



RENEWAL





NeuroDevNet's spiral logo communicates change, progression, and evolution. Its bright multi-colour palette emphasizes our focus on children.

VISION

To improve the lives of children with neurodevelopmental disabilities and their families by accelerating and integrating the discovery and utilization of knowledge about disorders of the brain, and their early diagnosis, prevention and treatment.

MISSION

NeuroDevNet is a national multi- and trans-disciplinary network dedicated to bringing hope to children with Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Fetal Alcohol Spectrum Disorder (FASD) and other neurodevelopmental conditions, as well as to their families and caregivers. NeuroDevNet focuses its funding on integrated, team-based research initiatives related to cause, early identification and treatment. Engaging families, clinicians, other stakeholders and partners nationally and internationally, NeuroDevNet leverages and enhances the talents of new and seasoned researchers to translate discoveries into effective tools for diagnosis and treatment as well as changes in policy and practice.

OBJECTIVES

IMPACTFUL DISCOVERY Conduct and implement high quality, collaborative research in high-impact areas as identified by partners, patients, and/or families.

TRAINING Develop a national training program to provide the next generation of researchers with enriched learning opportunities in developmental neurosciences, as well as skills to excel in the workforce.

AWARENESS Raise awareness of neurodevelopmental disabilities and collaborate with partners to accelerate social and economic policy change that improves the lives of affected children and their families and society as a whole.

PARTNERSHIP Expand the reach of the network and its impacts by developing and strengthening key national and international partnerships. Maximize the impact potential of Network discoveries and their uptake and implementation through integrated knowledge translation and commercialization.

SUPPORT

NeuroDevNet is made possible by the Networks of Centres of Excellence, a program of the federal government meeting Canada's needs by focusing a critical mass of research resources on social and economic challenges, commercializing and applying home-grown research breakthroughs, increasing private sector R&D, and training highly qualified people. NeuroDevNet gratefully acknowledges host support from the University of British Columbia and the Child and Family Research Institute.



a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA

RENEWAL

INDEX

Message from the Board Chair and Executive Director	4
Scientific Director's Celebration	5
NeuroDevNet by the Numbers	6
Creating a Culture of Innovation	8
<i>Theme I: Early Diagnosis</i>	10
<i>Theme II: Early Intervention</i>	15
<i>Theme III: Family Support</i>	22
<i>Theme IV: Meet our Social Determinants of Health/Health Economics Program</i>	27
Training	30
Kudos	36
Events	39
Financial Statements	44
Network Community	55

Message

from the Board Chair and Executive Director

From our Chair Mr. Patrick Lafferty and Executive Director Mr. Tom Philpott

We are proud to present this sixth annual recounting of the activities and increasing impacts of NeuroDevNet. Networks of Centres of Excellence don't necessarily make it through the arduous process of re-visioning, refocusing, and review entailed in a new funding cycle, yet we are delighted to announce that NeuroDevNet received the accolade of renewal in 2015 for five additional years!

The transformative potential of the work of our investigators, partners and trainees was clearly the key to our progress and success, and remains so today. This is reflected in the themes and stories in this report that depict life-changing research initiated in NeuroDevNet's first years, as well as programs and projects new to the Network in 2015-16.

In this second five-year cycle the Network will increasingly focus on driving our research toward implementation in practice and policy. Adjustments to our management and governance structures will facilitate this process. For example, renewal of our Research Management Committee with more representation from clinical, family and grass roots perspectives will help ensure that our research meets the needs of the community as well as the highest scientific standards.

The dedicated efforts of our Board of Directors and executive staff continue to ensure public investment in the wellbeing and full potential of the 1 in 6 children with neurodevelopmental disabilities is managed responsibly and transparently. Modernization of our bylaws, which include the adoption of best practices such as staggered terms on the board of directors, will allow for continuity of the Network while also providing continued opportunities to bring in new expertise to strengthen its skillset in all aspects of knowledge translation, exchange and exploitation (KTEE).

Governance, and indeed every level of the Network can be said to be evolving to ensure a stronger focus on knowledge translation (KT) and mobilizing findings into clinical and commercial practice as well as public policy. New board members included Dr. Jean-Paul Heale, as incoming host institution representative and KTEE expert from UBC, and Dr. Michael Fehlings, principal investigator representative. On this note, we would like to take this opportunity to thank the members of the board for their dedication and commitment, including those who finished their terms: Gary Wechsler, former Finance & Audit Committee chair (2012-2015), Angus Livingston, former Valorization Committee chair and host institution representative (2011-2015), and Dr. Jerome Yager, principal investigator representative.

Other key changes have included the appointment of a deputy scientific director. Dr. James Reynolds (Queen's University), co-lead of the FASD Research Group was appointed in September 2015 to significantly assist in moving Network research from discovery to application. The Network has also recruited a head of innovation. Dr. Sylvain Moreno (Simon Fraser University) joined the Network in the summer of 2015 to develop and further strengthen commercialization within the Programs and Projects. Dr. Moreno is also the Director of the Digital Health Hub at Innovation Boulevard.

These efforts combine to strengthen the Network and its impacts, as well as carry NeuroDevNet's renown beyond our borders. This is evidenced by a memorandum of understanding with Australia's prestigious Telethon Kids Institute signed in March 2016. The centerpiece of the agreement is translational activity focusing on many areas of shared interest, including diagnosis, treatment and a family orientation.

All Canadians can be proud of the way our investigators from across Canada have enthusiastically come together to lead to the breakthrough research and training excellence you will read about in the stories that follow. The members of NeuroDevNet are truly a winning team, transforming the lives of children and families every day.

We offer our thanks and appreciation to everybody involved: universities, institutes, international partners, industry, charities, and governments. Our change in name to the Kids Brain Health Network should help promote better public understanding of the important and innovative work of the Network as we push ahead into the future. ■

Patrick Lafferty
Chair of the Board
of Directors,
NeuroDevNet



Thomas Philpott
Executive Director,
NeuroDevNet

Celebration

From Scientific Director Dr. Daniel Goldowitz

The beauty of a network is that the whole is greater than the sum of its parts. Within NeuroDevNet, we're connected by our joint efforts to understand child brain development, and to mobilize this knowledge to improve the lives of children with neurodevelopmental disorders and their families.

In this report we celebrate the achievements made in our sixth year of activity as a Network of Centres of Excellence. I point with pride to the joint work of Autism Research Program co-lead and genetics pioneer Dr. Stephen Scherer, and outstanding cerebral palsy investigators Drs. Maryam Oskoui and Michael Shevell, who mined the NeuroDevNet-supported national Cerebral Palsy Registry to produce a hallmark finding related to early diagnosis and intervention in CP. This discovery could only be made through applying cutting edge genomic methodology with the power inherent in the Registry. This cross-disciplinary collaboration was transformational.

Our direct impact on families and children is wonderfully manifest in our parent-provided intervention that promotes language development and shared attention in toddlers at risk of ASD. Our Social ABCs project is now being evaluated for province-wide rollout in Ontario. Another new project is achieving unprecedented reach into the child welfare system, identifying at-risk children in early infancy so as to increase the potential to avert catastrophic outcomes in later life. At the heart of these successes, and the many other outstanding contributions you will find in this report, is collaboration.

That, for me, represents the true potential of the Network.

Ongoing collaboration with members of the Community for Brain Development—a group of leading Canadian organizations working in the child health and development space that convened during our first five years as a Network— has also yielded multiple important developments.



Dr. Daniel Goldowitz
Scientific Director,
NeuroDevNet



Most significant, perhaps, is the successful \$25M Strategy for Patient-Oriented Research (SPOR) proposal in neurodevelopmental disorders, CHILD-BRIGHT. Three NeuroDevNet investigators are leading this five-year initiative, which has a highly complementary focus on early and effective intervention, diagnosis and the mental health needs of children and youth, and extensive integration of investigators and partner organizations.

Partnership is essential to our capacity to enrich and support the training of the next generation of top neurodevelopmental researchers. Our new National Training Program in Developmental Neurosciences received a tremendous boost through a collaboration with Brain Canada and 9 top academic centres across the country.

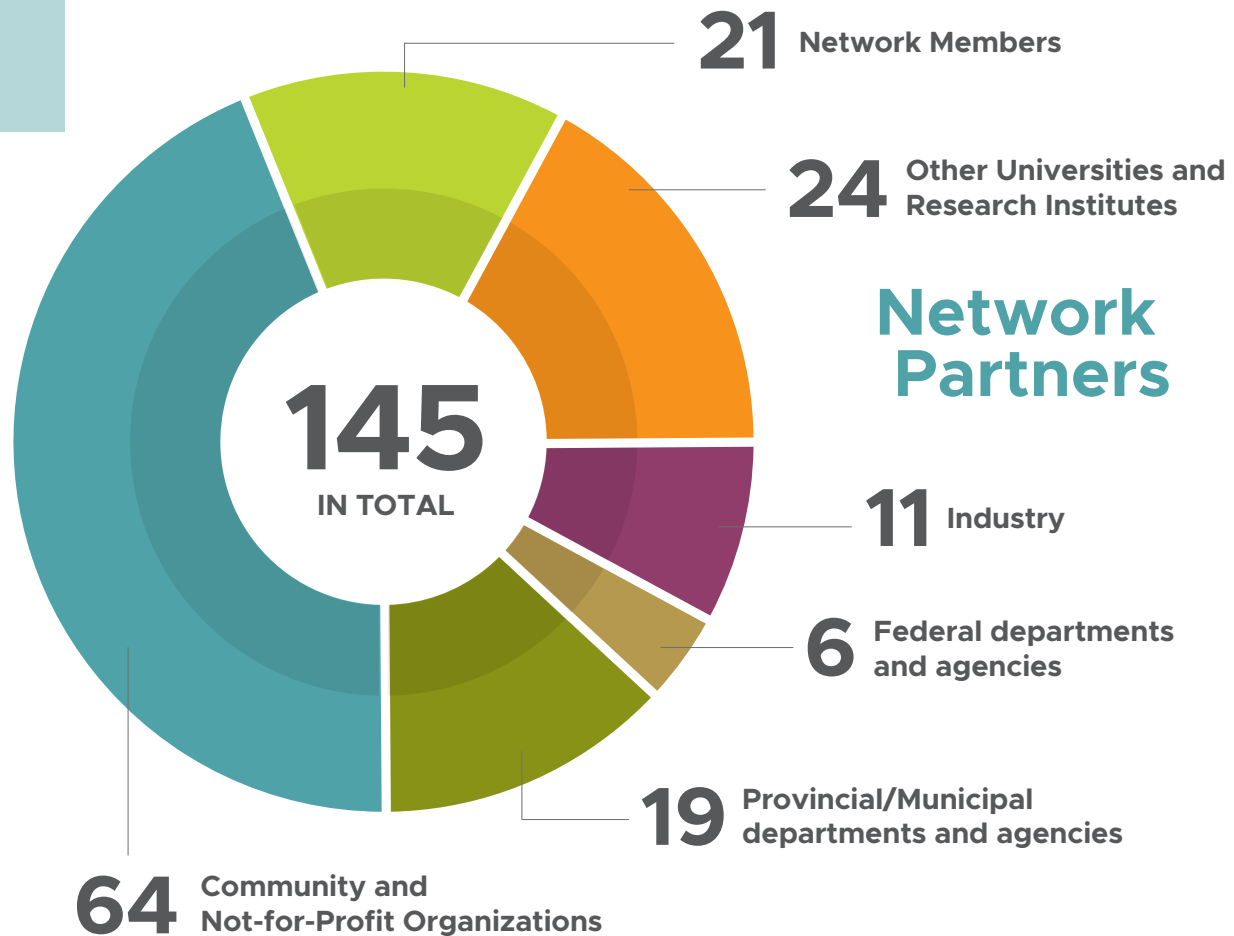
Scientific excellence is considered a given in the NCE program, but it rests on the efforts and capability of our talented investigators, trainees, and other research staff. Together, we have honed our collective focus on three key objectives: early diagnosis of neurodevelopmental disabilities, earlier application of evidence-based interventions, and support for child and family. The product of extensive scientific review during our renewal process, this emphasis is pushing us collectively toward clinical and real-world application of our efforts. Each Program within the Network has one or more projects involving stakeholders in evaluating novel interventions.

New to NeuroDevNet are five small projects and two program-level research groups. *Better Nights Better Days*—Neurodevelopmental Disorders focuses on evaluating an evidence-based intervention for the sleep disturbances that affect up to 90 percent of children with neurodevelopmental disabilities. Our drive to assess the socio-economic impacts of our collective activity is represented in the new Social Determinants of Health and Health Economics Program. In addition to bringing a multi-disciplinary lens to our work and its impacts, this group is also exploring the potential of a functional, rather than diagnostic approach to understanding and treating neurodevelopmental disabilities.

As patient-oriented care becomes the standard, our approach to discovery holds great promise for clinical and policy impacts and better outcomes. This is because relationships are the core of our activity and set our bearings. Children and youth, their parents and caregivers, and the individuals and organizations that provide care and services are helping guide the Network to address unmet needs in ways that research alone can help resolve. ■

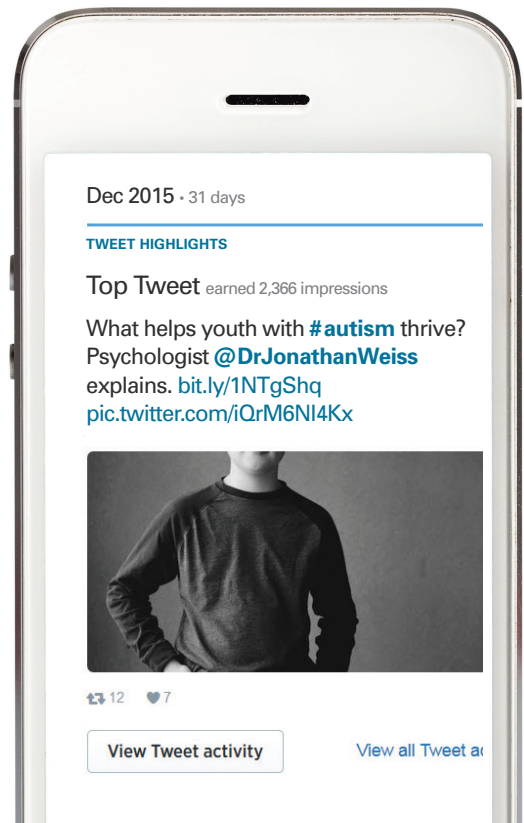
NeuroDevNet

by the Numbers



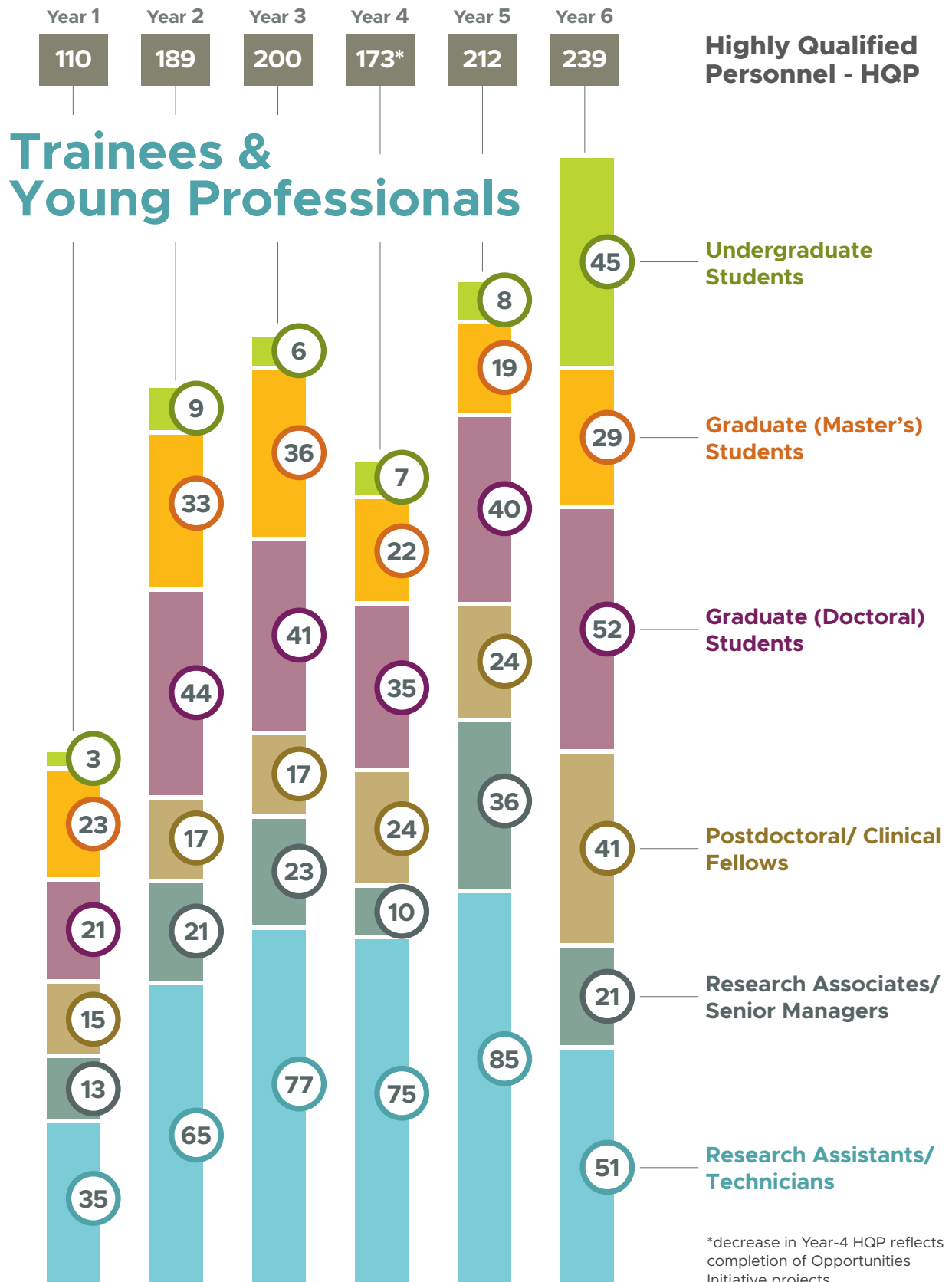
In journals such as: *Nature Communications, Annals of Neurology and Developmental Medicine and Child Neurology.*

Due to a new tracking system, cumulative numbers stated for 2014-15 have been updated.



NeuroDevNet

by the Numbers



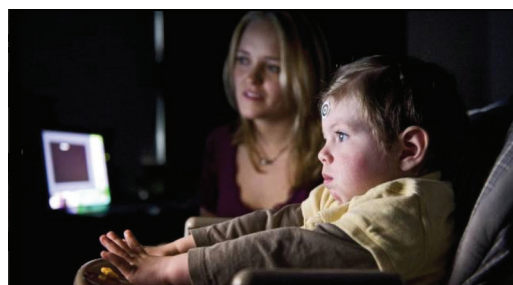
Creating a Culture of Innovation

R&D within the Network produces promising tools for diagnosis and treatment

We know how powerful technology has been in changing society. Within NeuroDevNet, we're harnessing that power to transform the lives of children and youth with disabilities. From more efficient and accessible means of screening, to devices that capture real-time data on seizures or improve mobility and social life, the ingenuity of our investigators captures our young research participants, and shows promise for a wider audience.

