





#### LOGO

NeuroDevNet's spiral logo communicates change, progression and evolution. Its bright multi-colour palette emphasizes the network's focus on children, starting from a smaller yellow neuron, denoting hope, the neurons rise to a crescendo, ending in a green neuron, signifying health. The fourth annual report aligns with the blue neurons in our spiral, conveying the theme of knowledge.

#### **VISION**

To improve the lives of children with neurodevelopmental disorders and their families, by accelerating and integrating the discovery and utilization of knowledge about disorders of the brain, 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 related neurodevelopmental disorders, as well as to their families and caregivers. NeuroDevNet focuses its funding on integrated, team-based, research initiatives related to cause, early diagnosis, and interventions. Engaging families, clinicians, other stakeholders and partners both nationally and internationally, NeuroDevNet leverages and enhances the talents of new and seasoned researchers to translate research findings into effective therapies and changes in policy and practice.

#### **OBJECTIVES**

#### **CAPACITY BUILDING**

Train the next generation of experts in brain development disorders

#### RESEARCH

Support and conduct multi-disciplinary research excellence

#### **KNOWLEDGE TRANSLATION**

Maximize the social and economic impacts of research and training in developmental brain disorders

#### **BUSINESS DEVELOPMENT**

Translate research findings into diagnostic, preventative and therapeutic applications

#### **SUPPORT**

NeuroDevNet is made possible by the Networks of Centres of Excellence, a program of the federal government to meet Canada's needs to focus a critical mass of research resources on social and economic challenges, commercialize and apply more of its homegrown research breakthroughs, increase private-sector R&D, and train highly qualified people.

NeuroDevNet gratefully acknowledges host support from the University of British Columbia and the Child and Family Research Institute.









## COMMENT FROM THE CHAIRMAN OF THE BOARD OF DIRECTORS



As Chairman of the NeuroDevNet Board of Directors, I am pleased to share with you this important annual report, capturing NeuroDevNet as this promising initiative hits its stride. In only in its third year of existence, NeuroDevNet has begun to show clear results that validate its significant role in child health and brain development, and reflect the Network's unique contribution to Canada, and the world.

Funded by the Federal Government's Networks of Centres of Excellence program, NeuroDevNet is the only North American research network dedicated to helping children overcome neurodevelopmental disorders. The Network's investigators seek to understand the causes of neurological deficits, how best to diagnosis these disorders at the earliest possible time, and strive to identify evidence-based, ethical interventions to improve the quality of life of affected children and their families.

NeuroDevNet leverages and enhances the talents of new and seasoned researchers in every province across the country, and engages families, clinicians, other stakeholders and partners—both nationally and internationally—to translate its findings into policy and clinical practice. It is the combination of all of these activities that makes NeuroDevNet unique in its vision and scope.

More specifically, NeuroDevNet is focused on deliverables, built on partnerships and achieving impacts. I would like to highlight three areas in particular where the Network is improving lives today, and working towards meaningful prevention and treatment for neurodevelopmental disorders in the future

We have made impressive strides toward proofs of principle for biomarkers for early diagnosis of autism spectrum disorder, cerebral palsy and fetal alcohol spectrum disorder. We also have made exciting inroads into the use of computer games and novel intervention programs to improve function and impact developmental trajectories.

NeuroDevNet is also building a 'Community for Brain Development' —a national action group focusing on the interconnection of key aspects of neurodevelopmental disorders including clinical innovations, issues surrounding transition to adulthood, and caregiver education. This Community will bring stakeholders together to leverage experience and ensure a unified and powerful voice articulating the importance of brain development to policy makers, educators and other stakeholders who are key to mobilizing the knowledge the Network is developing for best care and practice. This is yet another example of the uniqueness of our vision and scope.

As we head into our penultimate year of our first 5 year effort—one in which we apply the experiences of our first 36 months of highly productive collaboration, our goals in the home stretch—and the five year renewal beyond—are already taking shape.

