Big data means many things to different people, but most agree that more data means better information leading to better decision making. Take Netflix as an example. It gathers tons of data from our watching habits and uses it to provide personalized recommendations and develop new content to improve the user experience. Healthcare is not Netflix, but can we borrow their approach to ensure that data is used more effectively to improve people’s experience? To start, we need to rethink how we collect and use research data. This is why the Ontario Brain Institute and our partners have developed our data platform called Brain-CODE.
Redefining Neurodegeneration: A Global Collaboration To Share Deep Phenotyping Data

OBI in partnership with Nature Neuroscience and The Centre for Addiction and Mental Health hosted a conference in Toronto on December 4 – 6, 2018. There is consensus among the neuroscience community that global collaboration on data and informatics can help close the knowledge and treatment gaps for neurological disorders. The conference brought together international experts and stakeholders to discuss the value and opportunity to federate existing data sets and to establish partners in this endeavor.

The focus of this inaugural meeting was on the standardized approaches to the collection of neurodegenerative disease data and platform configurations for data sharing and analysis.

**OUTPUTS**
- Recognition of OBI Model
- Partnerships

**METRICS**
- 75 neuroscientists and neuroinformatics experts attended
- 26 national and international organizations participated

Advancing Knowledge
Stories From Our Roots

The OBI recently partnered with Ontario First Nations Young People’s Council, Chiefs of Ontario, and University of Western Ontario, to train First Nations youth in SafeTALK (suicide-alert training) and be facilitators for Photovoice (storytelling through photography) in their communities. Stories From Our Roots is a Photovoice project driven by First Nations youth. It’s a form of life promotion that uses photography to tell stories of hope, to help safeguard against the growing rates of suicide among First Nations youth in Ontario.

The first two of five workshops for the Stories From Our Roots project took place October 19 - 21 in Thunder Bay and November 16 -18 in Kenora, Ontario. Each workshop trained 15-20 First Nations youth. Read The Globe and Mail story on the project here.
Brain-CODE And ICES Data Linkage

The first linkage between Brain-CODE and the Institute for Clinical Evaluative Sciences (ICES) was successfully completed with a 99.6% match rate and involved 667 participant datasets from POND (OBI’s neurodevelopmental disorders research program).

The linkage was conducted as part of a broader research project, “Linkage of whole genome sequencing and administrative health data for the study of autism spectrum disorders” to strengthen the understanding of autism, help identify people with autism using administrative data and better understand their health journey.

Brain-CODE Featured In A Canadian Health Information Guide

Brain-CODE was featured in the 4th edition of Canadian Health Information: A Practical Legal and Risk Management Guide published in November.

The chapters ‘Brain-CODE Data Governance: an electronic service provider perspective’ (Chapter 18) and ‘Brain-CODE’s Governance Policy’ (Chapter 19) discuss the development of OBI’s governance framework, including best practices to enable large scale data sharing within Canada. Find the guide here.
Annual Research Program Workshops

EpLink, ONDRI and CONNECT (OBI’s epilepsy, neurodegenerative disorders and concussion research programs) hosted their annual workshops this quarter. The purpose of the annual workshop is to meet colleagues face-to-face, discuss achievements, obtain input from the program members about their planned direction for the next years, brainstorm on collaborations and partnership opportunities.

Family Days

POND and CP-NET (OBI’s neurodevelopmental disorders and cerebral palsy research programs) hosted their Science and Family Day this quarter. These events are co-organized with their patients and community advisory members. The Family Day allows researchers to share study findings and engage with patients on a range of topics, including transitions into adulthood and the impact of a diagnosis from the perspective of a patient, parent, and clinician.

Family Days are designed for patients and caregivers to connect, network and share information about the research and technology advancements in brain disorders.
Canadian ADHD Resource Alliance

The OBI presented at the 14th Annual CADDRA (The Canadian ADHD Resource Alliance) conference in Calgary, Alberta on the Top 10 research priorities from the Neurodevelopmental Disorders Priority Setting Partnership. CADDRA is an international conference that brings together researchers, clinicians and other professionals working in the area of ADHD.