Eye tracker screening tool for FASD

Using the Eyelink 1000 device developed by SR Research, Kanata, ON, NeuroDevNet researchers are building the evidence base to support the clinical utility of inexpensive and mobile eye movement tracking as a means to assess deficits in brain function caused by prenatal exposure to alcohol. The powerful technology will move forward the widespread identification of children with FASD, who often languish without diagnosis.



Functional Engagement in Assisted Therapy through Exercise Robotics

An upper-body rehabilitation tool being piloted for children with hemi-paretic—one-sided—cerebral palsy, “FEATHERS” harnesses video gaming and robotic technology to encourage use of the affected side as two-handed engagement is necessary to keep the game playing.

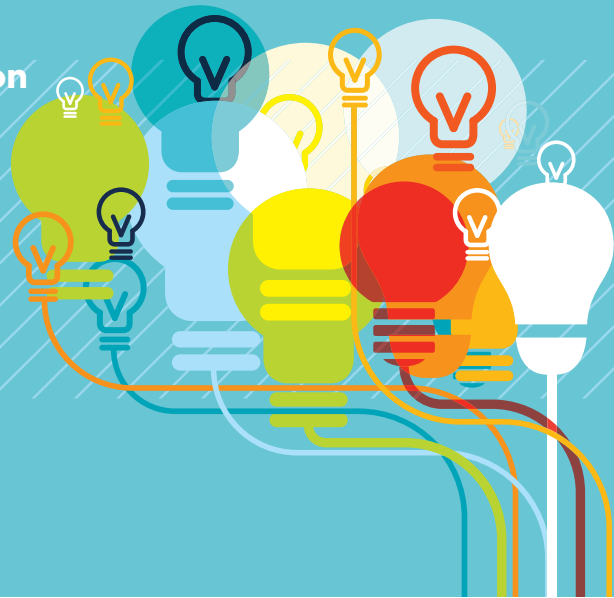


Caribbean Quest Video Game

A facilitated videogame created by NeuroDevNet researchers improves working memory, focus and the capacity to self-regulate in children with FASD and autism. In pilot studies on Vancouver Island, initial results indicate children learn to cope with setbacks as they play the game and receive coaching that supports executive functioning.



Creating a Culture of Innovation



AVERTUS Home Epilepsy Monitor

This EEG-based wireless headset monitors EEG readings, offers point-of-care monitoring and detection, and can be worn during the day or at night during sleep to detect and analyze signals of impending or occurring seizures. The headset provides timely information to the parent and clinician on a child's epilepsy without the cost or stress of multiple clinical visits.



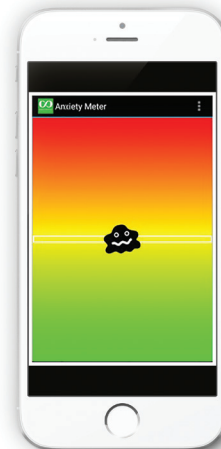
Liberi Exercise

Liberi is a new exergame that supports physical activity and social interaction among children and youth with cerebral palsy (CP). In pilot trials, participants using the exercycle to power a customized multiplayer video gaming system experienced both cardiovascular benefits as well as a decrease in feelings of loneliness and isolation. The same technology will be used in children with FASD to attain these benefits.



Anxiety Meter App

The *Anxiety Meter* is a smart-phone based app that detects and measures anxiety levels in children with autism by measuring heart rate and converting it into a visual representation of the child's anxiety level. The app is helpful for minimally verbal children, who have limited or no access to evidence-based anxiety treatments.



Theme I:

Early Diagnosis

Genetic and epigenetic discoveries push capacity for early diagnosis and hold promise for precision in treatment and care

Network cross-pollination yields groundbreaking discovery in CP and potential policy change

When a unique NeuroDevNet collaboration produced the landmark finding that genetics play a surprisingly strong role in cerebral palsy, a media flurry ensued.

“Cerebral palsy linked to genetic anomalies,” reads a CBC headline, one of 38 news organizations to carry a story about the *Nature Communications* finding during the first week of August in 2015.

This first-time insight now stands alongside stroke, oxygen deprivation and infections as a potential cause of CP, a disorder that occurs in two out of a thousand births.

The Network’s Canadian CP Registry, championed by CP research group investigators Dr. Michael Shevell and Dr. Maryam Oskoui (McGill University), was the source of samples from 115 children analyzed in “Clinically Relevant Copy Number Variants Detected in Cerebral Palsy.”



Autism Research Group Co-Lead Dr. Stephen Scherer (University of Toronto, SickKids Hospital), a renowned expert in identifying genetic variation in autism and other neurodevelopmental disabilities, used chromosomal microarray screening (CMA) of the entire genome to evaluate the samples. This powerful approach has identified the strong influence of copy number variation (CNV)—deletions, duplications and reorganization of segments of DNA in a person’s genetic code—as well as spontaneous mutations, in a growing number of developmental disorders.

In this case, the researchers found high rates of new mutations in genes thought to be relevant to CP among 10 percent of the children in the study. “When I showed the results to our clinical geneticists at SickKids, they were floored,” says Dr. Scherer.

How these changes inter-relate with other established risk factors remains to be fully understood. “Two newborns exposed to the same environmental stressors will often have very different outcomes,” says Dr. Oskoui. “Our research suggests that our genes impart resilience, or conversely, a susceptibility to injury that underlies CP.”

Chromosomal microarray screening for CNVs is standard care in diagnosis of autism, global developmental delay and intellectual impairment—but not for CP. The American Academy of Neurology previously strongly recommended against routine genetic screening in the evaluation of children with cerebral palsy. This study provides high quality evidence to revise these recommendations so that CMA is included as a standard diagnostic practice in CP, according to the researchers.

While widespread uptake of the CNV findings will likely take several years, individual doctors are already requesting this genetic test in their evaluation of children with CP. Dr. Oskoui says that after she nominated the topic, it was approved and given a high priority ranking by the American Academy of Neurology’s Guideline Development Subcommittee. An evidence report on genetic testing in children with CP will be produced by the AAN, with the aim of making screening for CNVs in CP the new standard of care in clinical settings. ■

Theme I:

Early Diagnosis

The influence of genomic and epigenetic factors on development and outcomes in ASD

Wielding the most advanced genetic tools in the search for the origins of autism

How do genetic and epigenetic factors influence developmental outcomes in Autism? The answer may lie in the genes and gene expression profiles of siblings, where one child is already diagnosed with ASD.

In 2015, Dr. Stephen Scherer published research that showed less than a third of siblings with ASD share the same risk genes for autism. This challenge to long-held assumptions has triggered an expanded investigation of heritability in ASD within the Network.

Investigators are now comparing how many differences and similarities occur between recently diagnosed children and their younger brothers and sisters, drawing from the longstanding Pathways in ASD and Baby-Siblings cohorts. Dr. Rosanna Weksberg (University of Toronto, SickKids Hospital) is leading epigenetic analyses, while Dr. Stephen Scherer (University of Toronto, SickKids Hospital) is responsible for the project's genomics analyses. Dr. Joseph Beyene (McMaster University) is assessing the relationships between children's early developmental pathways, in the context of the genomic and epigenetic profiles in this unique dataset.

Epigenetics refers to modifications to DNA, for example DNA methylation and its associated proteins that determine which genes are expressed, or turned on, at any given space and time in response to multiple influences. Genomic analysis evaluates the blueprint—all of the genetic coding an individual has carried since conception. Children who have a sibling with ASD have a 10-to-20 percent chance of developing the disorder themselves, Dr. Weksberg says, something that can't always be explained by genetics alone.

"We started looking at epigenetics because genetics really doesn't entirely explain the etiology (origins) of autism," she says, noting that factors such as air pollution, gestational diabetes, and fertility treatments could play a role in the development of ASD. "We saw that as an opportunity to look at a complicated situation with many factors involved to try and identify epigenetic factors which might contribute to the development of autism."

Dr. Weksberg's project will compare 100 typically developing sibling pairs as controls in the study, to 100 sibling pairs with ASD in order to identify epigenetic factors that may be linked to autism in these families.

The team is using a powerful epigenomic platform that assesses DNA methylation at more than 850,000 sites across the genome. DNA methylation variants (DMVs) have shown promise as potential biomarkers for other neuropsychiatric disorders. Under the leadership of Dr. Weksberg, the team will conduct a pilot epigenome-wide association study to identify DMVs predictive of ASD: the first of its kind in a high-risk infant cohort.

"We are hypothesizing that there are genetic, epigenetic, and environmental determinants in autism," says Dr. Weksberg, noting that the team hopes to discover biomarkers that can be used for the early detection of ASD. "Genetics is the blueprint, but epigenetics may give you a functional readout of the molecular error that underlies a developmental problem, and potentially detect therapeutic targets that are more accessible than those identified by genetic alterations."

Dr. Scherer's 2015 work demonstrated that a significant number of siblings with ASD have different genetic alterations – something that Dr. Weksberg says reflects the large number of genetic and epigenetic changes that can lead to ASD.

"There are so many variables to address in studies of epigenetics and autism that I don't think there have yet been studies large enough to tell us about their connections," she says. "NeuroDevNet is giving us an opportunity to actually research this properly—it's very exciting!" ■

Early Diagnosis

From Biosignatures to Behavioural Profiles in Autism Spectrum Disorders

'Eureka moment' leads to innovative new ASD diagnostic research

McMaster University research scientist Dr. Geoff Hall still recalls the moment he came up with the idea for the project "From Biosignatures to Behavioural Profiles in Autism Spectrum Disorders": it all began in the middle of the night.

"I had one of those "Aha!" moments where things collided in the middle of the night, and I got so excited about applying machine learning methods to the biology in terms of the copy number variants (CNVs)," says Dr. Hall, chuckling. Programming a computer to recognize subgroups of children with autism based on CNV patterns—gene duplications, deletions and relocations—among billions of pieces of genetic data "wasn't necessarily a novel idea, but for me it was one of those 'eureka' moments that was very exciting."

Dr. Hall immediately contacted Dr. Stephen Scherer (University of Toronto, SickKids Hospital), ASD research group co-lead. The duo is now collaborating on a project that aims to bring clarity to the diversity of symptoms and severity seen on the autism spectrum.

The team is developing a machine learning approach combining genetics and genomics data with brain imaging and "deep" behavioural phenotyping—a battery of neuropsychological tests and computer-based assessment tools. "If we start first by breaking the children into sub groups within ASD based on the biology, and then use that information to look at the phenotype (behaviour and observable symptoms), those phenotypes might make sense clinically," Dr. Hall explains, noting data for approximately 2,000 children participating in the Autism Genome Project will be analyzed in the study.

At the end of the project, Dr. Hall hopes the team will have identified and tested sub-groupings within the study sample. "To be able to map the developmental trajectory of this information and make better sense of how we can then influence the developing brain, and what kind of therapies to put into place at certain ages is really where I hope this will end up leading," he adds.

"The Network has been very supportive and encouraging, and I really have benefited from NeuroDevNet's support," Dr. Hall concludes. "I think we're really on the right track, and I feel really strongly how good the Network is." ■



Vivi enjoys lining up objects. Distinctive play behaviours are often seen in children with autism.



Early Diagnosis

Infant Screening and Intervention

Screening project means kids in foster care get developmental evaluation they'd otherwise miss

Dr. Chaya Kulkarni's intervention project began with a simple question: Who was looking at the development of children under the age of five in Canada's foster care systems, particularly those at risk of Fetal Alcohol Spectrum Disorder (FASD)?

The answer, it turns out, was no one.

"Nobody was actually looking at these children's early development, and very few were looking at their mental health," recalls Dr. Kulkarni, Director of Infant Mental Health Promotion (IMHP) at SickKids in Toronto. "And that was problematic because early mental health is so critical—brain plasticity peaks in the first few years of life. Not responding to it actually sets the child up for poor outcomes throughout their life."

Dr. Kulkarni's team identified an excellent screening tool that looks at overall development with a second component that focuses on social emotional development. "What we did then was create a tool that allows practitioners to prepare a plan for the child that can be used by any caregiver—including foster parents—that uses everyday language," says Dr. Kulkarni. "It offers clear developmental goals for the child and strategies that can be embedded into daily routines to support the child in reaching the goal."

In the final stages of obtaining ethics approval, the tool doesn't diagnose anything, notes Dr. Kulkarni, but indicates if a child is at risk of developmental delays in certain areas.

Once potential delays are identified, the tool allows a support plan to be developed and shared with every caregiver in that child's world to make sure "everyone's on the same page". Further, a database of early mental health and developmental goals by age is available for caregivers, along with support strategies.

The team is also collaborating with a new Network trainee and staff member at the Children's Aid Society of Toronto (CAST), Carmela Paolozza, [see Profile, p.34] and employing the FASD Research Program's eye tracking screening tool championed by NDN Deputy Scientific Director



A toddler tries out the eye tracker in a photo shoot for the Globe and Mail.

James Reynolds, Paolozza's advisor. Sixty infants have participated in the eye-tracking component of the study, which aims to identify children in care with FASD early in life.

"What the screening and intervention project enables us to do is get really detailed data about how the child is managing, where they are at risk for delays, and enables us to develop a plan of care," says Brenda Packard, supervisor at the Children's Aid Society of Toronto. "We know that by targeting specific domains where children are at risk for delays, we see better improvement than if we just provide an overall positive developmental experience."

The intent is to recruit other sites throughout Toronto and the GTA for the NDN project (Native Child and Family Services, Catholic Children's Aid, York CAS). Dr. Reynolds is also collaborating in the evaluation of the service plan approach in Calgary region child protection agencies, and participation across Alberta is expected to follow.

"When a child has had prenatal alcohol exposure, and is then in an environment that is not nurturing, we're pretty much guaranteeing a poor outcome," says Dr. Kulkarni.

"The best-case scenario for me is that any child who is in care, and especially where there is a high suspicion or confirmation of prenatal alcohol exposure, absolutely receives the screen as well as a developmental support plan." ■

Early Diagnosis

Neuroinformatics

Identifying the biological basis of neurodevelopmental disabilities

The Network's Neuroinformatics Core provides the scaffolding to hold, match and interpret the massive data sets needed to identify the role of genetics and gene expression in neurodevelopmental disabilities.

Neuroinformatics lead Dr. Paul Pavlidis, Core Manager Sanja Rogic, and former Core Manager Elodie Portales-Casamar (University of British Columbia) have led a small team with a big impact. The tools they have created and continue to develop play a pivotal role in Network research.

"The analytical expertise combined with the scientific excellence and the collegial spirit of the Neuroinformatics Core was instrumental in enabling us to rigorously explore the connection between FASD and epigenetics in the unique NeuroDevNet cohort," says Dr. Michael Kobor (University of British Columbia, BC Children's Hospital).

The research entailed a complex analysis of genetic and epigenetic material collected from cheek swabs, and a battery of neurobehavioral assessments conducted on 110 children diagnosed with FASD, or known to have a history of prenatal alcohol exposure, and compared to 96 age- and sex-matched controls aged 5-18.

"This is the first paper that takes the power of this large cohort and integrates detailed clinical observation, genetics and epigenetic data," says Dr. Elodie Portales-Casamar—co-lead with NeuroDevNet trainee Alexander Lussier on the study—submitted to *Epigenetics and Chromatin* in February 2016 and published after the time frame of this report.

The analysis involved the application of many statistical and neuroinformatics tools and techniques, including the Phenocarta gene-disease database, developed by the Neuroinformatics Core in Cycle 1 (the first five years of the Network).

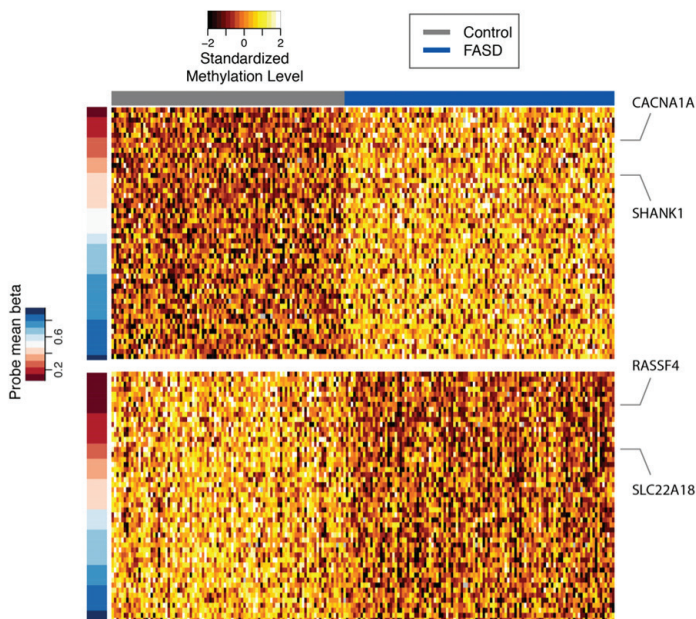
Collaboration between Neuroinformatics and the FASD research group continues, with a meta-analysis of publicly available datasets looking at gene expression in animal models of prenatal alcohol exposure (PAE). "The goal was to identify common gene expression changes that occur after PAE," says Dr. Pavlidis.

"One of the main challenges in FASD research is that molecular pathways associated with the disorder are rarely concordant across studies," adds Dr. Joanne Weinberg (University of British Columbia), NeuroDevNet's lead on FASD animal model work, and co-lead of the FASD research group.

"We're further investigating molecular pathways using animal models in work being led by PhD student Alexandre Lussier [See profile p. 35]," says Dr. Weinberg. "The Neuroinformatics Core is helping identify PAE-induced changes in gene expression common to both animal and clinical data. We're also identifying PAE-induced alterations in gene expression during early postnatal development in rat pups. We want to link our results to the important clinical observations in the collaborative work that was submitted to *Epigenetics and Chromatin*."

"I think the result of this collaboration is a wonderful example of what can be achieved when researchers from different disciplines combine forces and as such, it very much embodies the cooperative spirit of NeuroDevNet," concludes Dr. Kobor. ■

A map of up- (top) and down-methylated (bottom) parts of the genome in control (left) versus FASD (right) cases; from the journal *Epigenetics and Chromatin*.



Theme II:

Interventions

Targeting key symptoms through play, movement, stillness and sleep

Social ABCs

Starting treatment early in daily life, at the first signs of autism

A toddler is going down a slide at the playground over and over, enjoying the game. After a few minutes, an early childhood educator (ECE) gently blocks the little girl from going down the slide.

“Slide,” says the ECE worker, with a smile on her face.

“Slide,” repeats the girl, with a slight lisp. The ECE worker steps aside, and the child resumes her game.

This is Social ABCs at work, a program initially developed by Dr. Susan Bryson (Dalhousie University) and Dr. Jessica Brian (Bloorview Research Institute, University of Toronto) as a parent-delivered treatment approach for toddlers with signs of autism.

Diagnosing ASD at a very young age is challenging, and families face a number of barriers in accessing effective treatment. Social ABCs targets preschoolers waiting for diagnosis and treatment, boosting critical social and language skills in the interim.

“One of the things that we feel very strongly about is that if children can get intervention as soon as their symptoms start to appear, then we can capitalize on what we know about brain development and neuroplasticity—the brain’s ability to reorganize itself by forming new connections—to have a greater impact on their development,” says Dr. Brian.

In 2014-15, the Social ABCs was customized for Early Childhood Educators to trial in Toronto’s Humber College daycares, and was very well received. The original parent version of the program got a huge boost when it was selected by the Ontario Ministry of Children and Youth Services as one of four programs to be evaluated for potential roll-out on a province-wide basis as an early intervention for autism.



