro](#)
- [The Tanenbaum Open Science Institute: Leading a Paradigm Shift at The Neuro](#)



(Left to right) Larry Tanenbaum, Prime Minister Justin Trudeau, McGill University Principal and Vice-Chancellor Suzanne Fortier and Neuro Director Guy Rouleau at the launch of TOSI on December 16, 2016

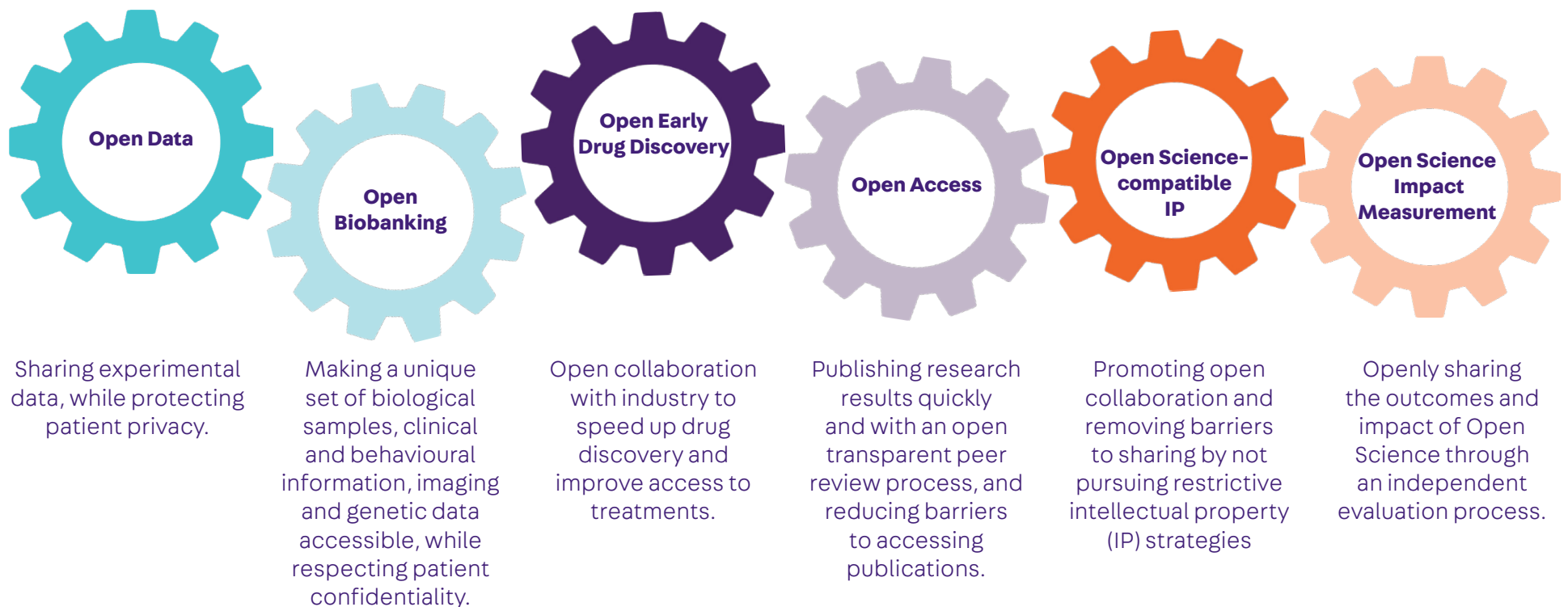
Open Science allows for “the transformation of research, the removal of barriers, the breaking of silos and, most of all, the courage of researchers to put patients and progress ahead of all other considerations.”

-Larry Tanenbaum

WHAT DRIVES THE NEURO'S
OPEN SCIENCE PRACTICES?

Science should be open, transparent, collaborative and create impact for the benefit of patients and their families.

The Neuro's Open Science practices are driven by institutional policies, infrastructures and relationships based on a comprehensive framework that includes:



Related resources:

[The Neuro's official Open Science guiding principles.](#)

**HOW IS THE NEURO PUTTING
OPEN SCIENCE IN ACTION?**

The Neuro's Open Science approach **puts the patient at the centre** of all that we do.

Open Biobanking Platform

The Neuro's Open Clinical Biological Imaging and Genetic Repository (C-BIG Repository) is a collection of biological samples, clinical information, imaging and genetic data from people with neurological disorders as well as from healthy research participants.

The C-BIG Repository facilitates investigation into the molecular biology underlying disorders and the discovery of biomarkers to improve diagnosis. The repository drives tissue-based translational research that will accelerate drug development now and into the future.

