



Institut-Hôpital  
neurologique de Montréal

Montreal Neurological  
Institute-Hospital

# Operationalization of Open Science at the Montreal Neurological Institute - Lessons Learned

## The Tanenbaum Open Science Institute

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NIH workshop

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Centre universitaire  
de santé McGill



McGill University  
Health Centre

# The Montreal Neurological Institute-Hospital

“The Neuro”:

- Founded in 1934 by neurosurgeon Dr. Wilder Penfield
- Recognized world-leading integrated neuroscience research and clinical center
- Unique breadth of expertise from genes to cells to animal models to patients
- Access to powerful data infrastructure and resources
  - ❖ **A place where we can make real advances in neuroscience and our understanding and treatment of neurological diseases**

# Neurological Diseases, the most unmet medical need

- Tremendous human suffering and economic load
  - 100M people suffering just in the US
  - Estimated annual cost of >\$790B for US
- Since 2016, leading cause of disability and second leading cause of death worldwide
- Very limited treatments and no cures to alter the course or eradicate

**Frustration... sense of urgency**

**Need to shift the pace and do things  
drastically differently**

# OS, a game changer with huge potential for neuroscience

- Accelerating the discovery of novel treatments needs **fundamental advances** in basic neuroscience
- The brain's complexity necessitates **massive collaboration** as well as access and integration of massive amount of data from various sources and format
- Basic neuroscience **needs** open science
  - Break down barriers for collaboration
  - Allow fast and reliable reproducibility of data
  - Leverage big data potential and personalized medicine
  - Faster identification of novel therapeutic targets and reduction of time to early clinical trials

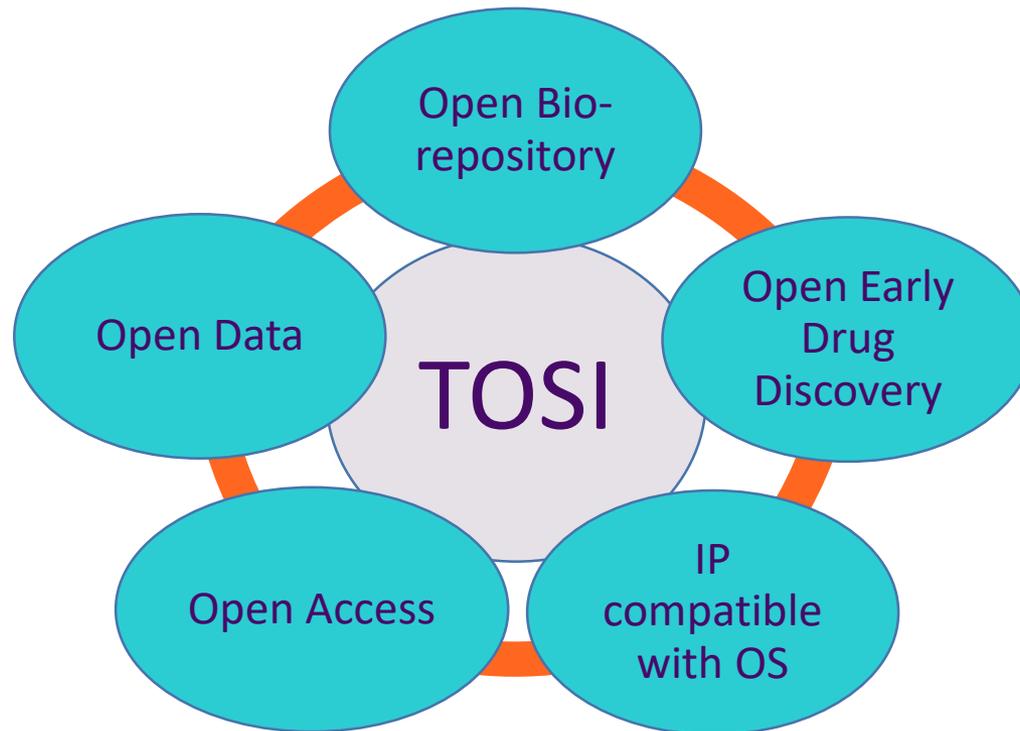
# OS, a mission enabler for The Neuro



**“Understand the brain,  
find cures and  
effectively treat people  
with neurological  
disorders”**

# Creation of Tanenbaum Open Science Institute

The Neuro is currently the only institution pursuing Open Science along 5 key axes



# C-BIG Open Repository

- Collects and makes freely available longitudinal deep phenotypic clinical information, biological materials, imaging, and genetic information (material/data) from patients and healthy controls
- Robust ethical framework, open MTAs
- >20K samples collected from ~1500 patients and healthy volunteers in three years
- Bio-banking core for numerous pan-Canadian open science projects
  - The Autopsy Consortium (TAC)
  - Azrieli Centre for Autism Research (ACAR)
  - Canadian Open Parkinsons Network (COPN),
  - CAPTURE-ALS project