Jack and his mother participated in early research on Social ABCs.

Dr. Brian’s group partnered with Hamilton Health Sciences, McMaster University, and a range of community partners who will be learning and delivering the Social ABCs to children in the region over the next few years. NeuroDevNet funds supported the refinement of the Social ABCs training manual, and will also be leveraged to enhance the analysis of the research outcome from the Ontario evaluation.

“I’m very excited,” says Dr. Brian. “The power of this intervention is really striking—Social ABCs can make a difference.” ■

Interventions

Better Nights Better Days – Neurodevelopmental Disorders

The importance of a good night's sleep

More than 90 per cent of children with neurodevelopmental disabilities also have sleep issues. Poor sleep doesn't only affect the child—the whole family suffers. NeuroDevNet's Better Nights Better Days for Neurodevelopmental Disorders (BNBD-NDD) team is working to help them all get a good night's rest by focusing on the child.

Dr. Penny Corkum (Dalhousie University) and Dr. Shelly Weiss (University of Toronto, SickKids Hospital) co-leads of the BNBD-NDD program, are developing an Internet-based intervention to treat insomnia, the most common sleep disorder in children with autism spectrum disorders (ASD), attention-deficit/hyperactivity disorder (ADHD), fetal alcohol spectrum disorder (FASD), and cerebral palsy (CP).

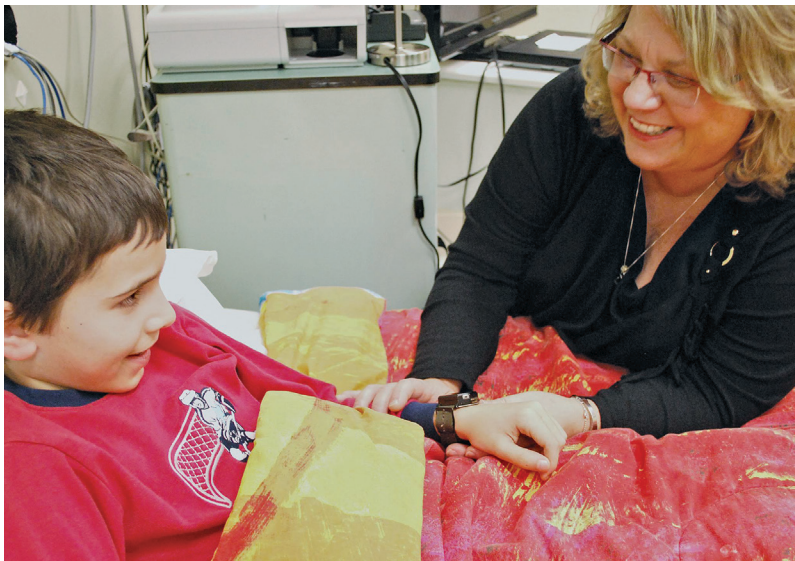
"Children with NDD's have specific challenges which affect their ability to sleep," says Dr. Weiss, noting that insomnia is defined as difficulties falling asleep, staying asleep, and waking up far too early in the morning.

The online intervention is being based on a modification of a program developed for typically developing children with sleep troubles. Parents will be able to access the multi-component, bilingual program 24/7, as long as they have Internet access. There will be modules with homework for caregivers, each one discussing a different aspect of insomnia, and how to address it.

"We're designing the intervention based on the children's challenges, rather than their diagnosis," Dr. Corkum says. "So if a child has anxiety that's interfering with their sleep, it doesn't matter if they have FASD, ADHD, CP or ASD, the parent learns how to teach a child to sleep that has a lot of anxiety."

Children's sleep and daytime functioning, as well as the effects on the wellbeing of caregivers, will be evaluated through a randomized controlled trial. If BNBD-NDD proves to be effective, the team will aim to make the program sustainable over time to help as many families as possible.

"Sleep issues take quite a toll on children and their families," says Dr. Weiss. "We're anticipating that the intervention will be successful to improve children's sleep, which will lead to improvement in daytime functions such as behavior, learning, memory, attention." ■



Dr. Penny Corkum chats with a child being monitored in her sleep lab.



Interventions

Constraint Induced Movement Therapy

What makes it work?

Exploring a popular physical CP intervention at the cellular level

Thirty years ago, the scientific community doubted a damaged brain could ever regenerate itself. Today, Dr. Derek van der Kooy and his University of Toronto team are focusing on interventions that may be key to reversing brain damage in children with cerebral palsy (CP).

“There is currently no cure for CP, and one of the primary treatments is Constraint Induced Movement Therapy (CIMT),” says Dr. van der Kooy, a neurobiologist at the University of Toronto. “We want to look at why this works, and improve its effects to boost the quality of life for children living with cerebral palsy.”

Constraint Induced Movement Therapy immobilizes the stronger limb, forcing the patient to use—and hopefully improve—function in the weaker one. Dr. van der Kooy and his team believe CIMT works by activating neural stem and progenitor cells in the brain.

Neural stem and progenitor cells are thought to produce new neurons and glial cells that could potentially regenerate the brain. The team’s goal is to test whether CIMT in a mouse model of CP stimulates these cells and causes observable recovery.

In a second project, the team will remove the neural stem and progenitor cells in the brains of mice to see if cell activation is required for the improvements seen in behaviour after CIMT—or not.

“If we remove these stem cells from the brain, the prediction is that CIMT will no longer work,” says Dr. van der Kooy, who refers to this component as ‘the heart’ of the project. “This is really an experiment that gets at causation, rather than correlation.”

The team is also exploring different ways of increasing activation of the stem and progenitor cells to encourage brain regeneration. For example, drugs such as Metformin, which is currently used to treat type II diabetes, may stimulate these cells to make new neurons, which could lead to behavioural improvements.



Constraint Induced Movement Therapy (CIMT) is offered at Holland Bloorview Kids Rehabilitation Hospital as a two-week summer camp for children aged 5-12 with hemiplegic (one-sided) cerebral palsy. Treatment involves repetitive practice with the affected arm of increasingly more difficult activities that improve motor control, strength, and sensory functioning.

Data suggests transplanting new brain cells derived from stem cells into animal brains—and eventually humans—could lead to even more improvement from CIMT intervention. Dr. Michael Fehlings (Toronto Western Hospital) is leading the project’s stem cell transplantation component, which is a long-term goal of the team.

“If we boost the number of new progenitor cells, new neurons, and new glial cells by transplanting cells into the brain, the question is can we actually improve the behaviour of kids with CP?” Dr. van der Kooy asks. “I’m very excited about the potential impact of all of these projects.” ■

Interventions

Empowering Steps Movement Therapy

Physical activity programs for children and youth with neurodevelopmental disabilities

Visit the Club Aviva gym in Coquitlam, B.C. on a weekday and you'll see a flurry of activity: elite gymnasts training for upcoming competitions alongside youth with neurodevelopmental disabilities practicing their own skills under the guidance of specially trained coaches.

Empowering Steps Movement Therapy (ESMT) is a B.C.-based structured training and treatment program for children and youth with neurodevelopmental disabilities. Dr. Jean-Paul Collet (University of British Columbia) and his team are evaluating the gymnastics-based movement program, assessing its effects as well as developing a practical framework for evaluating other holistic recreational therapies.

“Early intervention is an important point of our work, and our goal is to describe activity-based interventions,” says Dr. Collet, based at the University of British Columbia. “We are evaluating ESMT as a prototype, in order to better understand how this approach can work to improve the lives of children living with neurodevelopmental disabilities.”

Children with neurodevelopmental disabilities often have significant motor, social, and cognitive impairments. ESMT may help children and youth aged 4-19 to reach individual important goals through personalized training programs. These can range from something as simple as using the washroom independently, to participating in family hikes.

ESMT was developed by Club Aviva founder and senior manager Vivien Symington, and is run out of several other gyms in the Vancouver area—Poirier Sports and Leisure complex, and the West Vancouver Community Centre.

Twenty children are currently involved in ESMT through Club Aviva, a number Dr. Collet hopes to continuously expand. This year, the B.C. government gave the team funding to evaluate 10 other community-based sites operating other physical activity programs across the Lower Mainland.

Several programs are already involved in the study such as the Richmond Therapeutic Horse Riding, Surrey Recreational Park, West-Vancouver Recreational Park, and Soccer Dogs, as well as several programs offered by the Canuck Autism Network, the Special Olympics organization, and those organized by the Down Syndrome Research Foundation.

“Our over-arching goal is to generate evidence regarding the effects of physical activity programs and to use this data in order to inform policy makers in B.C.” adds Dr. Collet. “And to have these community-based interventions more recognized as ways to improve learning and development for children and youth with neurodevelopmental disabilities.” ■



Play with a purpose: a child works on strengthening and coordination at Club Aviva, cheered on by two coaches.

Interventions

TotTech: “Tangible, Organizing and Therapeutic Technologies to Engage Children”

Using technology to keep children and youth engaged in treatment

A teenage boy with cerebral palsy holds two glowing video game controllers, one in each hand. He waves them rhythmically, staring at a flashing computer screen as he plays a Facebook game. Suddenly the screen freezes—he forgot to keep using both hands.

“You have to exercise in a bimanual mode,” explains Dr. Mike Van der Loos, engineering professor at the University of British Columbia. “The goal is to build up the function of the weak side, and it’s much too easy for people to cheat by using their strong arm if one hand is weak and one is strong.”

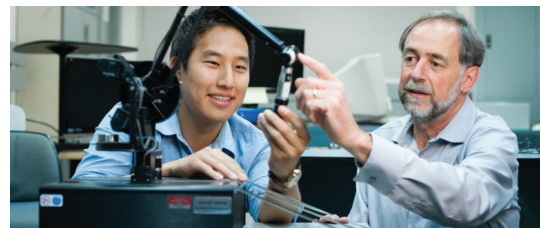
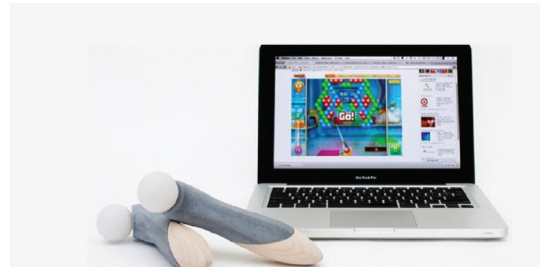
Dr. Van der Loos and his team have designed FEATHERS, or Functional Engagement in Assisted Therapy through Exercise Robotics, an upper-body rehabilitation tool for children with hemiparetic—one-sided—cerebral palsy and adults who have had a stroke. The video game project is one of two robot-based enterprises under the TotTech umbrella.

The system has been built around a multiplicity of available Facebook games, and embedded into social media to connect players with both the gaming community and their therapists—all from the comfort of their own home.

“The downfall of many home therapies is that they’re used for a couple of weeks and then put in a drawer, and people don’t do it again,” says Dr. Van der Loos. “We’re hoping that the gaming and the social media components will keep people engaged in the activity—and the kids seem to really like it so far.”

The first round of home trials were completed in December 2015, and early results are encouraging. For future trials, the team will develop games outside of Facebook, as well as offer additional technological support to the young people playing their games.

TotTech’s second project, SleepSmart, is designed to help the 90 per cent of children with neurodevelopmental disorders that also have sleep issues. [See Better Nights Better Days NDD story, p.16]



The controls and computer interface used in the FEATHERS project (top). Dr. Van der Loos and a colleague examine robotic arms that connect to the hand-held devices users wield to play videogames (below).

SleepSmart consists of a mattress topper that can measure human physiology such as breathing rate, heart rate, and restlessness, as well as the position and movement of people while they are sleeping. Unlike more intrusive sleep measurement methods, no sensors are placed on the body, and the monitoring can take place either in a clinical setting or at home.

Dr. Van der Loos and his team are collaborating with researchers at British Columbia Children’s Hospital to collect data, as well as partnering with other labs at the University of British Columbia to create a new and improved SleepSmart prototype adapted for children.

“SleepSmart will provide a new window into the relations between neurological disorders and sleep issues,” he says. “It’s really knowledge creation at this point.” ■

Interventions

MYmind

Meditating for Mindfulness

A group of teens with autism spectrum disorder (ASD) sits quietly in one room, their parents in another. As the class begins, instructors lead both cohorts through meditation exercises, breathing techniques and yoga.

The goal: to see if meditation and mindfulness can help reduce daily stressors for youth with ASD and their parents.

“We hope to be able to test whether teaching teenagers with ASD and their parents how to be more mindful can help them cope with the stressors they experience in their day-to-day lives, and hopefully improve their relationships, and help them be more independent and more mentally healthy,” says principal investigator Dr. Jonathan Weiss [York University].

Adolescents with ASD often experience issues such as aggression, stress, anxiety, and attention difficulties. Mindfulness-based therapy (MBT) can be a helpful counter



to these problems, says Dr. Weiss, and is based on Eastern meditation techniques that aim to “increase awareness of the present moment and enhance non-judgmental observation.”

The project is the first of its type in Canada, and one of the first internationally to examine mindfulness intervention in youth who have considerable emotional, social, and communication difficulties. The program is based on the parent-adolescent intervention MYmind, developed by Dutch researcher Susan Bögels at the University of Amsterdam, and the teams have been actively collaborating.

Two trials, each with nine parent-youth pairs, have been completed, and a third is set to begin January 2017. The 90-minute sessions run for nine weeks, and a booster session is offered three to six weeks after the last meeting. A full analysis of the data will be conducted after the final trial, but initial feedback from families has been very positive.

“The program has helped me maintain perspective during the ups and downs of daily life, and as a result is allowing me to more fully enjoy my days,” says a parent who participated in the trials. “It has given my child a tool to call on when he is feeling overwhelmed and something with which he can measure his own anxiety.”

“It’s inspiring to think there are programs like this that can help us get through life’s difficulties,” notes one of the youths. “It has helped me learn to be in the moment.”

“Having early intervention is always better to help build resilience and help address problems when they’re just starting,” adds Dr. Weiss. “Rather than waiting until they develop and then become hardwired, both physically and in terms of our dynamics and our behaviours.” ■



Interventions

Knowledge Translation

High impact KT planning –
“provocative, useful, and thought-provoking”

Hybrid Planning Tool

A new knowledge mobilization process is helping Network researchers experience the power and potential of a deliberate strategy for moving their findings beyond publication.

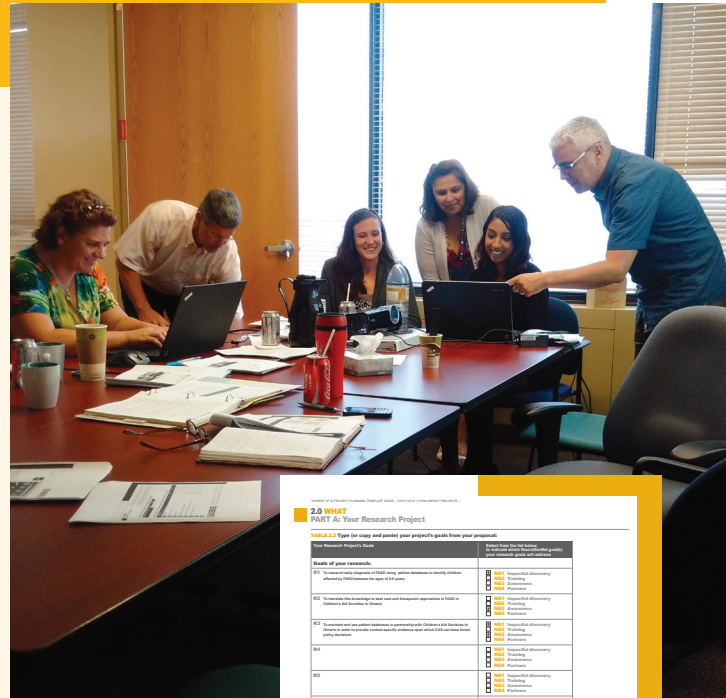
Charged with accelerating the uptake of Network research in the highest state of readiness for application in diagnostic, treatment and service-related settings, the Knowledge Translation (KT) Core has identified four projects for in-depth KT consultation.

Dubbed “High Impact Projects,” the research teams that have moved through the initial consultation include: the Social ABCs toddler intervention for children showing early signs of autism; the Liberi Exercycle, a customized exercycle that builds fitness and social engagement among youth with cerebral palsy; FASD screening and intervention project targeting very young children in care; and MYmind, a mindfulness program for youth with autism and their parents.

KT Manager Anneliese Poetz developed a comprehensive process based on a 2-5 year time frame that includes a “Hybrid KT Planning Tool”—a guide replete with examples and a fillable form for the plan itself—and an initial intensive 1.5 day consult between the research teams, Poetz and KT lead David Phipps. Follow up consists of quarterly check-ins and an annual refresh of each team’s plan.

“I think it’s great. When this whole concept of KT came out, when there was a push to do KT, I thought what is KT, and how do you add this in,” says Irene Drmic, a principal investigator on the MYmind project. “I thought KT was just about getting information out there, but it is really about making changes... It’s nice to think through it this way, because it makes your research really meaningful and it gives it new life. I am thinking of all kinds of new ideas [incorporating] things you are building in, like keeping in touch with clinicians, thinking about future research, and keeping those relationships.”

The KT Core works with members of the FASD Screening and Intervention Project on the Hybrid Planning Tool shown in the inset.



2.0 WHAT PART A: Your Research Project

What is your topic and what are your primary goals from your proposal?

What is your research goal?

Goal of your research	What is your research goal?	What is your research goal?
81. To research early diagnosis of FASD using either diagnosis in family settings or through MRI scans in a group of youth.	81	81
82. To research the knowledge, skills and resources available to children, youth and families in care.	82	82
83. To understand and explore the barriers to participation with children and families in research and to identify strategies to support their participation.	83	83
84.	84	84
85.	85	85
86.	86	86

Legend: FASD Screening, Intervention, Both, Other

Consults with the four teams took place over the summer and fall of 2015. Responses and styles of engagement among teams varied. In the end, it was a learning process, according to Poetz. “By the time we met with the fourth group, we found it was easier to meet without the planning form filled in. We were afraid to do that initially, but it was actually better to co-create the plan.”

“The information we gather with the tool provides the KT Core with the information we need to manage timelines and milestones for these KT plans during years 6-10 of the Network, and it also primes us in our work with the project teams, so that by the time we write our application for funding in years 11-15, we will have concrete examples of impact.”

“I found the Hybrid KT planning tool extremely thorough, some of the concepts were unfamiliar to me, but I actually found it incredibly helpful to think about and plan for how we are going to get to the stage of impact,” says Dr. Jessica Brian, principal investigator on the Social ABCs project. “It helped me operationalize things. We had the goals already, but it the tool helped me fine tune the steps toward getting there [the activities, steps in between to get to the big objective] it was very practical.” ■

Family Support

Working to understand perspectives of parents, children and youth—and providing support from infancy through adulthood

Fetal Alcohol Resource Program

NeuroDevNet-funded FASD project bridges the gap between families and services

Families raising children with Fetal Alcohol Spectrum Disorder often feel isolated and don't know where to find help—a challenge a new NeuroDevNet initiative is working to overcome.

"I often hear about a family that has felt isolated and lost, and really has no idea where to go to obtain the services and supports to help them and their child," says Dr. James Reynolds, the principal investigator of the FASD project who is based at Queen's University. "But what we've come to realize is that in many instances there are in fact supports available for families, but they aren't clear how to access them."