The Repository is supported by a robust and unique ethical framework that empowers patients and their families by encouraging them to take part in research aimed at advancing our understanding of their disorders. It also recognizes the importance of safeguarding the dignity, privacy and rights of participants through the informed consent process.

Lead: [Jason Karamchandani](#)

Key facts about the C-BIG Repository:

Patients feel empowered by taking an active role in Open Science at The Neuro:

- The C-BIG Repository platform has a recruitment rate of over 93% with over 1,500 participants as of June 2016.
- Various deeply characterized cohorts of patients in PD (875), ALS (200), MS (65), neuromuscular (85+), healthy volunteers (45).
- 24,500 specimens collected to date.
- Engaged in four ongoing collaborations with industry to enrich the C-BIG Repository.
- Our robust ethical framework is a key driver for patients, industry and clinicians who value transparency in access to data.

(Last updated: January 2020)

Related resources:

- [About the C-BIG Repository](#)
- [Open Science connects patients and researchers at The Neuro](#)

Open Early Drug Discovery

Working in open collaborations and strategic partnerships with academic and industry partners, The Neuro's Early Drug Discovery Unit (EDDU) aims to accelerate drug discovery in neuroscience and improve access to novel and next-generation treatments for people living with neurological disorders.

The unit uses patient samples from the C-BIG Repository to develop induced pluripotent stem cells (known as iPSCs) that can be reprogrammed into neurons and other cell types found in the brain and nervous system to test potential new treatments for specific disorders.

The unit works in an Open Science capacity to train the next generation of researchers to work with iPSCs, develop industry standards for fundamental research and technology and identify new and improved treatments for neurological disorders.

Leads: [Edward Fon](#) and [Thomas Durcan](#)

Related resources:

- [About the EDDU](#)
- [Thomas Durcan uses Open Science to make his work accessible and intelligible](#)

Open Neuroimaging and Neuroinformatics

Hub for developing advanced multimodal brain imaging methods, reference datasets, innovative software for biomedical image analysis and software tools, packages and platforms. Research shared with more than 30,000 registered users worldwide.

Lead: [Julien Doyon](#)

Related resources:

- [About the BIC](#)
- [Open iEEG Atlas](#), powered by [LORIS](#)
- Open MEG Archive ([OMEGA](#))
- [BigBrain](#), powered by [LORIS](#)
- Canadian Open Neuroscience Platform ([CONP](#))
- [Open software for neuroscience: Brainstorm](#) advances fundamental and preclinical electrophysiology research

Key facts about the EDDU:

We've been successful in:

- Building **collaborations** with industry, for example:
 - Takeda
 - Axol
 - GSK
 - Biosentica
 - Stem Cell Technologies
 - Ananda Devices
- Building **strategic partnerships** with non-profits, for example:
 - SGC
 - CDRD/Admare
- Raising **\$20 million** in 2 years:
 - 1/3 from research funders
 - 1/3 from philanthropy
 - 1/3 from pharma industry partners/private sector.
- Establishing **new and open collaborative models** that appeal to pharma, start-ups and emerging biotech companies.

(Last updated: January 2020)

Open Access Activities

Open publishing platform

The Neuro's [MNI Open Research](#), an open platform in partnership with F1000, a world leader in open access publishing, that allows researchers to publish their data within days of submission through a unique open-peer review process.

Offsetting open access fees

The Neuro has established a program to offset the Article Processing Charges for papers emerging from The Neuro. We provide funding equivalent to the submission charges to The Neuro's publishing platform (\$1,500) to each research group for one paper per year.

Connecting researchers to existing resources

Many researchers are unaware of the resources provided by McGill to assist with open access publications. We have engaged with McGill library staff to make sure that Neuro researchers are aware of the details of collective agreements that reduce Open Access [charges for certain journals](#), and how to use the McGill eScholarship repository to make articles published in closed access journals openly available after the journal's embargo period.

Lead: [Annabel Seyller](#)

Independent Evaluation and Monitoring Process

The Neuro is undertaking the following measures to demonstrate the impact of Open Science and encourage policy makers, patients and their families, academic institutions, researchers and clinicians, and others to embrace this new way to doing science:



Determine where openness is a more effective research and innovation strategy.



Measure results and encourage deeper understanding of the processes used to create, share and apply knowledge.



Develop standard measures so that institutions and governments can assess different innovation models.



Provide data to researchers around the world studying innovation systems and innovation models.

[Richard Gold](#) has led the effort to develop standard measures for Open Science at The Neuro. Along with his team, he is working with global organizations such as the Organisation for Economic Co-Operation and Development (OECD) to collect best practices and identify Open Science innovation models.