NeuroDevNet will continue to pursue the identification of new genes with a causal link to neurodevelopmental disorders, develop accessible, effective screening tools that shorten wait times for assessment, and move strength based gaming technologies toward the marketplace. We will build on the evidence base for use of stem cells as potential regenerators of a damaged or delayed nervous system, widen the scope of disorders we research, and bring together diverse groups who are passionate about making a difference for children with neurodevelopmental disorders.

NeuroDevNet's Board of Directors has played a crucial role in supporting the Network's initial three years of development as well as laying the aroundwork for the future.

This year, three valued members of our Board have stepped down after completing their term. Peter Allen was part of NeuroDevNet's inaugural board and served as its vice chair. A true champion of research, Peter has made and continues to make impressive contributions to the cause of science in Canada. For example, he was an instrumental partner in evolving the mission and activity of the Canadian Institute for Advanced Research (CIFAR) before showing early support for NeuroDevNet

## COMMENT FROM THE SCIENTIFIC DIRECTOR EXECUTIVE DIRECTOR



Martin Dee

Dr. Bernie Bressler was the Board's first Chairman, helping to recruit the Network's initial board, and also served as the chair of the Finance and Audit Committee. Bernie's contribution to R&D in Canada are also significant, both as an accomplished scientist in his own right and a pioneer in the commercialization of technology.

Dr. James Reynolds joined us this year as the representative of the Network's researchers on the Board. Dr. Reynolds is the principal investigator of NeuroDevNet's FASD Demonstration Project based at Queens University, and is an instrumental mover and innovator in FASD research in Canada.

Our profound thanks go to each of them, for helping ensure the current success of NeuroDevNet, and for paving the way for the achievements yet to come.

In all their diversity—the researchers, trainees, board, staff, partners and supporters who comprise and sustain NeuroDevNet-validate the NCE model. This unique structure and approach makes a difference scientifically, clinically, and societally for the one in six Canadian children affected by a neurodevelopmental disorder, for their families and their communities, and as an investment for the nation as a whole. For me, it is both an honour and a privilege to serve as Chairman of the Board of this magnificent enterprise.

Jem Roveld

Henri Rothschild

Chair of the Board of Directors, NeuroDevNet

In our third year, NeuroDevNet's passion for understanding the developing brain and helping children and families faced with neurodevelopmental disorders has continued unabated. We began translating the Network's discovery research into clinical practice. This process has been potentiated by our growing international presence, and stakeholder engagement that together have set the stage for years four and five of our original mandate, and are building momentum for our

A powerful example of this movement from lab towards clinic is the emergence of diagnostic tests for autism based on the discovery of four genes linked to this disorder. The lead scientist behind these findings, Dr. Stephen Scherer, has been a driving force behind the adoption of genetic microarray testing as standard diagnostic practice for autism spectrum disorder (ASD) across Canada.

Our fetal alcohol spectrum disorder (FASD) research group has established a cross-Canada data set linking behaviours seen in the disorder to brain structure and genetic profiles. This unprecedented synthesis will enable a more complete understanding of the state of a child with FASD, support the discovery of diagnostic biomarkers and help assess therapeutic interventions. International colleagues in France and the United States are taking note of this pioneering work: the Collaborative Initiative on FASD based at the US National Institutes of Health and a French group working with a high-risk population on Reunion Island in the Indian Ocean have initiated collaborations with our researchers.

How do maternal risk factors interact with the environment and geography in cerebral palsy (CP)? A trans-Canada CP registry championed by NeuroDevNet's CP research group is enabling Canadian researchers to probe these connections. Opportunities to pool data with Australia's Cerebral Palsy Research Alliance, and to promote and support registry development in Botswana are being driven by the international prominence and dedication of our CP team.

In early 2013, NeuroDevNet launched a Commercialization Committee to help move promising developments emerging from  $Neuro Dev Net's \, research \, towards \, the \, marketplace. \, Ten \, top \, opportunities \,$ will be actively promoted, including the CP Fit n' Fun Exergame that got its start within the NeuroGAMe project we co-funded with the GRAND NCF.

### COMMENT FROM THE SCIENTIFIC DIRECTOR EXECUTIVE DIRECTOR

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You'll find more information about all these developments among the pages in this annual report, as well as updates on our dynamic 344-member training and education program. Through direct funding, webinars, and expanded internship opportunities with Mitacs, our trainees have a tremendous range of opportunities to expand their horizons within their home lab and specialization, and beyond.