The answer to this problem is the first Fetal Alcohol Resource Program (FARP), launched in September 2015 in partnership with Citizen Advocacy Ottawa, the Children's Hospital of Eastern Ontario, the Children's Aid Society of Ottawa, and the Community Foundation of Ottawa. This collaboration brings together key community organizations and expertise from multiple sectors, such as child welfare, education, health and mental health and social justice, to coordinate service delivery for individuals and families living with FASD.

Dr. Reynolds represents NeuroDevNet as a FARP funding partner, and is also a member of the advisory committee that oversees the program. He says that one of the main goals of FARP is to maximize the efficiency of services and programs that already exist, versus reinventing the wheel.

Besides creating a list of existing services and supports, FARP has also developed workshops and training programs about how to best work with children, youth and adults with FASD. Over the past year alone they have provided 30 training workshops to over 350 individuals across multiple sectors, including health, justice, social services and education.

"We also train staff at agencies on how to recognize red flags that might indicate FASD in individuals who are undiagnosed or misdiagnosed, in order to provide FASD strategies for supports," says Nancy Lockwood, FASD Coordinator with Citizen Advocacy and FARP.

"By running these programs and offering these events we can actually improve not only access for individuals and families to services, but we can ensure that the services and supports they're going to receive are appropriate for FASD, and are of a high quality," notes Dr. Reynolds.

"Before FARP, there was this huge disconnect between what people in the FASD community knew was available and what was actually there. We're really trying to create the bridge between those two entities."

"As someone who has spent the last 15 years searching and advocating for services for individuals with FASD, I recognize that our Fetal Alcohol Resource Program was desperately needed and is already having a significant impact," says FARP's Lockwood.

"Families had been saying for years that supports did not exist in Ottawa," she adds. "The Fetal Alcohol Resource Program team has discovered that Ottawa is actually resource-rich, but too many agencies were not familiar with the unique needs of the FASD community and the best strategies for supporting individuals affected by prenatal alcohol exposure. Too many families were frustrated navigating the system, searching unassisted for FASD supports."

"It is tremendously rewarding to be part of a team working to build capacity in our community to better support individuals with FASD and their families, while increasing awareness and decreasing stigma." ■



#ConnectedCare initiative on FASD @CHEOhospital connecting hospitals all the way to Qikiqtaaluk #thinkdigitalhealth—



Fetal Alcohol Resource Program facilitators are collaborating with health professionals in hospital and community settings to ensure services meet the needs of children and adults with FASD. Left, an in-person meeting at CHEO provokes a tweet.

Family Support

ASD Voices

Understanding the perspectives of youth with autism spectrum disorders

A significant amount of research and literature has been produced on autism spectrum disorders (ASD) from an academic lens—but what about the perspectives of the youth themselves?

Collecting and understanding the lived experiences of young adults with autism is the focus of a new study, ASD Voices. Dr. Mayada Elsabbagh (McGill University), Dr. David Nicholas (University of Calgary) and Dr. Lonnie Zwaigenbaum (University of Alberta) are co-leading the project.

“The main goal of the project is to understand the perspectives of youth with ASD,” says Dr. Zwaigenbaum. “For example, what challenges do they find as they navigate high school and look towards adulthood? We want to know what it means to grow up with a diagnosis of ASD.”

Participants will be recruited from the Pathways in ASD cohort, which explores the trajectory and life course of children with autism from the time they are diagnosed onwards. The first children to join the cohort are now in their early to mid-teens. The researchers plan to recruit 15 to 20 participants at each of the two study sites in Montreal and Edmonton, and the plan is to extend the work to the other three Canadian sites of the Pathways study.

One of the goals of ASD Voices is to share the collected stories with the public, giving participants a platform to voice their priorities and opinions. A percentage of youth with autism are either minimally verbal or non-verbal, so a variety of data collection approaches will be explored as ways of better understanding the experiences of these youth. These include photography, drawing, and traditional oral interview techniques.

“For too long, the research community has under-addressed a careful examination of what really matters to children and youth with ASD and their families,” says Dr. Nicholas. “Examining their experiences is so important. The disability movement strongly upholds notions of engagement of communities, which includes intentionally seeking first-hand perspectives and priorities of the ASD community. This project is an important step forward.”



“We’re hoping to develop some vignettes using multimedia as a way of sharing the voices of the participants with a broader audience,” says Dr. Zwaigenbaum, noting that the team is being cautious to make sure they aren’t imposing their own assumptions and biases on how that type of information is interpreted.

“We want something that could be shared with the public and policy makers to give a voice to these young people beyond the clinic and the research.”

This is the first time a study of this nature is being conducted with youth living with autism, adds Dr. Zwaigenbaum, who is anticipating considerable variety in terms of experience and perceptions.

“It’s a bit sobering to realize how little work has been done in this area up until now,” he says. “I think we’ll find that young people with autism have a lot of the same hopes and dreams as other young people, but maybe a unique way of seeing their strengths and seeing the path forward. We genuinely want to learn what these youth have to say.” ■

Family Support

Strongest Families FASD

Adapting a successful behavioral support program for use in an Aboriginal community

What if there was a way for Canadian families raising children with Fetal Alcohol Spectrum Disorder (FASD) to access extensive support, without having to leave home?

Accessibility is a primary value of the Strongest Families FASD project, a study featuring an Internet-based program for the families of youth between the ages of 4 to 12 living with FASD.

“The intervention can be accessed anywhere in Canada from one central site,” says Dr. James Reynolds, principal investigator of the FASD project, who is based at Queen’s University. “Right now we’re getting very, very positive feedback from the families that are a part of the program.”

“Thank you so much for all the amazing support over the past weeks. We thought we had a good set of skills raising our daughter with FASD but this program really solidified our skills and gave us the consistent language we were needing to make a difference. Thank you!! I hope that the outcome of this study is a positive step in changing the view of FASD and how to work with these kids!”

- Parent participant in Strongest Families

Patrick McGrath, a Network investigator at the IWK Health Centre in Halifax, leads the project with Dr. Reynolds. The program’s coaches are all located at the IWK, but families as far away as B.C. and the Yukon are participating in the study. Behavioural support is provided via telephone sessions with trained coaches, and concepts and strategies are reviewed through video and audiotapes, as well as written manuals.

The project has already been running for several years, adds Dr. Reynolds, noting that the first clinical trials are coming to an end and an evaluation phase is set for the end of 2016.

The team is currently adapting the original Strongest Families project for First Nations communities. Dr. Chris Mushquash of Lakehead University will lead the initiative, and is collaborating with Dilico Anishinabek Family Care, as well as a community-based research advisory group.

First Nations communities have unique needs that the team is working to reflect in this project, says Dr. Reynolds, noting that building trust and deepening relationships is the current priority.

“Helping each individual child to achieve his or her maximum potential is what gets me up in the morning,” said Dr. Reynolds. “I think our project has been successful because of the openness of the group to think about new activities and explore new ideas.” ■



Family Support

“I never realized that as a parent I could make a difference. This group has given me the hope and proof that I can.”

– Parent participant

CanChild Family Engagement

Bridging the communication gap between researchers and families

Research in early diagnosis and treatment of neurodevelopmental disabilities has more impact when families, children and youth inform studies from concept through execution, uptake and rollout of findings in the form of programs, policies and services.

These central tenets of knowledge mobilization are a cornerstone of the family-researcher partnership CanChild promotes on behalf of NeuroDevNet as one of the Network’s knowledge translation initiatives. “We’re engaging with families and gathering knowledge with the aim of transforming lives,” says Dr. Jan Willem Gorter, Director of CanChild.

Bridging the communication gap and overcoming the perceived differences in relative power and knowledge that can exist between the scientific community and people raising children with neurodevelopmental disabilities takes place through individual research studies, Family Engagement Days and a closed and moderated Facebook group, *Parents Participating in Research*.

By March 2016, preparations were well underway for the April event titled “Opening doors to family-research partnerships today for a brighter tomorrow!” The event aimed at drawing families, children, youth, students, service providers and researchers from the Hamilton region and Greater Toronto Area for a day of collaboration, discussion, and fun. “The first step to research partnerships is building relationships. Our goal with the family engagement day is to provide a platform for families and researchers to initiate conversations and begin building relationships that will extend well beyond the day’s events,” says Andrea Cross, family engagement officer for CanChild.

Topics set for exploration between researchers and stakeholders include challenges and opportunities in family-research partnerships, physical activity for children with disabilities, transition to the workforce, and inclusive classrooms.

A second CanChild initiative, the *Parents Participating in Research* Facebook group, includes parents of children

with disabilities, youth and adults with disabilities, researchers and students. Led and moderated by two parents, the group has grown organically since its creation.

“I am both proud and humbled by the partnership we have created. Vibrant conversations erupt on a daily basis, from all directions and no topic is off limits. We bring forward issues that we face through all stages of life,” says Jenn Sprung, parent and facilitator of the Facebook group.



Facebook heading for the Parents Participating in Research Group

“The online community has been very positive for parents,” says Rachel Teplicky, Research Coordinator for CanChild. “Parents have found the community to be very respectful and supportive, and as such, have been very open. Researchers are beginning to find their voice, as well, which requires a balance of personal and professional communication.”

“I was not aware of the impact of the daily struggles that disabilities can have in the life of families,” observes a researcher participant. “Many of the topics brought up in the group have not been brought up in the same way in clinical encounters.”

The next step for the group is to create more opportunities for real-time online engagement (co-leading webinars and online discussions) and to move forward on some of the joint ideas that have emerged through the Facebook group discussion. “As we move forward with the group, I’m very excited with the level of commitment from parents and researchers,” adds Parent Facilitator Jenn Sprung. “Collaborating with CanChild has been a fantastic experience with true engagement. We have barely scratched the surface of what we can do together!” ■

Family Support



Neuroethics

ouR-HOPE: A reconsideration of ethics and sensitivity in sharing clinical predictions with parents

When a newborn baby is diagnosed with an acute brain injury, parents are often in shock.

They are also compelled to actively participate in decision making about the medical care of their infant at a time when they feel least prepared to evaluate their choices, and their longer-term impacts.

"I remember the doctor telling us, 'Your son has a serious brain injury. He has CP, mental retardation or both. He will never be normal.' I felt an other-worldly combination of relief, confusion and shock. I remember thinking, 'If there is a diagnosis here, I can learn about it. I can beat this through the power of my love and my will.' But then I realized that I knew nothing about medicine, disability or treatment. And I knew nothing about my son. He wasn't the baby I thought he was and in the weeks after the diagnosis, I gazed at him with an overwhelming sense of love and fear."

– Donna Thomson, NeuroDevNet Board Member, and mother of Nick, now 28.

At the same time, the clinicians sharing diagnoses and predicted outcomes with the parents must take what is known about the nature and impact of the injury in order to offer opinions and recommend services. They must do this, says Neuroethics Co-lead Dr. Eric Racine (Université de Montréal, Institute de Recherches Cliniques de Montréal), while faced with a significant amount of uncertainty.

"Although the science of neurological prognosis is progressing," says Racine, "with the discovery of new biomarkers, factors including neuronal plasticity [the capacity of the brain to remodel itself and recover function], the socioeconomic status of the family, parental involvement, access to specialized care, and the psychological state of both child and the family also affect outcomes."

"Will my child ever be happy?"

Parents' questions don't tend to approximate well with medical terminology when talking about what to expect.

"In the period after diagnosis, parents are in shock," says Thomson. "I think the first question they have, which is difficult to voice, is 'can I love my baby?' I think it's a deeply human question for parents to ask themselves because suddenly they feel they may not have the knowledge or skills to care competently for a complex infant. Parents need a lot of reassurance that they can love and care for their baby. Soon, questions become centred on their child's future. 'Will my child survive?' becomes 'Will my child be happy? Will my child be able to learn at school? Will he work and have a family?' These are the questions that are crucial for families, and doctors must address them with great compassion and kindness."

Recognizing the real need for improvement in these predictive interactions between the various specialists who oversee neurologically compromised infants and their parents, the Neuroethics Core convened a task force. "Ethics and communication of neurological prognosis" was the brainchild of Dr. Racine, and colleague Dr. Emily Bell. Participants included pediatric neonatologists and neurologists, parents of children with brain injury, and bioethicists.

Together with an advisory committee, the group followed a process set out by the American Academy of Neurology and the Society for Adolescent Health and Medicine with the intention of generating a position paper. "We are not proposing to provide a complete resolution to specific and explicit dilemmas," says Dr. Racine, "but rather to offer a set of reflections and questions to encourage clinicians to assess their own practice in light of a set of recommended attitudes and behaviours we have identified as being helpful."

The approach, known by the acronym ouR-HOPE, will be articulated in a position paper to be published in late 2016.

"It's not an exaggeration to say parents are dealing with an extremely stressful situation, having to make decisions about things they will live with and reflect on the rest of their lives. Our hope, in producing a position paper, is to support ethical communication and decision making and help align clinical practices with ethical principles and human values." ■

Social Determinants of Health and Health Economics Program

Discovering the reality of Canadian families raising children with neurodevelopmental disabilities through a socio-economic lens

What would it look like if Canadian society committed to ensuring every family raising a child with a neurodevelopmental disability had access to the right kind of supports and programs, at the right time, in a way that maximized quality of life for all concerned?

“How would we know that we had successfully achieved that noble goal,” wonders Dr. Lucyna Lach (McGill University). “How would we know what it would cost, in the short and longer term? Will there be cost savings to the health system and society, and bigger problems down the road prevented by addressing them earlier?”

The new Social Determinants of Health – Health Economics (SDOH-HE) Program is setting out to document the lives of children with neurodevelopmental disabilities in Canada, using a socio-economic lens. The group’s goal is to ascertain the impact our health and social programs are making in the lives of families raising children with neurodevelopmental disabilities.

Along the way, says Dr. Lach, co-lead of the Social Determinants Research group with Dr. David Nicholas (University of Calgary), they expect to answer some essential questions, such as: how many Canadian children are living with a brain-based disability? What do their families look like, compared to families raising children without disabilities? What is the impact of support on these families?

continued on next page



Social Determinants of Health and Health Economics Program

continued from previous page

“We’re trying to look at a baseline, so we can document the impact of the Network’s research,” says Dr. Herb Emery [University of Calgary], co-lead, along with Dr. Jen Zwicker [University of Calgary], of the Health Economics team.

One of NeuroDevNet’s core objectives is pushing the capacity of health and social care systems to identify neurodevelopmental issues earlier in children’s lives. But translating the value of an FASD diagnosis made at age 5 instead of 15 into a measurable change in quality of life is currently a challenge, and only one example.

“If we can assess the benefits a child experiences because of early identification, we can also begin to quantify the socio-economic impact,” says Dr. Lach. “This will help advocates provide policy makers with evidence they can use to make decisions about allocation of scarce health and community care dollars.”

Yet, these researchers face a fundamental challenge because of tremendous discrepancies in how children with neurodevelopmental disabilities are counted in Canada. “Not much is known about the social conditions in which they’re growing up,” says Dr. Nicholas. “Are they being raised by a single parent, two parents or other caregiving arrangements? What are trends related to these families’ income and costs? How and when are they accessing and using health and social services?”

“These are the really basic things we can’t currently articulate,” observes Dr. Lach, whose work in the social determinants of health with Dr. Nicholas focuses on analyzing patterns of—and barriers to—appropriate diagnosis and care.

Collectively, the interdisciplinary SDOH-HE research team is comprised of 24 researchers and stakeholders across the country. Currently in a discovery phase, the team is gathering and analyzing federal and provincial population-level data, as well as clinical data sets, to learn more about these children and their families, in addition to conducting interviews to learn more about their lived reality.

“Social support and timely access to health and social services are key SDOH,” says Dr. Lach. “We need to better understand what type of support is needed at different times in a child’s life, and then, we can begin to design supports that are informed by what they and their parents tell us.” [See ASD Voices story, p.23] ■

Health Economics focuses on the challenges of measurement

The SDOH-HE health economics team is collaborating with programs and projects within the Network, exploring how best to measure and/or demonstrate socioeconomic value of innovative interventions. Insights have come from many of these encounters. For example, the Social ABCs, a project that encourages toddlers showing early signs of autism in developing speech and social awareness skills [See Interventions, p.15] had as an outcome a shared smile between a child and a parent.

“It seemed like a small thing—how could a shared smile can be an important benefit,” reflects Emery. “But when we talked to parents of children with autism, it turns out that is actually really important. Yet, how do you translate that outcome into a socio-economic value?”

“That smile is just one aspect of quality of life,” adds Dr. Zwicker. Existing quality of life scales are a well-established method for measuring impacts of treatment as experienced by individuals, yet when used with children, individual differences in verbal and intellectual capacity may make describing changes they experience challenging, or even



Social Determinants of Health and Health Economics Program



impossible. “So a lot of what we’ve been pushing forward with is trying to understand the family’s perspective on what counts in economic evaluation,” says Zwicker.

“From a provincial payer perspective, we can identify how much an intervention costs, and the outcomes of those interventions,” she adds. “Looking at outcomes from a family’s perspective—or from a societal perspective—it’s obviously much harder to capture that information. At this point, we don’t know enough about non-medical kinds of costs. With short-term interventions, you often only measure outcomes for the child. What are the benefits for the parents, the siblings, and for the family? What are the unmet needs of children with neurodevelopmental disabilities and their families? We’re trying to match up how well research is meeting those needs.”

In health economics, Zwicker continues, measuring quality of life involves weighing preferences for one outcome over another, while a social determinants of health perspective takes a broader and more descriptive approach. “That is what is particularly unique about this interdisciplinary team. We each bring our own lens to the table, and give a broader perspective on the needs of families,” says Zwicker.

Increasing focus on functional capacity as well as diagnosis

Researchers within the Network are applying a non-categorical approach and paying attention to functioning alongside a child’s diagnosed health condition.

“Rather than focusing on one particular diagnostic group, we’re considering what is shared between diagnoses— impairments in mobility, cognition and expressive language cut across diagnostic categories,” observes Dr. Lach.

“At the same time, there is tremendous variability in children’s functional capacities within disabilities such as autism, FASD, and cerebral palsy,” she adds. “For example, if one child has autism and severe cognitive impairment, and another child has cerebral palsy and severe cognitive impairment, the diagnosis may not be what matters so much. Rather, it’s the cognitive impairment that informs what that child’s life is like—and what that family’s life is like.”

Similar considerations apply to behaviours in children diagnosed with neurodevelopmental disabilities—particularly difficult-to-manage behaviours, points out NeuroDevNet Investigator Dr. Anton Miller (University of British Columbia, Child and Family Research Institute), who is currently doing research in this area.

“It’s often difficult behaviours that affect quality of life for these families,” adds Dr. Miller. “Research within condition-specific silos obscures the rich lessons to be learned about the nature of neurodevelopmental disabilities as lived in everyday life, when we look more broadly across diagnosis types.”

This shift in emphasis aligns with what Dr. Miller and his co-author Dr. Peter Rosenbaum refer to as a much-needed recalibration of what they call disease and disability perspectives in child health in a forthcoming paper. “Attention to a child’s functional characteristics, including behaviours, and the contextual factors that affect them, lie at the heart of the disability perspective,” reflects Dr. Miller.