We have a responsibility to our patients and our researchers to deliver on the promises of Open Science.

By measuring the impact of our efforts, we hope to validate the approach and continue to expand the Open Science movement.

Related resources:

The Open Science Leadership Forums in Washington D.C. (Gates Foundation, 2017) and London (Wellcome Trust, 2018) were inspired by The Neuro's adoption of Open Science. Read [The OS Toolkit report](#).

Generating Global Momentum

Partnerships and community

We're setting a precedent for others to adopt Open Science, and have opened communications with interested stakeholders. This includes – to name a few – the G7 Working Group on Open Science, the European Commission, the governments of Canada and the UK, the leaders of the Open Government working group; as well as Polytechnique School, Pasteur Institutes, Fiocruz Institutes, NIH, Douglas Research Centre, University of Toronto, University of Oxford, Stanford University, and Hotchkiss Brain Institute.

We are also creating innovative partnerships between the scientific community and the pharmaceutical industry to find cures for the most devastating neurological disorders.

Open Science Grassroots Initiatives Committee

The Committee encourages and promotes Open Science grassroots initiatives and research practices at The Neuro and beyond for the advancement of knowledge and clinical care, and the welfare of the community. It aims to:

- Collect and understand what researchers at The Neuro need to adopt Open Science practices and deliver concrete outcomes in research and education
- Keep our Open Science model at the cutting-edge by providing practical and strategic insights on current Open Science research worldwide
- Define top priorities for implementation at The Neuro and report to TOSI's [Leaders Council](#).

The Neuro's Open Science Symposium

The Neuro hosts an annual Open Science Symposium to engage and exchange around Open Science in action at The Neuro and beyond. The event draws national and international speakers - including researchers, ethicists, lawyers, industry partners, philanthropists, clinicians and people living with neurological disorders. Together, participants exchange ideas, lessons learned and best practices on how to be open and work together towards finding treatments and cures for people with neurological disorders.

Increasing openness in science, and operating along principles of collaboration improves transparency, reliability, and the impact of our research.

Related resources:

- [Open Science Grassroots Initiatives Committee](#)
- Open Science [Symposium](#) and Open Science in Action: [Inaugural Symposium Program](#)
- [NeuroOme](#): Open Science partnership to develop precision drugs for amyotrophic ALS and Parkinson's

GENERAL QUESTIONS AND ANSWERS ON OPEN SCIENCE

1. What will the Open Science model mean to patients treated at the Neuro?

Open Science reflects the original vision of Dr. Wilder Penfield, the founder of The Neuro. This vision focused on patients receiving the highest quality of care, while simultaneously inspiring innovation in the treatment of their conditions.

Patients are at the very centre of this initiative and benefit from this collaborative model once discoveries are made on treatments for neurological disorders. They are empowered to take part in the research process, for example, by providing consent to The Neuro to use their data and bio specimens for research now and into the future.

2. What drives The Neuro's Open Science practices?

Through the practice of its [Open Science principles](#), The Neuro envisions cohesion, long-term sustainability and synergy between its transdisciplinary teams of researchers and clinicians, as well as the patients and communities it serves:

a) Making data and other scientific resources publicly available

The Neuro's researchers will publish open access articles. They will make all positive and negative numerical data, models used, data sources, materials, reagents, algorithms, software and other scientific resources publicly available no later than the publication date of the first article that relies on this data or resource.

b) Transparent external research partnerships

All publications, data and scientific resources generated through research partnerships – whether with commercial, philanthropic, or public sectors – are to be released publicly and without restrictive intellectual property rights no later than the publication date of the first article that relies on this data or resource.

c) Ethical, sustainable and accessible research materials and tools

- The Neuro will maximize the contributions made by research participants and the scientific resources made by Neuro researchers and collaborators by supporting and sustaining long-term and cutting-edge research, data collection, and sharing.
- These resources will be managed in a financially self-sustaining way and used to strengthen knowledge and further content development.
- The Neuro respects the rights, dignity and privacy of patients and healthy participants. It also recognizes the primacy of safeguarding participants' samples and materials, and its own responsibility to offer ethical and transparent informed consent processes.

d) Removing the barriers of restrictive intellectual property

- Subject to patient confidentiality and informed consent given, The Neuro will not obtain or enforce restrictive intellectual property protection for data and research outputs.
- The Neuro will not obtain restrictive intellectual property protection for any jointly created research outputs.

e) Researcher and patient autonomy

The Neuro respects the autonomy of its stakeholders, including but not limited to researchers, staff, trainees and patients, by supporting their right to decline to participate in Open Science research and associated activities. However, The Neuro will not commit resources to activities that contradict its [Open Science principles](#)

3. Where does The Neuro stand on intellectual property tools like patents?

Intellectual property is often a big part of discussions around science and innovation. While restrictive IP – whether patents, copyright, trade secrets, or technical barriers to accessing research outputs – may be needed to bring treatments to the market, The Neuro is not the right place to generate them.