As part of OBI’s dissemination plan for the Top 10, Dr. Jessica Jordao, OBI Research Program Lead, shared the process and outcomes of this initiative with the ADHD community and encouraged attendees to work with OBI to address these research priorities. Dr. Jordao participated in a panel and shared views on the importance of incorporating the patient voice in research as well as strategies to raise awareness of the shortlisted priorities for ADHD and other neurodevelopmental disorders.

Annual Society For Neuroscience Conference

OBI set an exhibit at the Annual Society for Neuroscience (SfN) conference on November 3 - 7, 2018 in San Diego. Researchers came together from across the globe to exchange ideas, present research and network with like-minded people.

This year OBI showcased the capabilities of Brain-CODE, highlighted OBI’s initiatives and accomplishments in neurotechnology, and promoted posters and presentations related to OBI’s Integrated Discovery Programs. Brain-CODE was presented as part of the Canada Node at the International Neuroinformatics Coordinating Facility booth.

OUTPUTS

Access to Information

Evidence-Informed Community-Based Interventions

Recognition of OBI Model
OBI Participates In Panel At The TRP Talks

Dr. Garth Smith, Director of Industry Relations at OBI, was present at the TRP Talks (Translational Research Program) to talk about ‘Pathways to Market’ on October 30, 2018. TRP Talks are geared to an inter-professional community of clinicians, researchers and trainees to stimulate discussion and community building. Dr. Smith shared the stage with Dr. Fredrika Scarth Director, Health Quality Ontario (HQO), Liaison and Program Development, Ontario Ministry of Health and Long-Term Care (MOHLTC); Sandy Schwenger CEO m-Health Solutions & Patientcare Solutions and Dr. Michael Farkouh, Vice-Chair, Research, Department of Medicine, University of Toronto.

He shared his perspective on what it takes for early-stage ventures to succeed in the neurotechnology industry and benefit the patient community; the stages involved in converting idea to a product and how develop a solid business strategy. He also informed attendees about the programs available in Ontario including OBI’s ONtrepreneurs and NERD (Neurotech Early Research and Development) programs that support startups with funding and mentorship to launch and grow their own ventures.

Learn The Love Spectrum

At the launch event of Samsung’s Learn The Love Spectrum campaign, October 25, 2018, Dr. Azedeh Kushki, POND researcher (OBI’s neurodevelopmental disorders research program) at Holland Bloorview Kids Rehabilitation shared a panel with Dr. Stephen Shore, internationally recognized autism speaker (TEDTalks) and professor at Adelphi University in the U.S.; Dave Caballes, a parent from the Autism Speaks Canada network, and Avery Swartz a well-known media personality and parenting advocate.

The panel discussed their insights, experiences, and resources to support the ASD community in Canada. Learn the Love Spectrum campaign aims to raise awareness of autism in Canada and to bring a deeper understanding of how technology can impact the lives of families by deepening family connections and help a child share their love with the world.
The Neuroinformatics Internship program was developed to address the technical and managerial talent needed to support the growth of informatics within Ontario and increase the number of highly trained and qualified personnel for careers in the for-profit and not-for-profit industry.

During each cycle of the Neuroinformatics Internship program, OBI supports the recruitment, mentorship and training of five recent graduates with experiences relevant to informatics and/or neuroscience. The interns are hired by OBI partner institutions and directly support the ongoing neuroinformatics activities of OBI-funded research programs. OBI is committed to offering exciting experiences “away from the bench” to recent graduates to explore new career opportunities and provide training in data management and the growing field of informatics.

**We welcome five new interns for our Neuroinformatics program**

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hibah Naviwala</td>
<td>University of Toronto, ONDRI</td>
<td>A University of Toronto graduate with a double major in statistics and cognitive science. Hibah is passionate to learn about neurodegenerative diseases and the application of statistics in neuroscience.</td>
</tr>
<tr>
<td>Ernest Ho</td>
<td>St. Michael’s Hospital, CAN-BIND</td>
<td>A PhD in computational neuroscience and completed post-doctoral research in epilepsy. Ernet’s interests lie in mathematical modelling and is currently working as a data scientist.</td>
</tr>
<tr>
<td>Marina Nikolopoulos</td>
<td>Holland Bloorview Kids Rehabilitation Hospital, CP-NET</td>
<td>A neuroscience graduate from the University of Toronto, Marina is keen on developing her skills in programming and foray into the neurotech sphere at the U of T.</td>
</tr>
<tr>
<td>Basma Chamas</td>
<td>University of Toronto, EpLink</td>
<td>A University of Toronto graduate with a double major in mental health studies and french. Basma is interested in brain health and the use of data to inform healthcare.</td>
</tr>
<tr>
<td>Jievitha Sitha</td>
<td>SickKids, POND</td>
<td>With a background in mechanical engineering, Jievitha is interested in applying the skills she acquired from her engineering training in the field of neurotechnology.</td>
</tr>
</tbody>
</table>