NeuroDevNet's National Training Program

Developing the next generation of leaders in developmental neurosciences

As part of our renewal process NeuroDevNet has emphasized expansion and enrichment of our National Training Program in Developmental Neurosciences. This year, we launched a new Fellowship/Studentship trainee support initiative in partnership with Brain Canada and institutions across Canada. We also offered career development and capacity-building training and knowledge translation events aimed at enhancing trainees' knowledge base across a wide range of neurodevelopmental disabilities.

NeuroDevNet 102

Early 2016 saw the launch of the Network's second distance learning webinar series, "Perspectives on Research in Neurodevelopmental Disorders."

The twenty-week course targeted a broad range of issues and themes surrounding neurodevelopmental disorders and their presentation, engaging 32 of Canada's top graduate students and post-doctoral fellows in a novel exploration of stakeholder perspectives.

"I thought the idea of breaking the class into various stakeholder groups was a novel way to engage the class and think about the course through a different lens."
- participant

Building on the lessons and successes of its predecessor NeuroDevNet 101, topics in the new course ranged from assessment and diagnosis to the potential to reverse neurodevelopmental disorders.

"I really enjoyed being able to learn about different research through the webinars as it provided me with a designated time to learn about new material and areas of interest."
- participant

Ten bi-weekly sessions offered lectures from experts in the field of neurodevelopmental disorders, complemented by in-depth discussion periods and group activities to further explore each week's theme. Structured with an emphasis on collaboration, perspective taking, and knowledge creation, NDN 102 encouraged the development of a shared vocabulary derived from clinical and basic sciences among its students.

"Coming from a basic science background, my previous graduate training did not emphasize the importance of stakeholder perspectives and knowledge translation, when defining the field of neurodevelopmental disorders. As a result, NDN102 was a perfect stepping stone to gain such knowledge."
- participant

As a key element in the new national training program in developmental neurosciences, this supplemental course aimed to improve understanding of trends and issues as well as explore ways in which more effective treatments for neurodevelopmental disabilities can contribute to the well-being of children and their families, in addition to enhancing the research community as a whole.

"Overall, I am confident that the skills, perspectives, and knowledge I have developed and gained during the course will be beneficial for my PhD research, given that I will be working with families of children at risk for autism. I will not only have a shared understanding of the issues and concerns parents and/or children may possess when going through the process of autism diagnosis, but also a greater ability to empathize and facilitate dialogue with these families."
- participant



NeuroDevNet's National Training Program

Brain Canada - NeuroDevNet Developmental Neurosciences Research Training Awards

NeuroDevNet and Brain Canada are cultivating interest in neurodevelopmental disabilities among Canada's top neuroscience trainees through an innovative fellowship program.

An exceptional partnership between the two organizations and post-graduate institutions across Canada produced a highly competitive awards competition that attracted more than 60 applicants from a broad range of disciplines. Just 17 graduate students and post-doctoral fellows—"the elite of the elite," according to Research and Training Manager Dr. Doug Swanson, were awarded a two-year fellowship.

"The applicants were top-level candidates with well-designed proposals from research areas across the developmental neurosciences," adds Dr. Swanson. Original proposals submitted by candidates target the origins, early detection and treatment of disorders in brain development.

"The fellowships are one of the pillars of NeuroDevNet's new national training program," says Network Scientific Director Dr. Daniel Goldowitz. Partnerships with the nine Canadian research institutions and academic programs that host the awardees brought \$1.51M in new funds to support developmental neuroscience training.

"We're very pleased that through agreements between these institutions, NeuroDevNet and Brain Canada, we are able to enhance career development for this exceptional group of young researchers," adds Dr. Goldowitz.

"Our hope is that beyond their own research, exposure to our NeuroDevNet 102 course and the Winter Institute will encourage ongoing interest in neurodevelopmental disabilities," says Dr. Swanson. [See stories about NeuroDevNet 102 p.30 and Winter Institute p.42]



Brain Canada



In their first year as Brain Canada fellows, continues Swanson, "the awardees have stepped up to leadership opportunities in our trainee advisory committee and the trainee policy and advocacy committee."

Twenty-eight institutions indicated interest in participating in the Brain Canada-NeuroDevNet fellowship program. Partner institutions support half the cost of studentships valued at up to \$30,000 per year for a maximum funding term of two years, and postdoctoral fellowships valued at up to \$50,000 per year for a maximum funding term of two years.

Recipients list of the inaugural Brain Canada-NeuroDevNet Studentships begins on the next page.

NeuroDevNet's National Training Program

Brain Canada - NeuroDevNet Developmental Neurosciences Research Training Awards

POST-DOCTORAL FELLOWS

Name: Kristin Kernohan
Mentor: Kym Boycott
Institution: Children's Hospital of Eastern Ontario (CHEO) Research Institute
Project Title: *Application of RNA sequencing to elucidate disease etiology of novel rare neuro-developmental disorders*

Name: Kamila Szulc
Mentor: Donald J. Mabbott
Institution: The Hospital for Sick Children
Project Title: *Recruitment of endogenous neural stem cells to promote brain repair following acquired brain injury in children*

Name: Yicheng Xie
Mentor: Ann Marie Craig
Institution: Brain Research Centre, University of British Columbia
Project Title: *In vitro and in vivo functional assessment of neuropsychiatric disease-related synaptic gene mutations*

Name: Regula Neuenschwander
Mentor: Tim Oberlander
Institution: Child and Family Research Institute
Project Title: *Developmental origins of stress and self regulation and implications for interventions to improve childhood behavior*

Name: Jelena Popic
Mentor: Nahum Sonenberg
Institution: McGill University
Project Title: *Impaired translational regulation of brain development in autism spectrum disorders*

Name: Rebecca Merkley
Mentor: Daniel Ansari
Institution: University of Western Ontario
Project Title: *Uncovering early neurocognitive risk factors for mathematical learning disorders*

Name: Sarah Hutchison
Mentor: Louise Mâsse and Tim Oberlander
Institution: Child and Family Research Institute
Project Title: *Prenatal serotonin reuptake inhibitor (SRI) antidepressant exposure on brain development, cognition and activity related risk for obesity: A longitudinal study with 10 year olds*

Name: Laura Donovan
Mentor: Michael D. Taylor
Institution: The Hospital for Sick Children
Project Title: *Immunotherapy as a targeted low-impact treatment of paediatric brain cancers*

Name: Trish Domi
Mentor: Andrea Kassner
Institution: The Hospital for Sick Children
Project Title: *Investigating blood brain barrier permeability in an experimental model of juvenile stroke using advanced MR imaging*

Brain Canada Fellows meet for the first time as a group



NeuroDevNet's National Training Program

Brain Canada - NeuroDevNet Developmental Neurosciences Research Training Awards

DOCTORAL STUDENTS

Name: Emily Bremer
Mentor: John Cairney
Institution: McMaster University
Project Title: *Movement skills, physical health, and behaviour in children with autism spectrum disorder*

Name: Alexandre Lussier
Mentor: Michael Kobor
Institution: Child and Family Research Institute
Project Title: *DNA methylation signatures in a rat model of Fetal Alcohol Spectrum Disorder*

Name: Andrea Constantinof
Mentor: Steven Matthews
Institution: University of Toronto
Project Title: *The effects of glucocorticoids on the developing brain*

Name: Graham Little
Mentor: Christian Beaulieu
Institution: University of Alberta
Project Title: *Combined analysis of brain magnetic resonance images towards patient specific diagnosis of Fetal Alcohol Spectrum Disorder*

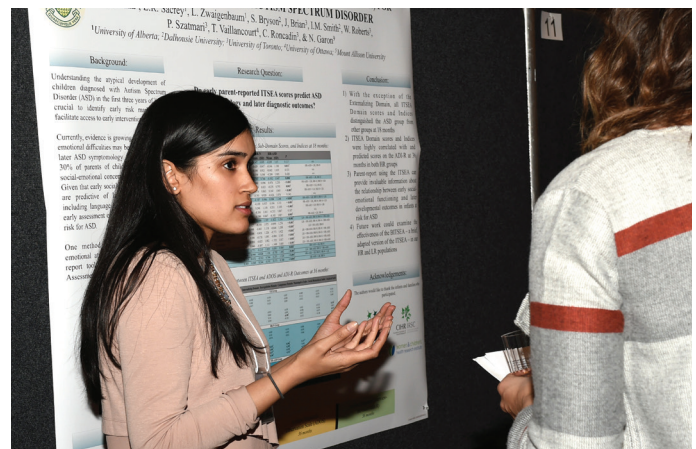
Name: Sara Izadi-Najafabadi
Mentor: Jill Zwicker
Institution: Child and Family Research Institute
Project Title: *Does rehabilitation improve brain structure/function and motor outcomes of children with developmental coordination disorder?*

Name: Sarah Raza
Mentor: Lonnie Zwaigenbaum
Institution: University of Alberta
Project Title: *The role of attention control and emotional regulation in the emergence of autism spectrum disorder (ASD): Identifying early behavioral markers of ASD in at-risk infants*

Name: Kathryn Post
Mentor: Kurt Haas
Institution: Brain Research Centre, University of British Columbia
Project Title: *A multi-platform approach to the functional assessment of ASD gene variants*

Name: Lawrence Chen
Mentor: Michael Meaney
Institution: McGill University
Project Title: *Maternal care and child neurodevelopment: A longitudinal gene x environment analysis of socio-emotional development with an integrated approach*

Sarah Raza, Brain Canada Fellowship doctoral award recipient, explaining her research in autism.



Meet our Trainees

The three trainees portrayed here all work within NeuroDevNet-supported research programs. They are active members of our trainee network, along with nearly 300 master's, doctoral, and postdoctoral trainees—the lifeblood of the Network. Their accomplishments over the past year are positioning them for future leadership in developmental neuroscience. We share their stories in order to highlight the high caliber and breadth of trainees within NeuroDevNet, whose growing expertise ranges from basic science/genetics to community based interventions, to the socio-economic impacts of Network research.

Carmela Paolozza, Master's student

When Carmela Paolozza joined NeuroDevNet as a trainee, she brought with her an unusual opportunity. Before starting a Master's degree in neuroscience at Queen's University, Paolozza had been employed as a member of the Infant Mental Health Promotion program at the Hospital for Sick Children in Toronto, where she worked on programs aimed at improving outcomes for high-risk populations. That connection provided the basis for the new FASD Research Program project focusing on screening infants in care. [See story, p.22]

Paolozza's research under the mentorship of NeuroDevNet's Deputy Scientific Director Dr. James Reynolds and Dr. Chaya Kulkarni [SickKids Hospital] focuses on the impact of prenatal alcohol exposure on the brain development of infants and toddlers in care, with an emphasis on determining if early intervention improves outcomes for these children.

With ten years' experience working with children and their families in a professional capacity, "my research project has such deep meaning for me," says Paolozza.

Paolozza first became acquainted with NeuroDevNet through a family connection, as her sister, Dr. Angelina Paolozza (now working on a post-doc at the University of Toronto), was a trainee working with Reynolds on the FASD Research Group's eye tracking project. Since then, Carmela and Angelina have collaborated on one eye tracking project, and Carmela was funded by a Mitacs internship to develop eye tracking protocols that she is currently using with infants in the child welfare system. Carmela has also been involved in numerous Network conferences, meetings, and training opportunities, most recently participating in the "NeuroDevNet 102: New Perspectives on Research in Neurodevelopmental Disorders" course. [See story, p.30]



Learning to use the eye tracker.

"Being a trainee is not only informative and exciting, but it's also fun," says Paolozza. "Through my involvement with the Network over the last two years, I've had the chance to meet students and professionals in my field that I never would have met otherwise." ■

Meet our Trainees



Alexandre Lussier, PhD candidate

Alexandre Lussier wasn't always planning to study the effects of prenatal alcohol exposure on the developing brain. After graduating with a degree in biochemistry from Montreal's McGill University in 2012, he was on the verge of entering the cancer research track.

Yet when he was offered a position in the labs of Drs. Joanne Weinberg and Michael S. Kobor at the University of British Columbia analyzing the effects of prenatal alcohol exposure on the developing brain using a rat model of FASD, Lussier jumped at the chance.

"I thought this was a wonderful opportunity to perform more applicable and translational research, so I seized it," Lussier says, noting that NeuroDevNet currently funds the vast majority of his research. "When I complete my PhD, I aim to become a clinician scientist, leaning towards pediatrics and research on neurodevelopmental disorders."

Lussier has participated in many aspects of the NeuroDevNet trainee experience, such as presenting posters at the Brain Development conference for the last three years, attending the bi-annual Winter Institute, participating in the NeuroDevNet 102 course, and serving as a member of the Trainee Advisory Committee and the Research Training Committee. He was also a recipient of the new and highly competitive Developmental Neurosciences Research Training Award from Brain Canada and NeuroDevNet.

"NeuroDevNet has helped focus my career goals and given me some of the tools necessary to reach them," says Lussier. "I am tremendously grateful for the opportunities NeuroDevNet has given me to succeed, and the personal connections I have formed through my involvement in the Network." ■



Jennifer Zwicker, MPP, PhD

Dr. Jennifer Zwicker is a rising star working in a unique niche: her innovative work focuses on the socioeconomic impact of neurodevelopmental disability research and interventions as a means for informing evidence-based policy development.

A freshly minted PhD in neurophysiology at the University of Alberta when she joined the Network, Dr. Zwicker also holds a Master's in Public Policy from the University of Calgary. Now the manager of the Health Economics component of the Social Determinants of Health Program-Health Economics Program within the Network, her interest in research and an academic career was enkindled by participation as an undergraduate in Alberta Innovates Health Solutions' summer youth research program.

As a doctoral student in neurophysiology, Dr. Zwicker's research focused on the developing brain's control of breathing. This background, combined with experiences in leadership, science outreach and policy development all contribute to her expanding role within the SDOH-HE program. Together with Dr. Herb Emery, she successfully proposed the inclusion of health economics in NeuroDevNet's renewal application, as well as in the new CHILD-BRIGHT patient-oriented research program, in which the Network is a partner.

As a mentor/advisor to the Trainee Policy Advocacy Committee, Dr. Zwicker brings practical experience and a pragmatic approach. "Policy development doesn't occur in isolation," she reflects, "It's through leadership, informed by collaboration and consultation with the neurodevelopmental disability and pediatric rehabilitation communities that NeuroDevNet is going to have impact."

Being part of the Network, and connected to its diverse community of investigators benefits her work, and enriches NeuroDevNet's cultivation of the next generation of leaders in developmental neurosciences, she says. "NeuroDevNet provides expanded opportunities for trainees and puts resources into supporting academics working to improve the quality of life for those with neurodevelopmental disability and their families—that's really essential." ■

ASD Research Group Accolades

Leading a group of international experts, Dr. Lonnie Zwaigenbaum and colleagues made headlines this year as three of his team's publications received international accolades. A series of best practice reviews on the early identification, screening, and intervention of Autism Spectrum Disorder (ASD), the studies were included among the US Federal Interagency Coordinating Committee's list of the leading 20 research advances in the area of ASD in 2015.

Dr. Zwaigenbaum, along with Drs. Stephen Scherer, Stelios Georgiadis and Jonathan Weiss, has also been selected to head the National Autism Project, a national advisory committee convened by the Public Health Agency of Canada (PHAC), and the Canadian ASD Alliance (CASDA). The Project team will develop a national strategy for inter-sectoral and inter-provincial collaboration on complex issues that impact on the lives of people living with ASD. ■

Dan Goldowitz awarded prestigious Hannah professorship at Michigan State

NeuroDevNet Scientific Director Dr. Dan Goldowitz was renewed as a Tier 1 Canada Research Chair (CRC) in Developmental Neurogenetics. One of only 150 new and renewed research chairs announced in April of 2015, Dr. Goldowitz's chair was funded as part of a \$139 million federal investment in the CRC program to promote innovation in research and discovery.

Eleven months later, while on a sabbatical focusing on child development in an urban setting cultivation of national and international linkages to support the Network, Dr. Goldowitz was appointed Visiting Hannah Distinguished Professor at Michigan State University.



The Hannah professorship is Michigan State's most prestigious faculty award, recognizing Dr. Goldowitz's contribution to the structuring of a new MSU research program focusing on autism, intellectual and neurodevelopmental disabilities. ■

CHILD-BRIGHT initiative in patient-facing research funded

Scientific Director Dr. Dan Goldowitz, NeuroDevNet investigators, stakeholders and staff joined forces to make a successful application for the 2015 Strategy for Patient-Oriented Research (SPOR) competition. A \$25M, five-year CIHR/partner-matched grant will establish the Child Health Innovations Limiting Disability – Brain Research Improving Growth and Healthy Trajectories (CHILD-BRIGHT) network. Headed by NeuroDevNet Principal Investigator Dr. Annette Majnemer and based at McGill University, and co-directed by BC Children's Hospital and SickKids, CHILD-BRIGHT will include a patient-oriented research program, a citizen engagement program, and knowledge translation and training initiatives in order to develop new therapies and better services to promote the healthy development of children with these disabilities.

"The CHILD-BRIGHT Network will bring together Children's Hospitals and their Foundations across Canada to embark on a transformational journey to improve the care of premature infants at risk, provide evidence-based interventions to improve outcomes and the quality of life in children with neurodevelopmental disabilities and work throughout the developmental years to help families navigate the care system at key points in their child's or youth's life trajectories," says Dr. Dan Goldowitz, co-director of the initiative. Dr. Stephen Miller, also a NeuroDevNet investigator, is co-director of CHILD-BRIGHT.

"A key ingredient to the success of CHILD-BRIGHT is the active engagement and participation of patients and families, healthcare providers, policymakers and health decision-makers, together with the researchers in all facets of our research program as well as sharing our knowledge and our findings to the right target audiences," says Dr. Majnemer. ■



Kudos

Jill Zwicker receives CIHR New Investigator Award

Dr. Jill Zwicker was awarded a 2015 CIHR New Investigator Award to support her ongoing research on the understanding and rehabilitation of children with Developmental Coordination Disorder (DCD).

A condition characterized by difficulties with movement and coordination that significantly impact children's abilities to perform and participate in activities of daily life, DCD is a life-long disorder affecting motor abilities and coordination of affected individuals, often leading to difficulties in school, interpersonal relationships, and leisure activities. The disorder affects 5-6% of Canadian school-aged children who often feel anxious, lonely and depressed because of their challenges.

Zwicker's proposed study will rely on neuroimaging to compare the brains of children with DCD and ADHD, which affects up to 50 percent of children diagnosed with coordination issues. Brain images of affected children and typically-developing controls will be compared to determine if rehabilitation can improve their motor functioning and evoke changes in the brain.

Dr. Zwicker, a former NeuroDevNet post-doctoral fellow, was one of only 40 investigators to receive the highly-competitive new investigator funding. Her five year grant of \$300,000 will also help translate insights from neuroimaging into improved treatment approaches for children living with DCD.

"I am honoured to receive this award, said Zwicker, "not only to be recognized nationally as a promising early career investigator, but more importantly that my research aimed at improving outcomes for children with developmental coordination disorder is worthy of national funding." ■



David Phipps awarded Association of Commonwealth Universities fellowship

Dr. David Phipps, NeuroDevNet Knowledge Translation Lead and Executive Director of Research and Innovation Services at York University, was awarded a fellowship from the Association of Commonwealth Universities (ACU) in the Fall of 2015. The Gordon and Jean Southam Fellowship supports the interchange of people, knowledge, skills and technologies globally. Phipps says of the December 2015 award ceremony at Coventry University that the fellowship "has allowed me to work with colleagues in the UK to develop some unique perspectives on knowledge brokering and research impact."