Most of The Neuro’s research is focused on basic science, and putting up restrictive IP barriers can hinder Open Science collaborations and basic neuroscience. For example:

- Good science relies on barrier-free sharing and scientific objectivity. IP rights held by universities and researchers over research outputs may discourage researchers from undertaking IP burdened projects or sharing outputs subject to IP. IP also encourages researchers and universities to only share in ways likely to increase value. In turn, this interferes with scientific progress and sharing by introducing financial interests into scientific objectivity.
- Restrictive IP practices can also introduce unnecessary and costly delays to the transfer of knowledge and materials – hindering potentially life-changing discoveries.
- Research institutions based on public funding should be producing public goods accessible to all. IP turns research outputs into private goods that can break down or delay collaboration and risk interfering with the public research ecosystem.
- The increasing importance placed on patents has led to an increase in the number of patents and patent infringement lawsuits, including many directly involving universities. If public research institutions are seen within the market primarily as producers of IP for companies, and willing to spend public money to defend their IP, they can become legitimate litigation targets for companies that want to impede the work of competitors or, more direly, patent trolls that profit by bringing infringement suits.

By not filing for or enforcing intellectual property over The Neuro’s research outputs, we avoid these issues while creating the barrier-free environment needed to generate the novel discoveries necessary for neuroscience and those suffering from neurological disorders.

4. Will pharma see the value in embarking in Open Science partnerships?

Yes. Since 2016, The Neuro’s Early Drug Discovery Unit (EDDU) has been successful in building collaborations with the pharma industry, securing funding and forming strategic alliances. The Unit regularly hosts and engages in dialogue with interested pharma prospects.

These partnerships demonstrate that industry can embark in Open Science partnerships – to their advantage – by using open platforms based on shared interests and by pooling together shared expertise and resources with us on tough problems with broad social or economic effects, such as understanding and treating some of the world’s currently incurable neurological disorders.

Open Science is a solution for the problem of data reproducibility and the failure to develop drugs for neurological conditions. This is where, collectively, academia and pharma can make a big difference to the field, and the community. A new model could lead to more efficiency, sharing the risk of research, and rewarding companies that commit to affordable pricing.

5. How do you work with industry partners in an open way to accelerate discoveries and drive innovation in the field of neuroscience?

To work with industry partners under an open framework, we have developed an innovative and paradigm shifting 80-20 funding model. By collaborating with The Neuro's Early Drug Discovery Unit (EDDU), an industry partner commits to:

1. Pursuing the development of tools, assays, technology in an open and accessible manner, with funds from the partnership going towards this goal.
2. Respecting The Neuro's open values, committing to putting data into the public domain, paying it forward for other projects and collaborators.
3. Understanding that funding from projects within this partnership will not be applied towards patenting or pursuing IP rights.

We do however understand the need for any industrial partner to pursue and work with technology they might have developed and have IP on. For instance, a company can bring their own proprietary compound in to be tested and these findings will not be disclosed. Moreover, if a product or technology emerges from a partnership that has value, the partner is free to pursue IP or patenting of a technology or therapy independently based on further work building on results that might emerge from a partnership, but we will not provide support or funding for these purposes.

By working together under this new model, we aim to work with industry to accelerate innovation while driving the development of new therapies.

6. Will implementing an Open Science policy deter young researchers from joining The Neuro?

No. The Neuro is currently undergoing a unique rejuvenation phase, with over 30 new researchers joining our team in the last 3 years (from early career to senior). Some of these new recruits chose The Neuro specifically because it was an Open Science institute and are eager to take part and engage in the movement.

We believe that Open science should be embraced to support and encourage an emerging generation of researchers, who have among other things, become disillusioned with a traditional peer-review model of publishing that has attended primarily to its own interests. Also, major research partners can be enticed to take part in an open science platform if that is where the best young talent is working.

7. Open Science requires a culture change. What can The Neuro do to initiate that process?

We believe that in order to affect change, we need to build the infrastructure to share openly using FAIR (findability, accessibility, interoperability, and reusability) principles; train the next generation in Open Science practices; and create incentive and recognition for Open Science practitioners, including redefining evaluation criteria for promotion and tenure, starting by recognizing publishing in Open Science journals.