# Open Early Drug Discovery Unit

1<sup>st</sup> institutional platform completely built on Open model:

- Leverage breakthroughs in stem cell (iPSC) technology towards building a suite of industry-standard assays
- Work with pharma and other partners to build “in house” expertise, with the goal of building new technologies and discovering new patient-centric therapies
- Very successful in their approach:
  - 8 industry partners
  - \$25 million in funding
  - 12 Online SOPs
  - 80 Catalog of iPSCs
  - Spinning out companies

# Open Neuro-informatics Platform

- Receive, consolidate and curate multi-domain data
- Maintain data security and subject privacy
- Disseminate data to researchers and various users groups

# TOSI: a living-lab experiment

Changing the culture of research:

Promoting engagement through bottom-up approaches

- internal buy-in process
- Open Science Grassroots Committee

Identifying and developing incentives for our researchers

Measuring impact of Open Science

# Internal buy-in process

- **An 18 month consultation process and bottom-up approach:**
- Definition of Open Science for The Neuro
- Mapping of existing open science activities
- Consultation process with Faculty, staff and students
- Social science study of potential barriers and limitations related to Open Science
- Definition of Guiding Principles with final buy-in

<https://gatesopenresearch.org/documents/4-15>

# TOSI's Open Science Grassroots Committee

Present **practitioners** of OS at The Neuro (**not activists**)

Encourage the adoption of open-science practices by other Neuro researchers

Collect researchers' needs for **concrete outcomes** in research & education

- ◉ pragmatic: focus on concrete aspects, big and small ideas.
- ◉ OS to simplify and strengthen science practices, not complicate them (science is complicated enough).

# Incentives for researchers

Careers

direct incentives  
for adoption

- **Evaluate, validate and recognize** open-science contributions in career evaluation and promotions:

- For recruitment and tenure
- For salary awards and prizes
- In the evaluation of research grants, as a token of PI productivity.

# Incentives for researchers

Careers

direct incentives  
for adoption

**For adoption** of open-science tools and resources:

- **Discounted access** to infrastructure, with commitment to data sharing
- **Special prizes and awards:**
  - TOSI open-science awards
  - TOSI Fellowships for students/PDFs engaged in OS
- Annual **Neuro/TOSI Grand Challenge on CBIGR data reuse** and original research method.



# Importance of measuring impact

Culture change is an education process

Evidence-based approach through impact measurement

Nucleated creation of a social science network to monitor and evaluate what we do:

Independent Open Science Impact Committee

Chaired by Richard Gold

International social scientists from Biomedical Ethics, Economics and Innovation policy

Objective to define appropriate metrics and evaluate the open science model in order to identify academic, innovation, and research policies that promote global economic and social well-being.

<https://gatesopenresearch.org/documents/2-54>

# Perceptions Vs Reality

***“Implementing an Open Science policy might restrain young researchers to join The Neuro”*** Unique rejuvenation phase of > 30 researchers over the last 3 years

***“OS will prevent new collaboration projects with external stakeholders”*** Increase in \$ and number for external collaborations, including non-traditional collaborators (AI)

***“Will clinicians see the benefits?”*** On-going or planned usage of the OS platforms

***“Will ethics be an issue?”*** Robust ethical framework in place. Patients highly supportive.

***“Pharma will not see the value of OS and will not embark”*** Open Drug Discovery Unit: \$25M funding in 3 years, a 1/3 from pharma.

***“Will public funders engage and support?”*** Great support from both Federal and Provincial funders, as well as policy-makers

***“Will donors embark?”*** Great support from philanthropy (400% increase in \$)

# Lessons learned

## *What has worked well:*

- **Bottom-up approach with an active internal buy-in process**
- **Strong institutional commitment**
- Crafted as an experiment (living-lab approach)
- Philanthropy as a kick-starter and a key driver
- OS as a magnet to attract philanthropic support
- **Robust strategic partnerships within the ecosystem**
- Continuous sharing of lessons learned
- Continuously act outside of our comfort zone

# Lessons learned

## *What has been more challenging:*

- Limited financial capacity: difficult to simultaneously implement all infrastructures
- **Culture change is a long process**
- Ingrained biases against “open”, especially at Universities’ level
- **Need new ways to acknowledge OS practice**
- Being first, no model to emulate
- Great hype within academia BUT cautiousness about **perceived risks**

“You cannot solve a problem  
using the same consciousness that  
went into creating it.  
You must see the world anew”  
Albert Einstein