In addition to his Fellowship, Phipps was one of two senior research administrators at York University to receive recognition from the Canadian Association of Research Administrators (CARA) in May 2015. Dr. Phipps was presented with the Research Management Excellence Award, in recognition of his work in knowledge mobilization and the implementation of Canada's controlled goods legislation. The CARA prize is given to an exceptional research manager who has made outstanding contributions to the profession both nationally and internationally, through innovation, creativity, hard work and dedication.

"David's work across Canada in these two distinct areas has helped to increase York's international recognition for innovation in research services," says Robert Haché, vice-president of research and innovation at York University. "David is most deserving of this award from Canada's research administration community." ■



James Reynolds appointed Deputy Scientific Director

FASD Research Group Co-Lead Dr. James Reynolds has been appointed Deputy Scientific Director of the Network, working alongside Scientific Director Dr. Dan Goldowitz. The Network's Board of Directors encouraged Dr. Goldowitz to appoint a Deputy Director to help promote greater emphasis on translating research and encouraging uptake in clinical care and policy. "With Dr. Reynolds' commitment to the Network and his emphasis on clinical research with a strong basic sciences background, he was an obvious choice for the deputy scientific director position," says Dr. Goldowitz. "Thankfully, James accepted the new responsibilities and has been working closely with me on many key initiatives for NeuroDevNet." ■



Penny Corkum awarded a CIHR eHealth Innovations Partnership Program Grant

NeuroDevNet Investigator Dr. Penny Corkum was one of eight researchers awarded the 2015 CIHR eHealth Innovations Partnership Program (eHIPP) Grant. This funding opportunity, providing almost \$300,000 over three years, will allow Corkum and her team to move forward with a project entitled "Teacher Help: Novel technologies for meeting the immediate needs of youth with mental health disorders in Canada."

Teacher Help is a web-based resource designed to assist teachers in supporting students with conditions such as Attention Deficit Hyperactive Disorder (ADHD) and Autism Spectrum Disorder (ASD). Providing access to information and expert coaching and peer support, Teacher Help is the first and only research-validated eHealth program designed for real-time assistance in the classroom. With the resources provided by the eHIPP funding, Corkum and her team hope to bring their project to fruition and begin implementation within Canadian classrooms. ■



Judy Illes appointed President of the International Neuroethics Society

NeuroDevNet Neuroethics co-lead Dr. Judy Illes has been appointed 2016-2018 President of the International Neuroethics Society (INS). With a two-year term that began January 28, 2016, Dr. Illes became the third president of the INS since its 2010 inception. An original founder of the organization, Dr. Illes has been an active board member and participant in the society, developing a journal for INS publications and providing support for events and collaborations.

As INS president, Dr. Illes hopes to improve engagement with the community, focusing on connections with government and development of a mentorship program for INS members. ■



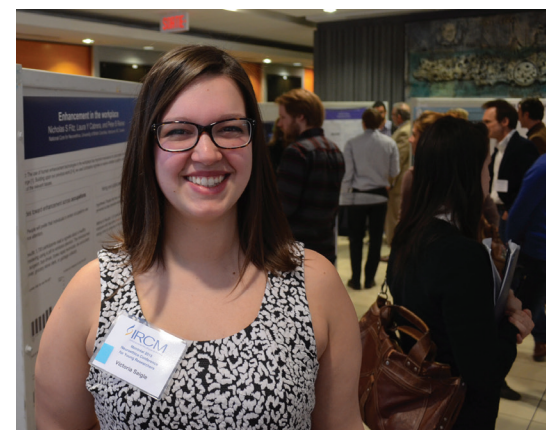
Events

Montreal Conference introduces Neuroethics to young researchers

NeuroDevNet collaborated with the Montreal Neuroethics Network to produce the inaugural Montreal Conference for Young Researchers, held on April 17, 2015. Hosted by the Institut de Recherches Cliniques de Montréal (IRCM), the event included a range of poster presentations and roundtable discussions offering practical advice on achieving success in the field. In addition to the “Social Responsibility of Neuroscience,” a panel discussion chaired by Dr. Emily Bell, participants were engaged by a keynote lecture, “The Neurobiology of Morality,” delivered by Dr. James Blair of the National Institute of Health.

Designed as a method of introduction to the field of neuroethics for new researchers, trainees, and students, the conference presented the opportunity to network with like-minded individuals and experts, while gaining valuable insights into current research. The one-day conference saw 93 participants from a variety of disciplines gather from 9 countries, working together in an exploration of neuroethical issues and tools.

The event also featured an essay competition with winners receiving fast-tracked publication in the neuroscience publication, *Neuroethics*, and its French counterpart, *BioethiqueOnline*. Five publications were selected for the English and French journals respectively, resulting in two special issues where these articles were displayed. Winners included Dr. Nadia Gligorov, Brigitte Brabant, Christopher Daley, Jared Craig, and Sarah Arnaud. The finished publication can be found here: <http://link.springer.com/journal/12152/9/2/page/1> ■



Events

Sixth Annual Brain Development Conference

NeuroDevNet's Sixth Annual Brain Development Conference brought together Network investigators, trainees, and researchers from September 19-21, 2015 in Ottawa, Ontario. With attendees from as far as Qatar, the conference presented a diverse program showcasing new themes surrounding brain development, while laying the groundwork for the Network's new direction towards a non-categorical approach to neurodevelopmental disorders.

Speakers explored topics of sleep and movement as therapeutic interventions, and Dr. Tom Boyce of the University of California San Francisco offered a fascinating Fraser Mustard Lecture. Entitled, "Embodied Misfortune: An Unheralded Convergence of the Biological and Social Sciences," Boyce discussed the overlap between social contexts and molecular-level genetics in determining susceptibility to health complications throughout the lifespan. This exploration of the neurobiology of misfortune tied physiology to social determinants of health, drawing attention to new research on the area of human pathogenesis and the innumerable factors involved.

"An amazing Ottawa conference in 2015!"

- attendee evaluation

ottawa
2015 brain
DEVELOPMENT CONFERENCE
CONFÉRENCE SUR LE DÉVELOPPEMENT DU CERVEAU

A session devoted to sleep research shed light on the neurobiological underpinnings of NeuroDevNet's sleep program. Drs. Mark Blumberg, John Peever, and Penny Corkum highlighted the advancements in understanding the relationships between sleep, sensorimotor processing, and brain development, as well as the connection between sleep processes and symptom expression of neurodevelopmental disorders.

Also touched upon was the importance of physical activity towards brain development—a session that served as a precursor to the NeuroDevNet-led Physical Activity Workshop that took place the following month in October 2015. This segment emphasized linkages between motor functioning, physical activity, and cognition in healthy brain development. ■

Trainees enjoy a session on leadership.



Poster sessions are a highlight of the Network's annual conference.



Scientific Director Dan Goldowitz confers with Senator Jim Munson.

Events



PHYSICAL ACTIVITY & BRAIN DEVELOPMENT WORKSHOP

NeuroDevNet and partners laid the foundations for a national project on physical activity and brain development during a two-day event November 20-21, 2015. One hundred and fifty experts in these fields gathered in Whitby Ontario along with policy makers, clinicians, educators and organizations working with developmental disabilities.

“Is Exercise Really Snake Oil for the Brain,” a dynamic keynote by Dr. John Ratey, clinician and author of *Spark: The Revolutionary New Science of Exercise and the Brain*, opened the Physical Activity and Brain Development Conference.

Other sessions focused on the effect of exercise on children’s ability to absorb information and adapt to changing circumstances, as well as the importance of activity in achieving optimal wellbeing and improving brain functioning. Emerging research examining exercise and its contributions to the structural and functional development of the brain were also highlighted in Ratey’s presentation.

“The focus on exercise and its impacts on children with disabilities as well as typically developing kids at this gathering was significant,” says NeuroDevNet Scientific Director Dr. Daniel Goldowitz, “Physical Activity is holistic, given its impacts on cognition and the wellbeing of the whole body, and it’s non-invasive. Best of all, it speaks to children’s natural inclination to play, and can involve the whole family.” ■



Events

Winter Institute draws top neuroscience trainees for an exceptional experience

The Third Biennial ART-NeuroDevNet Banff Winter Institute took place at the Banff Centre, Alberta, between March 30 and April 2, 2016. A pivotal part of the Network's training program, this institute saw 94 participants interact in a micro-conference-type setting to tackle issues of neuroethics, stakeholder engagement, and the mechanics of participatory research.

A range of subjects were considered through guest plenaries and panel discussions surrounding standards of care, clinical discovery and research. The workshop also featured two half-day sessions focusing on professional development, including alternative career path choices, mentoring and lab management styles, the use of social media to mobilize science, and tips for sharpening presentation skills.

"This year's Winter Institute featured a fantastic combination of theory and cutting edge research," said event organizer Dr. Douglas Swanson, NeuroDevNet Research and Training Manager. "A real highlight for the trainees was the chance to connect with stakeholders and community organizers to share ideas and perspectives on what research means to children and families, and how best to incorporate stakeholder's needs in research directions in the future."

The 2016 event played host to twenty stakeholders, facilitating bi-directional exchanges and collaboration on research translation, participatory research, and insights into training for youth. ■

Ample opportunities for interaction between and among trainees and senior researchers are a highlight of the Winter Institute.



Events

Developers line up to participate in the Apps4Kids Hackathon

Hackathon focuses on developing apps for kids with neurodevelopmental disabilities

Technology holds potential benefits for simplifying medical care of children with complex profiles.

Providing kids, families and clinicians with more assessment and treatment options was the premise of Apps4Kids, a Hackathon held at the University of British Columbia June 12-19, 2015 in collaboration with NeuroDevNet and UBC's Department of Electrical and Computer Engineering [ECE].



The brainchild of UBC Medical School student Ameen Amanian, the Hackathon drew students, developers, parents and parent groups to create and refine apps targeting health challenges for children and youth with chronic care needs. While a source of significant knowledge building, the week-long event also produced several proposals for new applications as well as a developed prototype of another aimed at children and youth with Down syndrome.

NeuroDevNet Investigator Osman Ipsiroglu, the faculty lead of Apps4Kids, collaborated with UBC's Department of Paediatrics, the Child Family Research Institute, the Canadian FASD-Research Network, TELUS, Children's Sleep Network, and the Down Syndrome Research Foundation to make the Hackathon a success, providing funding for the event and incentives for the participants who demonstrated the most aptitude in app refinement and development. Prizes were awarded based on innovation in design, meeting the needs of the community, and the capacity of the apps to support the optimization of chronic care management. ■

Team 9 focuses on developing an app to help improve handwriting in children with fine motor issues.



Workshop on Ethical Implications of FASD Screening

A workshop on FASD and health inequalities led by Drs. Nina Di Pietro and Judy Illes entitled "International Workshop on Ethical Implications of FASD Screening in Low-Resource Settings" was held May 20-21, 2015 in Vancouver.

The highly successful event sought to identify the lived experience of FASD among under-resourced populations across the globe, while recognizing the ethical and social challenges to screening, diagnosis, and treatment.

The two-day workshop was the result of collaboration between the Neuroethics Core and Dr. Dan Stein from Cape Town, South Africa, focusing on their joint efforts to disseminate knowledge on current and emerging trends in FAS biomarker screening for rural and underprivileged populations. The audience, comprised of researchers,

advocacy leaders, parents, and members of the CanFASD Family Advisory Committee also engaged in presentations on the ethical, legal, and social implications of using biomarkers such as eye tracking, genetic testing, and neuroimaging for FAS diagnosis in Canadian and South African contexts.

Material presented at the gathering has been translated into "Ethical Challenges in Contemporary FASD Research and Practice: A Global Perspective," a peer-reviewed paper crafted by Drs. Di Pietro, Illes, Stein, and several other Network associates. Soon to be published in the highly accredited Cambridge Quarterly Healthcare Ethics Journal, the piece provides a "framework to maximize benefits and minimize harms, promote justice, and foster respect for persons living with FASD within a global context," according to Dr. Illes. ■

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2016 and 2015



900 – 1450 Creekside Drive, Vancouver BC V6J 5B3
P 604 734 1690 F 604 336 8959 E creekinfo@hay-watson.bc.ca

Independent Auditor's Report

To the Directors of NeuroDevelopment Network, Inc.

We have audited the accompanying financial statements of NeuroDevelopment Network, Inc., which comprise the statements of financial position as at March 31, 2016 and 2015, the statements of operations and changes in net assets and of cash flows for the years then ended, and a summary of significant accounting policies and other explanatory information.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with Canadian Accounting Standards for Not-for-Profit Organizations, and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with Canadian generally accepted auditing standards. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements present fairly, in all material respects, the financial position NeuroDevelopment Network, Inc. as at March 31, 2016 and 2015, and its financial performance and its cash flows for the years then ended, in accordance with Canadian Accounting Standards for Not-for-Profit Organizations.

A handwritten signature in black ink that reads 'Hay & Watson'.

Chartered Professional Accountants
Vancouver, British Columbia
July 11, 2016

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2016 and 2015

Statements of Financial Position As at March 31, 2016 and 2015

	Mar 31, 2016	Mar 31, 2015
	\$	\$
Assets		
Current assets		
Cash – held in trust by University of British Columbia	832,537	1,070,930
Cash – held at bank	446,354	101,387
Accounts receivable	74,833	42,418
Contributions receivable	4,000	98,469
Unspent research grants paid to participating institutions (note 5)	1,792,680	633,857
Prepaid expenses	43,970	30,399
	3,194,374	1,977,460
Furniture and equipment (note 6)	5,721	4,262
	3,200,095	1,981,722
Liabilities		
Current liabilities		
Accounts payable and accrued liabilities	160,360	248,572
Deferred contributions (note 7)	2,879,148	1,580,864
Deferred capital contributions (note 7)	5,721	4,262
	3,045,229	1,833,698
Net assets	154,866	148,024
	3,200,095	1,981,722

The accompanying notes are an integral part of these financial statements.

APPROVED BY THE BOARD OF DIRECTORS



Patrick Lafferty, Chair, Board of Directors



David Ure, Chair, Finance and Audit

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2016 and 2015

Statements of Operations and Changes in Net Assets Years Ended March 31, 2016 and 2015

	2016	2015
	\$	\$
Receipts		
Contribution from Networks of Centres of Excellence (note 7)	3,578,680	3,712,434
Contribution from other agencies and organizations (note 7)	219,828	–
Conference registration fees and other support	73,314	66,887
Amortization of deferred capital contributions (note 6)	1,749	739
	3,873,571	3,780,060
Expenditures		
Communications	33,157	46,087
Amortization	1,749	739
Insurance	7,527	7,334
Professional and consulting fees	126,073	20,578
Research grant expenditures (note 5)	2,451,190	2,214,018
Research support and training	383,845	343,324
Salaries and benefits	555,852	582,697
Supplies and office costs	36,816	18,391
Travel, meetings and networking	270,520	520,559
	3,866,729	3,753,727
Excess of receipts over expenditures	6,842	26,333
Net assets, beginning of year	148,024	121,691
Net assets, end of year	154,866	148,024

The accompanying notes are an integral part of these financial statements.

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2016 and 2015

Statement of Cash Flows

Years Ended March 31, 2016 and 2015

	2016	2015
	\$	\$
Cash flows from (used in) operating activities		
Excess of receipts over expenditures	6,842	26,333
Non-cash items		
Amortization	1,749	739
Changes in working capital items		
Accounts receivable	(32,415)	[42,418]
Contributions receivable	94,469	[89,969]
Unspent research grants	(1,158,823)	[4,392]
Prepaid expenses	(13,571)	3,515
Accounts payable and accrued liabilities	(88,212)	98,644
Deferred contributions	1,299,743	[727,039]
	109,782	[734,587]
Cash flows from (used in) investing activities		
Purchase of furniture and equipment	(3,208)	[4,034]
Increase (decrease) in cash	106,574	[738,621]
Cash, beginning of year	1,172,317	1,910,938
Cash, end of year	1,278,891	1,172,317
Cash composed of:		
Cash – held in trust by University of British Columbia	832,537	1,070,930
Cash – held at bank	446,354	101,387
	1,278,891	1,172,317

The accompanying notes are an integral part of these financial statements.

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

*Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015*

1. OPERATIONS

Neurodevelopment Network (“NeuroDevNet” or the “Network”) is a not-for-profit program established by the Government of Canada’s Networks of Centres of Excellence (“NCE”) program. The Network was established to promote research in disorders of brain development and the implementation of real life solutions to improve the lives of affected children and families. The Network pursues its mission by distributing awards to its principal investigators through their participating institutions for approved research projects.

Neurodevelopment Network, Inc., the manager of the Network, was formally incorporated under Part II of the Canada Corporations Act as a non-profit organization on December 9, 2009.

The Network received \$19,572,000 in funding from the NCE for the period from 2009 to 2015. In December 2014, the Network was awarded a second cycle of funding of \$19,572,000 from the NCE for the period from 2015 to 2020 (Note 4).

On January 22, 2010, NeuroDevNet entered into a Network Agreement with the University of British Columbia (“UBC”) under which UBC will serve as the host institution for the Network, providing facilities and services for NeuroDevNet’s administrative centre. A new Network Agreement with UBC was entered into on February 1, 2016 for the second cycle of NCE funding.

On June 24, 2016, NeuroDevNet entered into a service contract with the Institute for Health System Transformation and Sustainability (“IHSTS”), under which NeuroDevNet was granted \$2,125,000 to support eligible neurodevelopment programs during a period of three years, from June 24, 2015 to March 31, 2019.

NeuroDevNet’s receipts and expenditures are primarily composed of contributions received from the NCE program and disbursed on its behalf. NeuroDevNet may not be able to maintain its current level of operations should this funding be significantly reduced or ended.

2. BASIS OF PRESENTATION

Statement of Compliance

These financial statements have been prepared in accordance with Canadian Accounting Standards for Not-for-Profit Organizations (“ASNPO”) effective as of March 31, 2016.

Basis of Presentation

These financial statements have been prepared on the historical cost basis, except for certain financial instruments which are measured at fair value, as explained in the accounting policies set out in Note 3. These financial statements are presented using the deferral method of accounting for contributions.

3. SIGNIFICANT ACCOUNTING POLICIES

Accounting Estimates and Judgments

The preparation of these financial statements requires management to make estimates and judgments and to form assumptions that affect the reported amounts and other disclosures in these financial statements. The estimates and associated assumptions are based on historical experience and various other factors that are believed to be reasonable under the circumstances. The results of these assumptions form the basis of making the judgments about carrying values of assets and liabilities that are not readily apparent from other sources. Actual results may differ from these estimates under different assumptions and conditions.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognized in the period in which the estimate is revised if the revision affects only that period or in the period of the revision and further periods if the review affects both current and future periods.

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

*Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015*

3. SIGNIFICANT ACCOUNTING POLICIES continued

Accounting Estimates and Judgments continued

Critical accounting estimates are estimates and assumptions made by management that may result in material adjustments to the carrying amount of assets and liabilities within the next financial year.

Critical accounting judgments are accounting policies that have been identified as being complex or involving subjective judgments or assessments. Critical accounting judgments used by the Network include the estimated useful life and future operating results from furniture and equipment and the recoverability of accounts receivable and contributions receivable.

Cash

Cash contributions from the NCE are considered restricted and are to be held in trust and administered on NeuroDevNet's behalf by the University of British Columbia ["UBC"], the Network's host institution.