8. Can hosting large, open datasets create barriers to access?

Our ability to rapidly analyze and visualize data, in shared and collaborative environments, with tools developed and vetted by and for the community is crucial. Priorities include removing the technical barriers, defining common languages for standardizing data formats, and addressing the major challenge of hosting large open datasets.

9. What role can philanthropy play in accelerating the Open Science movement?

The role of philanthropy and funders is key. They play an important role in advocating for research and helping to reshape and redefine research and the Open Science space. Philanthropy helps to support and reward the creators and maintainers of open outputs that enable collaborative and reproducible research and helps to make these critical contributions to science more visible, fundable and recognized.

10. What are the benefits of The Neuro being an Open Science institute to McGill, Canada and the world?

Benefits to McGill:

- Cementing McGill and The Neuro's position as global leaders in innovative neuroscience research practice
- Forging new collaborations in the fields of structural biology, epigenetics and others
- Potential to move other established, funded programs to McGill, including SGC-led NSERC/CREATE and Gates TB/malaria programs
- Opportunity to forge deeper and wider links between McGill and global pharma
- Enriching McGill's ties with SGC (Structural Genomics Consortium) collaborating institutions, most notably the University of Oxford

Benefits to Quebec and Canada:

- Positioning Quebec as a true leader in the life sciences – and as leaders working to transform how medicines are invented – and deepening Canadian and global pharma's stake in the province
- Giving local patients first access to promising drug trials
- Forging novel partnerships between McGill and its sister institutions in Quebec and across Canada
- Attracting new, large-scale investment from foundations, corporations and other funders within Canada and around the world
- Establishing a unique “knowledge hub” which will attract and retain top researchers, graduate students and scientists, enriching Quebec and Canada's human capital

Worldwide benefits:

- Finding new treatments and even cures for devastating neurological disorders within our lifetime
- Offering hope to patients and families worldwide
- Relieving the economic burden of aging populations
- Forging a new model of collaborative science that could revolutionize academic and industry partnerships for generations to come.

11. Give an example of a quick elevator pitch for joining the Open Science movement?

We can't do it alone. Join the Open Science movement and adopt our model.

The principles are simple: seek opportunities for open collaboration and allow research to move from one team to another, between disciplines and toward the creation of cutting-edge ideas, treatments and business models.

Together, we can advance a new global era of open discovery and innovation – and transform the lives of patients and their families forever.

12. What does The Neuro envision for the future of Open Science?

Open Science is transforming every aspect of the scientific method. The trends are irreversible, with people are implementing Open Science practices beyond their individual projects and across disciplines.

We must continue to place the needs of our patients at the centre of our work – collaborating, faster and more efficiently than ever, to offer them the best possible treatments and discover new and much needed cures.

We will continue to work with all stakeholders (funders, pharma, patients and advocates, clinicians, researchers, government and public policy makers, etc.) to collect and share data openly, create impact measurement systems and increase our credibility. Together, we must also continue to mobilize key opinion makers and political leaders, bringing additional partners on board, develop committed user bases, and make sure we are the go-to destination for open neuroscience.

Website and Social Media

Information about The Neuro's Tanenbaum Open Science Institute is available [online](#). The website and social media platforms (especially Twitter) help to promote The Neuro as the go-to destination and pioneer in Open Science, raise awareness and incentivize others to participate in our Open Science model.

Join the conversation! What you can do:

1. Follow us at:



2. Re-share our posts

3. Tag The Neuro in your own posts

4. Add our handle to your profile

5. Use our hashtags: #OpenScience | #OpenScienceinAction | #TanenbaumOpenScience

Related resources:

- The Neuro [Open Science Discussion Group](#) on LinkedIn
- [The Neuro's Social Media Policy](#)

Contacts

For more information about Open Science at The Neuro, strategic partnerships and general inquiries contact:



Annabel Seyller

Chief Operating Officer
Tanenbaum Open Science Institute
The Neuro (Montreal Neurological Institute-Hospital)
Tel. 514-398-7094 | annabel.seyller@mcgill.ca

For assistance with general communications, branding, design, copyediting, presentations and media-relations contact:



Damien Chalaud

Senior Director
Communications
The Neuro (Montreal Neurological Institute-Hospital)
Tel. 514-791-0389 | damien.chalaud@mcgill.ca

For philanthropic projects, contact:



Anièle Lecoq

Executive Director
Philanthropy
The Neuro (Montreal Neurological Institute-Hospital)
Tel. 514-398-5770 | aniele.lecoq@mcgill.ca