**OUTPUTS**

- Jobs
- Experienced HQPs
Mouse Study Supports Stem Cell Therapy for Cerebral Palsy

A collaboration between Krembil Research Institute, UofT Medicine, Western University and CP-NET (OBI’s cerebral palsy research program) has published a paper regarding stem cell therapy for cerebral palsy to address the underlying brain injuries responsible for common movement disorders.

Dr. Fehlings (a member of OBI’s CP-NET) and colleagues published a paper describing a new rat model of brain injury that will be useful for testing human-derived neural precursor cells as a mechanism for repairing the brain after injury. This model provides an important tool for researchers to help translate these findings into the clinic. Read full paper here.
Achievements

Congratulations to Dr. Mandar Jog, ONDRI’s Co-Principal Investigator (OBI’s neurodegenerative disorders program), for this year’s Lawson Health Research Institute Innovation Award 2018. The award recognized Dr. Jog’s development of a personalized therapy that has successfully treated over a hundred research patients with tremors in their arms and hands. The Innovation Award is given to a scientist whose research has resulted in translation into advances in health care either through commercialization or adoption of new clinical practice.

Congratulations to Dr. Jorge Burneo on being chosen as the first Jack Cowin Chair in Epilepsy Research and on being named one of TD’s 10 Most Influential Hispanic Canadians. Dr. Burneo is the Co-Director of EpLink, OBI’s epilepsy program, and a professor in clinical neurological sciences, and epidemiology and biostatistics at Schulich Medicine & Dentistry.

Congratulations to Dr. Anthony E. Lang (Co-Lead on ONDRI, OBI’s neurodegenerative disorders program) on winning the Weston Brain Institute International Outstanding Achievement Award 2018. This $40,000 award recognizes an exceptional researcher who has made significant advances in accelerating the development of therapeutics for neurodegenerative diseases of aging through translational research, has demonstrated remarkable leadership, and has a record of impeccable citizenship in the research community. Dr. Lang is considered the world leader in movement disorders with more than 700 publications and 87,000 citations in the area.

OBI & Indoc Research were recently selected to receive funding through the CANARIE Research Data Management award which funds the development of software tools that enable best practices in managing research data. The funded project will develop a data portal software to enable research teams to securely and seamlessly capture, query, and visualize patient data; collaborate and share datasets; and access support and training resources. The project will serve the needs of teams using Brain-CODE as well as those from collaborating institutions and the broader medical research community.
In The Media

- Co-founder of Atomwise returns to U of T to speak about starting his AI-powered drug discovery business
- Award: Dr. Jorge Burneo named one of 10 Most Influential Hispanic Canadians
- Announcement: Dr. Jorge Burneo appointed as the Jack Cowin Chair in Epilepsy Research
- U of T study links slowed brainwaves to early signs of dementia
- CANARIE AWARDS UP TO $3.2M IN FUNDING TO 9 RESEARCH TEAMS TO DEVELOP RESEARCH DATA MANAGEMENT SOFTWARE TOOLS
- AMO Pharma Reports Positive Data from POND-Led TIDE Study of AMO-02 in Autism Spectrum Disorder
- DIGGING DEEP
- Mapping new neuroscience pathways, with Dr. Tom Mikkesen
- SIX NEUROTECH STARTUPS RECEIVE $50,000 FROM ONTARIO BRAIN INSTITUTE
- Photography workshops teach Indigenous youth to speak with vision

Employment Opportunities at OBI

Executive Assistant (Deadline: February 15, 2019)

Program Lead, Informatics Governance (Deadline: February 24, 2019)

Internships: (Deadline: February 10, 2019)
- Informatics Intern
- Industry Relations Intern
- Outreach Intern
- Research Programs Intern

Upcoming Events

April 23, 2019: OBI Public Talk
Topic: Children and pain management