Financial Assets and Liabilities

Financial assets and financial liabilities are initially measured at fair value adjusted by, in the case of a financial instrument that will not be measured subsequently at fair value, the amount of transaction costs directly attributable to the instrument. The Network subsequently measures its financial assets and financial liabilities at amortized cost. As at March 31, 2016, the recorded amounts of financial assets and financial liabilities approximate fair values.

Financial assets measured at amortized cost are tested for impairment when a significant adverse change has occurred during the period in the expected timing or amount of future cash flows. The amount of the write-down is recognized in net income and may be reversed in future periods if the assessment of impairment is revised.

Unspent Research Grants Paid to Participating Institutions

Research grants paid to participating institutions are deferred until the participating institution incurs eligible research costs, at which time they are recognized as research expenditures.

Furniture and equipment

Furniture and equipment are recorded at cost and amortized on a declining balance basis over their respective estimated useful lives at annual rates of 20% [furniture] and 30% [computers].

Recognition of Receipts

The Network follows the deferral method of accounting for contributions, which include government grants. Funds are received from agencies of the Canadian federal government, the host institution, and other private and public sector partners. Contributions which have external restrictions governing the types of activities which they can be used to fund are deferred and recognized when the eligible expenditures are incurred. Contributions approved but not yet received at the end of the reporting period are accrued.

Under the terms of the NCE agreement and IHSTS service contract, the funding received from the NCE and IHSTS will be directed to the granting of awards to the Network's participating institutions and the payment of operating and capital expenditures. When received, NCE and IHSTS contributions are deferred and recognized as revenue in the period in which the related expenditures are incurred by the Network or a participating institution.

Restricted contributions applied toward the purchase of furniture and equipment are deferred and recorded as receipts at the rate corresponding to the amortization rate of the related equipment. Unrestricted contributions, including conference registration fees and sponsorships, are recognized as receipts in the current period if the amount to be received can be reasonably estimated and collection is reasonably assured.

In-Kind Contributions

In-kind contributions from the host institution and other organizations are not included in these financial statements.

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015

3. SIGNIFICANT ACCOUNTING POLICIES *continued*

Employee Future Benefits

NeuroDevNet's staff are eligible to join the UBC staff pension plan. The UBC staff pension plan provides benefits based on 2% of the average best three years' basic salary multiplied by the number of years of contributory service, less an adjustment to Canada Pension Plan contributory earnings. NeuroDevNet's contribution for staff is approximately 9% of salary. In the event of funding deficiencies, NeuroDevNet's contributions remain fixed and benefits for members may be reduced. Accordingly, NeuroDevNet records contributions to this plan as expenditures in the year the contributions are made. Contributions to the plan made during the year amounted to \$26,500 [2015 - \$23,539].

Income Taxes

NeuroDevNet is a not-for-profit entity and is not subject to Federal or Provincial income taxes.

4. FUNDING AGREEMENTS

Contributions from the NCE

In 2009, the Natural Sciences and Engineering Research Council ("NSERC"), the Social Sciences and Humanities Research Council ("SSHRC"), and the Canadian Institutes of Health Research ("CIHR") agreed to contribute funding of \$19,572,000 to the Network over five years ending on December 23, 2015. This funding cycle was completed during the current fiscal year.

In December 2014, the same agencies agreed to contribute \$19,572,000 for a second cycle of funding from 2015 to 2020, as follows:

Fiscal Year	Total	
2014 - 2015	\$ 1,046,000	<i>received</i>
2015 - 2016	4,203,000	<i>received</i>
2016 - 2017	4,039,231	
2017 - 2018	3,867,387	
2018 - 2019	3,278,382	
2019 - 2020	3,138,000	
Total Funding	\$ 19,572,000	

The annual contributions will be released subject to the following conditions:

- Parliamentary appropriation of the funds in each fiscal period;
- Satisfactory progress, as determined by the NCE Secretariat, towards predetermined milestones for the NCE Network;
- Continuing eligibility of the NCE Network Host and the NCE Network; and
- Compliance with the terms of the funding agreement.

Contribution from the Host Institution

The Network Agreement between NeuroDevNet and UBC provides a cash grant of \$200,000 over 5 years from 2016 to 2020 as well as in-kind support. In-kind support is not recorded in the financial statements and includes legal services, payroll, purchasing and grant management, management of intellectual property, information technology support and web hosting services.

Contribution from the IHSTS

On June 24, 2015, NeuroDevNet entered into a service contract with the Institute for Health System Transformation and Sustainability ("IHSTS") under which NeuroDevNet was granted \$2,125,000 to support eligible neurodevelopment programs during a period of three years, from June 24, 2015 to March 31, 2019. As at March 31, 2016, NeuroDevNet had received the Year 1 instalment of this grant of \$840,000.

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015

5. RESEARCH GRANTS AND EXPENDITURES

NeuroDevNet provides research grant funding for eligible research projects to the host institution of the principal investigators of approved research projects. Research grant funds are held in trust by the host institutions and are recorded as unspent research grants by NeuroDevNet until eligible research expenses are incurred by the principal investigators.

	Unspent Balance - Mar 31, 2015 \$	Current Year Research Grants \$	Current Year Research Expenditures \$	Unspent Funds Returned \$	Unspent Balance - Mar 31, 2016 \$
IHSTS grants					
Emily Carr University of Art + Design	-	15,000	[8,715]	-	6,285
Holland Bloorview	-	17,500	-	-	17,500
Queen's University	-	127,700	[104,284]	-	23,416
Simon Fraser University	-	32,750	-	-	32,750
University of British Columbia	-	86,525	[20,683]	-	65,842
University Health Network	-	47,500	-	-	47,500
University of Victoria	-	15,525	[21,146]	-	[5,621]
	-	342,500	(154,828)	-	187,672
NCE grants					
Dalhousie University	-	363,932	[39,476]	-	324,456
Holland Bloorview	42,439	181,935	[192,660]	[20]	31,694
Hospital for Sick Children	199,700	219,270	[373,773]	-	45,197
Institut de recherches cliniques de Montréal (IRCM)	-	81,000	[29,672]	-	51,328
IWK Health Centre	46,926	172,973	[110,155]	[8,492]	101,252
King's University College	-	5,700	[5,700]	-	-
McGill University	57,462	365,445	[159,332]	[125,129]	138,486
McGill University Research Institute	-	142,588	[25,697]	-	116,891
McMaster University	34,538	177,436	[51,259]	-	160,715
Memorial University of Newfoundland	-	3,900	-	-	3,900
Mount Sinai Hospital	-	36,000	[23,872]	-	12,128
Queen's University	5,097	90,000	[84,085]	-	11,012
University Health Network	-	169,251	[155,283]	-	13,968
University of Alberta	80,559	211,926	[229,482]	-	63,003
University of British Columbia	74,448	559,296	[422,719]	-	211,025
University of Calgary	-	241,745	[99,392]	-	142,353
University of Manitoba	7,412	-	[211]	-	7,201
University of Ottawa	-	37,100	[2,719]	-	34,381
University of the Fraser Valley	21,987	-	[13,896]	-	8,091
University of Toronto	-	72,000	[71,998]	-	2
University of Victoria	35,484	-	[14,727]	-	20,757
York University	27,805	269,657	[190,254]	-	107,208
	633,857	3,401,154	(2,296,362)	(133,641)	1,605,008
Totals	633,857	3,743,654	(2,451,190)	(133,641)	1,792,680

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015

6. FURNITURE AND EQUIPMENT

Cost

Balance, March 31, 2014	\$	14,681
Additions		4,034
Balance, March 31, 2015		18,715
Additions		3,208
Balance, March 31, 2016	\$	21,923

Accumulated amortization

Balance, March 31, 2014	\$	13,714
Amortization		739
Balance, March 31, 2015		14,453
Amortization		1,749
Balance, March 31, 2016	\$	16,202

Carrying amount

Balance, March 31, 2015	\$	4,262
Balance, March 31, 2016	\$	5,721

7. DEFERRED CONTRIBUTIONS

Deferred Contributions Relating to Expenditures of Future Periods

	Mar 31, 2016	Mar 31, 2015
	\$	\$
NCE funds		
Balance - Beginning of year	1,577,864	2,311,197
Grants from the NCE	4,203,000	2,963,135
Grants from Host Institution	60,000	20,000
Amounts recognized as receipts during the year	(3,578,680)	(3,712,434)
Amounts applied toward furniture and equipment purchased during the year	(3,208)	(4,034)
	2,258,976	1,577,864
BC IHSTS funds		
Balance - Beginning of year	-	-
Grants from IHSTS	840,000	-
Amounts recognized as receipts during the year	(219,828)	-
	620,172	-
Other restricted funds		
Balance - Beginning of year	3,000	-
Grants received during the year	24,983	23,250
Amounts recognized as receipts during the year	(27,983)	(20,250)
	-	3,000
Balance - End of year	2,879,148	1,580,864

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015

7. DEFERRED CONTRIBUTIONS *continued*

Deferred Capital Contributions Relating to Furniture and Equipment

	Mar 31, 2016	Mar 31, 2015
	\$	\$
Balance - Beginning of year	4,262	967
Allocation of deferred contributions	3,208	4,034
Amounts amortized to revenue	(1,749)	[739]
Balance - End of year	5,721	4,262

8. KIDS BRAIN HEALTH FOUNDATION

On March 9, 2016, NeuroDevNet incorporated the Kids Brain Health Foundation (“KBHF”) in British Columbia under the Canada Not-for-profit Corporations Act. The purpose of KBHF is to raise awareness of and funds for NeuroDevNet’s research activities as well as the implementation of research discoveries. As at March 31, 2016, KBHF has not received any contributions or donations. NeuroDevNet incurred professional fees, travel and communication costs of \$20,343 related to the establishment of KBHF for the year ended March 31, 2016 which are included in the statement of operations and changes in net assets.

9. RISK MANAGEMENT

NeuroDevNet’s activities expose it to financial risks which include credit risk, interest rate risk and liquidity risk. The Network’s risk management program focuses on the unpredictability of financial markets and seeks to maximize the Network’s ability to meet its mandate.

Credit Risk

Credit risk is the risk of financial loss to NeuroDevNet if a counterparty to a financial instrument fails to meet its contractual obligations. The Network is exposed to credit risk from its cash and accounts receivable. The Network considers this risk to be minimal as cash is on deposit at insured financial institutions and significant accounts receivable are due from major universities and government funding partners.

Interest Rate Risk

Interest rate risk is the risk that changes in interest rates will affect the fair value or future cash flows of NeuroDevNet’s financial instruments. The Network is not exposed to significant interest rate risk.

Liquidity Risk

Liquidity risk is the risk that the Network will not be able to meet its financial obligations as they come due. Accounts payable and accrued liabilities are due within the current operating period. NeuroDevNet’s overall exposure to liquidity risk is minimal as the Network has sufficient assets to meet outstanding obligations.

Financial Statements

NEURODEVELOPMENT NETWORK, INC.

Notes to the Financial Statements
For the Years Ended March 31, 2016 and 2015

10. CAPITAL MANAGEMENT

NeuroDevNet defines its capital as the amounts included in net assets, deferred contributions and deferred capital contributions.

NeuroDevNet's capital management objectives are to meet its obligations under its funding agreements and to safeguard its ability to continue to pursue the objectives of the Network.

NeuroDevNet has certain external restrictions on the use of deferred contributions and deferred capital contributions, as set out in note 5. NeuroDevNet has internal control processes to ensure that the restrictions are met prior to utilization of these resources and has been in compliance with these restrictions throughout the period.

11. COMPARATIVE AMOUNTS

Comparative amounts on the statement of operations and changes in net assets for the year ended March 31, 2015 have been reclassified to match the presentation used current year.

Network Community

Network Investigators (112)

Evdokia Anagnostou
John Andersen
Gail Andrew
Rubab Arim
Erin Barker
Christian Beaulieu
Sue Becker
Teresa Bennett
Joseph Beyene
Rachel Birnbaum
Patricia Boechler
Rollin Brant
Jessica Brian
Cary Brown
Susan Bryson
David Buckley
Peter Carlen
Albert Chudley
Jean-Paul Collet
Evelyn Constantine
Jocelynn Cook
Penny Corkum
Irene Drmic
Eric Duku
Salhab el Helou
Mayada Elsabbagh
Herbert Emery
Carl Ernst
Alan Evans
Nora Fayed
Darcy Fehlings
Michael Fehlings
Christoph Fusch
Victoria Galea
Stelios Georgiades
Roger Godbout
Helly Goez
Daniel Goldowitz
Jan Gorter
JP Gouin
Geoffrey Hall
Ana Hanlon-Dearman
Antony Hodgson
Gabriella Horvath
Grace Iarocci
Judy Illes
Osman Ipsiroglu
Kathy Keiver
Kimberly Kerns
Adam Kirton
Dafna Kohen
Chaya Kulkarni
Azadeh Kushki
Lucyna Lach
Catherine Lebel
Nicole Letourneau
Louise Mâsse
Sarah Macoun
Annette Majnemer
Patrick McGrath
William McKellin
Steven Miller
Anton Miller
Pat Mirinda
Cindi Morshead
Christopher Mushquash
Andras Nagy
David Nicholas
Tim Oberlander
Maryam Oskoui
Paul Pavlidis
Jacqueline Pei
Alan Peterson
David Phipps
Alison Pritchard Orr
Éric Racine
Carmen Rasmussen
Graham Reid
Jim Reilly
James Reynolds
Wendy Roberts
Gabriel Ronen
Colin Ross
David Rothwell
Stephen Scherer
Sarah Shea
Michael Shevell
Keiko Shikako-Thomas
Graham Sinclair
Isabel Smith
Ranil Sonnadara
Sylvia Stockler
Peter Szatmari
Suzanne Tough
Wendy Ungar
Tracy Vaillancourt
Derek van der Kooy
Machiel Van der Loos
Clara van Karnebeek
Esias van Rensburg
Naznin Virji-Babul
Joanne Volden
Charlotte Waddell
Wyeth Wasserman
Joanne Weinberg
Jonathan Weiss
Shelly Weiss
Rosanna Weksberg
Ellen Wood
Jerome Yager
Lonnie Zwaigenbaum
Jill Zwicker

Network Community

Associate Investigators (136)

May Abou Zahra	Veronica Ghazarian	Sarah Nikkel
Yasser Ad-Dab'bagh	Sylvie Girard	Sebastien Normand
Julia Alleyne	Helly Goez	Lise Olsen
Dana Anaby	Courtney Green	Ipek Oruc
Linda Andersen	Ruth Grunau	Lucy Osborne
Peter Anderson	Gillian Hanley	Nicole Pigeon
Daniel Ansari	Gina Harrison	Quentin Pittman
Anthony Bailey	Heather Henderson	Maria Pompeiano
Anne-Claude Bedard	Geoffrey Hicks	Marco Prado
Michal Begin	Anne-Lise Holahan	Denise Pugash
Emily Bell	Liisa Holsti	Mojgan Rastegar
Armando Bertone	Mary Jane Hornaas	Peter Reiner
Nathalie Berube	Suzanne Johnson	Philippe Robaey
Elaine Biddiss	Shannon Johnson	Peter Rosenbaum
Gunnar Blohm	Bhushan Kapur	A. Jane Roskams
Francois Bolduc	Muralidharan Kesavan	Dawa Samdup
Virginia Bourget	Louise Koclas	James Sanders
Derek Bowie	Sri Krishnan	Carol Schuurmans
Signe Bray	Deborah Kurrasch	Sidney Segalowitz
Marie Brossard-Racine	Céline Lamarre	Ronald Garth Smith
Richard Brown	Nancy Lanphear	Veronica Smith
Michael Brudno	Bruce Lanphear	Laurie Snider
David Buckley	Anna Lehman	Marla Sokolowski
Jacob Burack	Stephen Lomber	Isabelle Soulieres
Catherine Cameron	Christine Loock	Kaye Spratt
Andrea Chernin	Katelyn Lowe	Greg Stanisz
Douglas Cheyne	Jan Lutke	Sylvia Stockler
Sterling Clarren	Karon MacLean	Pat Stroman
Emma Climie	Frank MacMaster	Jane Summers
Michael Colicos	Janet Mah	Heidi Sveistrup
Melanie Couture	Krisztina Malisza	Anne Synnes
Suzanne Curtin	Désirée Maltais	Margot Taylor
Deborah Dewey	Paola Marignani	Christine Tipper
Graziella Di Cristo	Hassan Marzban	Hasan Uludag
Nina Di Pietro	Chris Maxwell	Larry Unsworth
Adele Diamond	Adam McCrimmin	Tracy Vaillancourt
David Eisenstat	Audrey McFarlane	Alexander Velumian
Margaret Fahnstock	Kaitlyn McLachlan	John Vincent
Tiago Falk	Robert McMahan	Naznin Virji-Babul
Bridget Fernandez	Gerlinde Metz	Joanne Volden
Jane Foster	Fiona Miller	Charlotte Waddell
Martin Frasch	Aleksandra Mineyko	Lucie Wade
Liisa Galea	Kishore Mulpuri	Rosanna Weksberg
Luke Gauthier	Doug Munoz	Ellen Wood
	Diane Munz	Virginia Wright
	Kara Murias	Jaynie Yang

Network Community

Network Trainees (167)

Kelsey Adams

Tony Ahn

Nicole Ali

Sheliza Ali

Jordan Ali

Babak Alipanahi

Basma AlJabri

Abdullah Alshememry

John Aspler

Hooman Bagheri

Samantha Baglot

Ashley Bahry

Sacha Bailey

Kayla Baker

Soela Bandalay

Vanessa Bao

Stephanie Beldick

Emily Bell

Mai Berger

Nadia Beyzaei

Nathalie Binnion

Aline Bogossian

Tatiana Bregman

Priscilla Burnham Riosa

Roxanne Caron

Michelle Chakraborti

Lawrence Chen

Isabelle Chouinard

Phil Chrapka

Patrick Ciechanski

Andrea Constantinof

Jenna Crawford

Erik de Jong

Kiret Dhindsa

Nina Di Pietro

Trish Domi

Laura Donovan

Sarah Dorsey

Colby Draney

Britt Drogemoller

Ellen Drumm

Lisa Dzadzamia

Derek Eng

Mariam Faiz

Stephanie Fehertoi

Katherine Flannigan

Gila Foomani

Ellis Freedman

Ian Garber

Emily Gardiner

Genevieve Gariepy

Heather Gautreau

Aisha Ghani

Kamaldeep Gill

Mojgan Gitimoghaddam

Jeff Grab

Raquel Graham

Rachel Grant

Madeleine Green-Holland

Jessie Guo

Carolin Hahnel

Drew Halliday

Eva Haspels

Parker Holman

Sharmin Hossain

Sarah House

Sarah Hutchison

Sara Izadi

Melanie Jeffrey

William Jones

Aamena Kapasi

Precilia Kong

Kayla Kozma

Thanos Kritharis

Brian Krug

Alexandra Kruse

Andrea Kuczynski

Jessica Lee

Jonathan Leef

Brenna Li

Justin Licari

Nathaniel Lim

Graham Little

James Liu

Xiangyu Long

Krista Longeway

Lei Lu

Alexandre Lussier

Ogan Macarci

Jennifer MacSween

Jonathan Marr

Sabah Master

Allison Matthews-Cotton

Andrea Maughan

Graham McAllister

Daniele Merico

Rebecca Merkle

Taylor Mutis

Regula Neuenschwander

Antoinette Nguyen

Bryce Odell

Sezgi Ozel

Larissa Padua

Angelina Paolozza

Carmela Paolozza

Soh Yun Park

Jennifer Poole

Jelena Popic

Kathryn Post

Ann-Marie Przyslupski

Sarah Pyne

Lisa Anne Rasmussen

Sarah Raza

Amber Rieder

Gabrielle Rigney

Prakasham Rumajogee

Frank Russell

Nadia Sachewsky

Lori-Ann Sacrey

Sandra Salem

Sarah Sarabadani

Tal Savion-Lemieux

Derek Schaper

Veronica Schiariti

Rilla Schneider

Ryan Sefid

Gabrielle Semail

Mariane Sentenac

Aidan Shair

John Sheehan

Meaghan Shevall

Navid Shirzad

Michelle Siu

Kaylee Sohng

Christinal Sooklal

Rianne Spaans

Samantha Sterling

Peter Sterling

Kamila Szulc

Dan Szymczak

Jennifer Talbot

Kim Tan-MacNeill

Dmitry Tebaykin

Abe Teklemariam

Rackeb Tesfaye

Shelby Thompson

Victoria Ting

Lilah Toker

Elaine Toombs

Shreejoy Tripathy

Kerrie Tsigounis

Daisuke Umebayashi

Bulmaro Valdés

Balazs Varga

Reaz Vawda

Ilan Vonderwalde

Natalie Wagner

Alexandra Wagner

Jessica Walesch

Brad Watson

Yicheng Xie

Samantha Yammine

Mandy Yee

Jenny Yoon

Amber Young

Connie Yuen

Rosslynn Zulla

Network Community

Network Senior Research Staff (21)

Paul Bradshaw
Helen Carlson
Lara El-Khatib
Susan Kobus
Ni Lan

Sydney Dale-McGrath
Dayle McCauley
Anneliese Poetz
Charlis Raineki
Lysanne Rivard
Christine Rogers
Sanja Rogic
Christopher Saunders

Lauren Switzer
Maja Tarailo-Graovac
Sarah Treit
Carol Wilson
Ephrem Zewdie
Linhua Zhang
Dongming Zhou
Jennifer Zwicker

Network Highly Qualified Personnel (HQP) (51)

Svetlana Altamentova
Edward Armstrong
Kate Bernardi
Mike Chalupka
Brie Chauncey
Stephanie Chow
Brenda Coles-Takabe
Lorna Colli
Olivia Conlon
Russel Cooper
Nicole Cousins
Danielle Dalziel
Erin Dowds
Paula Dunn
Sasha Dyck

Annahita Ehsan
Linda Ellis
Kirsten Graham
Kevin Griffin
Jordana Hildebrandt
Michal Krawczyk
Ramesh Lamsal
Lisa-Marie Langaigne
Nina Lantinga
Justin Leong
Anya Lundy
Alexander MacIntosh
Stacey MacWilliam
Neemat Mahmud
Michael-Anne Markham
Terry McCormick
Dianne McGrath
Mary McNeil

Shanthini Mylvaganam
Irene O'Connor
Kathleen O'Grady
Adeena Persaud
Meera Ramani
Jana Roberto
Ellen Robertson
Stacie Ross
Susan Scott
Michelle Shalinsky
Sonya Strohm
Venki Subramaniam
Larry Tuff
Amber Vance
Sophie Wang
Diane Wickenheiser
Wayne Yu
Natalie Zizzo

Founding Investigators (42)

Ronald Barr
Bruce Bjornson
Tom Boyce
Lara Boyd
Jessica Brian
Jim Frederick Brien
Richard E. Brown
Max Cynader
Marc Del Bigio
David Eisenstat
Jan Friedman
Deborah Giaschi
Ruth Eckstein Grunau

Richard Hawkes
Michael Hayden
Anthony Herdman
Clyde Hertzman
William Honer
Sheila Innis
K.S. Joseph
Michael Kobor
Bryan Kolb
Evelyn Lambe
Suzanne Lewis
Catherine Limperopoulos
Bruce McNaughton
Michael Meaney
Ravi Menon

Freda Miller
Tim F. Oberlander
Timothy O'Connor
Catharine Helen Rankin
Urs Ribary
Bryan S. Richardson
Stuart Shanker
Isabel M. Smith
Moshe Szyf
Derek van der Kooy
Wyeth W. Wasserman
Daniel Weeks
Janet Werker
Ian Q. Whishaw

Network Community

Associate Trainees (131)

Noor Al Dahhan
Kimberly Armstrong
lilach Ashtamker
Thierno Madjou Bah
Omkar Prasad Baidya
Craig Bailey
Janet Bang
Omer Bar Yosef
Vichithra Batuwita Liyanage
Helen Beaton
Esmot Begum
Hiwote Belay
Jeff Bennett
Britney Benoit
Mark Bichin
Tamara Bodnar
Zachary Boychuck
Heather Brown
Susanne Brummelte
Derrick Matthew Buchanan
Kayleigh Campbell
Lucia Capano
Maheen Ceizar
Ning Cheng
Stephanie Cheung
Tricia da Silva
Charles de Leeuw
Dane De Silva
Dennis Dimond
Christine Dobson
Lucien Daniel Durosier
Amr El Shahed
Stacey Espinet
Gabrielle Freire
Rosaria Furlano
Joey Gareri
Nurit Gazit Gurel
Matthew Gazzellone
Tamara Germani
Allyson Graham
Melody Grohs
Jacalyn Guy
Mohammed Habash

Eva-Maria Hahler
Layla Hall
Atiq Hassan
Nina Hedayati
Kasey Hemington
Amy Hewitt
Alicia Hilderley
Jacquie Hodge
Kaia Hookenson
Linda Horwood
Pingzhao Hu
Chloe Hudson
Chai-Ting Hung
Marnie Hutchison
Carl Jackson
Jessica Jarmasz
Jessica Jeong
Jenni Karl
Cassandra Kinch
Shannon Knights
Esther Ko
Yavar Korkian
Pauline Léveillé
Jonathan Lai
Johanna Lake
Lisa Marie Langevin
Élizabel Leblanc
Grace Lee
Danielle Levac
Damon Li
Annie Li
Yingxiang Li
Anath Lionel
Jonathan Lipszyc
Hai Lun Liu
Sarah Mah
Jen Marshall
Candace Marsters
Stacey McHenry
Hannah McNeill
David McVea
Kirti Mittal
Rae Mitten
Corinne Montes-Rodriguez
Marie Morimoto

Liz Munn
Catherine Nevin
Chiara Nicolini
Ramsha Noor
Anna Patten
Francesco Pisani
Vickie Plourde
Magda Price
Kathryn Rancourt
Manon Ranger
Anna Raphael
Lisa Rivard
Tara Rodas
Shikha Saxena
Jean-Francois Schmouth
Taimoor Sheikh
Sneha Sheth
Ruslan Shuvalov
Tabrez Siddiqui
Anna Sinova
Stephanie Snow
Yvonne SONDY
Nick Stabler
Alex Szubra
Dina Tabatabaei
Aoi Tajiri
Kayla Ten Eycke
Veronique D. Therien
Justin Tong
Jenna Traynor
Jillian Vinall
Sarah Vinette
Susan Walker
Glenys Webster
Hong Weng
Emily White
Jocelyne Whitehead
Katherine Wyper
Alex Xu
Armin Yazdani
Afiqah Yusuf
Robby Zachariah
Fabiola Zucchi

Network Community

Corporate Information

Administration

Daniel Goldowitz, *Scientific Director*
James Reynolds, *Deputy Scientific Director*
Tom Philpott, *Executive Director*

Board of Directors

Patrick Lafferty, *Chair, NeuroDevNet Board of Directors; Partner of PricewaterhouseCoopers LLP [retired]*
Sheila Laredo, *Vice Chair, NeuroDevNet Board of Director; Assistant Professor, University of Toronto; Chief of Staff, Women's College Hospital*
Margaret Clarke, *Professor, University of Calgary; Vice-President, Sinneave Family Foundation and the Ability Hub*
Michael Fehlings, *Medical Director, Krembil Neuroscience Centre, University Health Network; Professor, University of Toronto*
Glenys Godlovitch, *Associate Professor, University of Calgary [retired]*
Dan Goldowitz, *Scientific Director, NeuroDevNet [ex-officio]*
J.P. Heale, *Interim Managing Director, University-Industry Liaison Office, University of British Columbia*
Mark Jones, *Senior Pharmaceutical Executive, AstraZeneca [retired]*
Peter Morand, *President, Peter Morand & Associates Inc.*
John O'Neil, *Professor and Dean of the Faculty of Health Sciences, Simon Fraser University*
Carol Richards, *Professor, Université Laval*
Henri Rothschild, *President and Chief Executive Officer, Canada-Israel Industrial Research & Development Foundation*
Donna Thomson, *Instructor, The Advocacy School; Co-founder, Lifetime Networks Ottawa*
Kathleen Thurber, *Director, Corporate Communications, Alberta Innovates – Health Solutions*
David Ure, *Senior Vice President, Finance, Mercer International Inc.*

Scientific Advisory Committee

Samuel Weiss, *Chair, NeuroDevNet Scientific Advisory Committee; Professor, University of Calgary*
Bernie Devlin, *Professor, University of Pittsburgh*
Joseph Fins, *Director of Medical Ethics and Attending Physician, Weill Cornell Medical College [USA]*
Jay Giedd, *Principle Investigator, National Institute of Mental Health [USA]; Adjunct Professor, Johns Hopkins*
Mark Hoffman, *Director, Translational Bioinformatics, Children's Mercy Hospital [USA]*
Ivica Kostovic, *Professor, University of Zagreb*
Pat Levitt, *Professor, University of Southern California*
Edward Riley, *Professor, San Diego State University*

Network Community

Corporate Information

Research Management Committee

Richard Hawkes, *Chair, NeuroDevNet Research Management Committee; Senior Associate Dean, University of Calgary*
Julia Alleyne, *Associate Professor, University of Toronto*
Mark Bieda, *Assistant Professor, University of Calgary*
Jim Brien, *Professor, Queen's University (retired)*
Chris Fibiger, *Chief Scientific Officer, MedGenesis*
Jan Friedman, *Professor, University of British Columbia*
Daniel Goldowitz, *Scientific Director, NeuroDevNet*
Mary Johnston, *Acting Associate Director (retired), FASD Initiative, Public Health Agency of Canada*
Bryan Kolb, *Professor, University of Lethbridge*
Lucy Osborne, *Professor, University of Toronto (ex-officio)*
James Reynolds, *Professor, Queen's University (ex-officio)*
Vivien Symington, *Founder, Club Aviva*
Laura Williams, *Director, Patient, Caregiver and Public Engagement (interim), Health Quality Ontario*

Research Training Committee

Lucy Osborne, *Chair, NeuroDevNet Research Training Committee; Professor, University of Toronto*
Christian Beaulieu, *Professor, University of Alberta*
Richard Brown, *Professor, Dalhousie University*
David Eisenstat, *Professor, University of Alberta*
Kathryn Murphy, *Professor, McMaster University*
Bryan Richardson, *Professor, University of Western Ontario*
Jill Zwicker, *Assistant Professor, University of British Columbia*

Staff

Bethany Becker, *Communications Manager*
Erica Lamb, *Communications Assistant*
Kirsten Lawrie, *Senior Administrator*
Tom Philpott, *Executive Director*
Anthony Santelices, *Project Coordinator*
Anita Sham, *Administrative Assistant*
Pierre Zwieggers, *Interim Administrative Assistant*
Shum Sidhu, *Finance Manager*
Doug Swanson, *Research and Training Manager*

Auditors

Hay & Watson, Chartered Accountants

Legal Counsel

Borden Ladner Gervais LLP, Vancouver BC

Network Community Partners

Network Members

1. Dalhousie University
2. Holland Bloorview Kids Rehabilitation Hospital
3. Institut de recherches cliniques de Montréal (IRCM)
4. Izaak Walton Killam (IWK) Health Centre Foundation [Halifax]
5. King's University College at Western
6. McMaster University
7. Memorial University of Newfoundland
8. Mount Sinai Hospital
9. Queen's University
10. The Hospital for Sick Children
11. The Governing Council of the University of Toronto
12. The Governors of the University of Alberta
13. The Governors of the University of Calgary
14. The Research Institute of the McGill University Health Centre
15. The Royal Institution for the Advancement of Learning / McGill University
16. The University of Western Ontario
17. Université Laval
18. University Health Network [Ontario]
19. University of British Columbia
20. University of Ottawa
21. York University

Other Affiliated Universities and Research Institutes

1. Centre for Molecular Medicine and Therapeutics [CMMT]
2. Douglas College
3. Genome Canada
4. Humber College
5. Karolinska Institutet
6. Kennedy Krieger Institute, Johns Hopkins School of Medicine
7. Lakehead University
8. Mount Sinai Hospital [New York]
9. Neuroscience and Mental Health Institute, University of Alberta
10. Ontario Institute for Regenerative Medicine
11. PopDataBC
12. Simon Fraser University
13. Sunny Hill Health Centre for Children
14. Telethon Kids Institute [Australia]
15. Thompson Rivers University
16. Toronto Western Hospital, Krembil Research Institute
17. University of Amsterdam
18. University of Manitoba
19. University of Sydney
20. University of Victoria
21. University of Western Ontario
22. University of the Fraser Valley
23. Wayne State University
24. Women's and Children's Health Research Institute

Network Community Partners

Industry Partners and Supporters

1. Athena Diagnostics
2. Avertus Epilepsy Technologies
3. Cell Cure Neuroscience Ltd
4. Club Aviva
5. Conquer Mobile
6. Dymaxia
7. Guarana Technologies
8. PARTEQ
9. REDCap [Research Electronic Data Capture] Software
10. SR Research
11. Vancouver Sun

Federal Departments and Agencies

1. Canadian Institutes of Health Research
2. Institute of Human Development, Child and Youth Health (IHDCYH)
3. NSERC/CIHR – CHR P
4. Ministry of Sports and Disabilities
5. Statistics Canada
6. Public Health Agency of Canada

Provincial and Municipal Departments and Agencies

1. Alberta Children's Hospital Research Institute
2. BC Ministry of Children and Family Development
3. BC Ministry of Education
4. BC Ministry of Health
5. BC Ministry of Social Development and Social Innovation
6. BC Women's Hospital & Health Centre
7. Centre Integre Universitaire de Sante et Service Sociaux de Centre-Ouest
de l'Île de Montreal - Centre de réadaptation MAB-Mackay
8. Dalhousie University Industry Liaison and Innovation
9. Office des Personnes Handicapés du Québec
10. Ontario Brain Institute
11. Ontario Ministry of Child and Youth Services
12. Régie de l'assurance maladie du Québec
13. Central Elementary School
14. Chilliwack School District SD33, British Columbia
15. City of Toronto Children's Services
16. Gulf Islands School District SD64, British Columbia
17. Sooke School District SD62, British Columbia
18. Sullivan Heights Secondary, Surrey BC
19. Vancouver Technical Secondary

Network Community Partners

Non-Profit Organizations

1. Abilities Center (Whitby, ON)
2. Allen Institute for Brain Science
3. Alva Foundation
4. Autism Canada
5. Autism Community Training society (ACT)
6. Autism Speaks Canada
7. Baby Siblings Research Consortium
8. BC Paediatric Society
9. Canada FASD Research Network
10. Canadian Association of Paediatric Health Centres (CAPHC)
11. CanFASD
12. Catholic Social Services
13. Centre de réadaptation Marie Enfant
14. Centre for ADHD Awareness Canada (CADDAC)
15. Centre for Commercialization of Regenerative Medicine
16. Cerebral Palsy Association in Alberta
17. Cerebral Palsy Association of BC
18. Cerebral Palsy Association of Manitoba
19. Cerebral Palsy Association of Saskatoon
20. Cerebral Palsy Foundation of New Brunswick
21. CHILD-BRIGHT SPOR
22. Child Health BC
23. Children's Aid Society Toronto
24. Children's Hospital of Eastern Ontario
25. Children's Hospital of Philadelphia
26. Citizen Advocacy Ottawa
27. Club Aviva
28. CP Canada Network
29. Down Syndrome Research Foundation
30. Edith Strauss Foundation
31. FASD London Regions Assessment Clinic
32. Geneva Centre for Autism

continued on next page

Network Community Partners

Non-Profit Organizations *continued*

33. Glenrose Rehabilitation Hospital Foundation
34. Grandview Children's Centre
35. Hamilton Health Sciences
36. Home of Hope
37. Humber Child Care Centre
38. Interior Health Authority
39. International Neuroinformatics Coordinating Facility (INCF)
40. Janus Academy
41. Lawson Foundation
42. Manitoba FASD Centre
43. Micha Books
44. Miriam Foundation
45. MITACS
46. Montreal Children's Hospital Foundation
47. Ontario Federation for Cerebral Palsy
48. ParticipACTION
49. ResearchImpact
50. RICHER Initiative, BC Children's Hospital
51. Rick Hansen Foundation
52. Shailah Interactive
53. Sick Kids – Infant Mental Health Promotion
54. Simons Foundation Autism Research Initiative
55. Sinneave Foundation - Ability Hub
56. Strongest Families Institute
57. Summit School
58. Sunny Hill Health Centre for Children
59. Thames Valley Children's Centre
60. THREE TO BE Foundation
61. Toronto General and Western Hospital Foundation
62. Trevor Williams Foundation
63. Wellness Resiliency and Partnership Project
64. YMCA Quebec and Atlantic



CONTRIBUTORS

Bethany Becker, *Communications Manager*

Katelyn Verstraten, *Writer*

Erica Lamb, *Communications Coordinator*, Events and Kudos stories

DESIGN bay6creative.com

PHOTOGRAPHY

Creating a culture of innovation [page 8]

Eye Tracker: Canadian Press; Robotics: Katelyn Verstraten; Caribbean Quest: University of Victoria

Creating a culture of innovation cont. [page 9]

Epilepsy Monitor: Avertus; Exercycle and App: Holland Bloorview Kids Rehabilitation Hospital

Groundbreaking discovery in cerebral palsy [page 10]

Katelyn Verstraten

From biosignatures to behavioural profiles [page 12]

Anneliese Poetz

Infant screening and intervention [page 13]

Canadian Press

Social ABCs [page 15]

Holland Bloorview Kids Rehabilitation Hospital

Better nights better days [page 16]

Corkum Lab, Dalhousie University

Constraint induced movement therapy [page 17]

Holland Bloorview Child Development Program/Neuromotor Team

Empowering Steps [page 18]

Club Aviva

TotTech and FEATHERS [page 19]

Katelyn Verstraten

High Impact Projects [page 21]

SickKids Infant Mental Health Promotion

Fetal Alcohol Resource Program Tweet [page 22]

FARP

Brain Canada Fellows [pages 32 & 33]

Candice Ward

Carmela Paolozza [page 34]

Katelyn Verstraten

Neuroethics for young researchers [page 39]

Institute de recherche clinique de Montréal

Brain Development Conference [page 40]

Cynthia Münster

Physical Activity Workshop [page 41]

Club Aviva and Anneliese Poetz

Winter Institute [page 42]

Banff Centre

Hackathon [page 43]

Kevin Quach, BC Children's Hospital Innovation Office

RENEWAL





A CANADIAN NETWORK OF CENTRES OF EXCELLENCE



NeuroDevNet

The University of British Columbia
Child and Family Research Institute
950 W. 28th Avenue
Vancouver, BC V5Z 4H4

www.neurodevnet.ca

604.875.2424 ext 5436