Our autism investigators were key participants in two high profile national newspaper series that spurred prospective policy change in ASD services in the Province of Ontario. Following the coverage, Ontario established an expert panel to guide and streamline autism services, a move that had been promised, but delayed for two years. Three NeuroDevNet researchers are members of this provincial panel.

Our Network is continuing to create capacity for policy impact in other venues. Through our annual Day on the Hill, and continued engagement with policy makers, we are helping raise the profile of neurodevelopmental disorders on the floor of the House, as well as cultivating national consideration of their prevalence and status in Canada through HESA, the Federal Standing Committee on Health. We have also begun laying the groundwork for a Community for Brain Development—an alliance of organizations that come together because of shared interest in brain development and joint action to improve the lives of children.

Many people stand behind these achievements. We particularly thank the Network researchers, the members of our Board, our Research Management Committee, our Research Training Committee and our Scientific Advisory Board for their valued contributions and guidance.

There are many more exciting developments to come as we work toward the renewal of the network in the coming year, and are thankful for your interest as together we reach for the goal of helping children and families overcome neurodevelopmental disorders.

Dr. Daniel Goldowitz

Scientific Director, NeuroDevNet

Nicola Lewis

Executive Director, NeuroDevNet

## **IRECTORS**



#### Margaret Clarke, MD

Dr. Clarke is currently a Professor in the Faculty of Medicine, Departments of Pediatrics and Psychiatry and is also a Professor in the Department of Child Studies at Mount Royal University. She was the founding Executive Director of the Sinneave Family Foundation and The Ability Hub. She is now the Senior Vice President of the Foundation and leads for science, practice and policy areas for the Foundation. She held the Fraser Mustard Chair in Childhood Development at the University of Calgary until 2011. Dr. Clarke has served on the National Expert Advisory Committee of the Centres of Excellence for Children's Well-Being and the Board of the Alberta Centre for Child, Family and Community Research. She also chaired the Expert Advisory Panel on Autism for the Province of Alberta. Dr. Clarke teaches and supervises many undergraduate and graduate students from medicine, nursing, psychology and education as part of her strong commitment to interdisciplinary education. She has designed new clinical practice guidelines and educational programs for physicians, judges and child care professionals through the Brain in Mind program at the University of Calgary, Child Development Centre. Dr. Clarke has also developed a number of innovative community outreach programs in schools, women's shelters and rural communities all aimed at getting earlier and better identification of children and youth with developmental and mental health concerns. She was named one of the 100 top physicians of the century by the Alberta Medical Association and received a Centennial Medal in recognition of her unique contributions to the field of child health and development in Alberta. In 2013 Dr. Clarke was awarded Queen Elizabeth II Jubilee Medals in recognition for her contributions in the field of autism.

## BOARD OF DIRECTORS NEW MEMBER PROFILES



#### Sheila Laredo, MD, PhD

Dr. Sheila Laredo is an Assistant Professor at the University of Toronto in the Faculty of Medicine. Her clinical interest is in women's reproductive health, and particularly, polycystic ovary syndrome (PCOS). Her research interest in PCOS focuses on the role of insulin resistance and obesity on reproductive health outcomes. Dr. Laredo received her MD from the University of Toronto in 1991, and specialized in endocrinology and metabolism. She holds a PhD in clinical epidemiology. She is an enthusiastic teacher, has supervised many students, residents and fellows, and has been the recipient of research and teaching awards. At Women's College Hospital, she has been recently appointed Chief of Staff. She is also the parent of four children, two of whom have Autism Spectrum Disorders (ASD). She has advocated for 13 years for effective evidence-based interventions for children with ASDs. This has included her participation in a Charter of Rights challenge (Wynberg et al v. Ontario) as a litigant and expert witness. Dr. Laredo has worked with individual families to help them obtain services, with the Ministries of Children and Youth Services and Education in the Government of Ontario (member of Autism Reference Group and Expert Clinical Panel), and participated in the legislative process (e.g. Senate of Canada at the Enquiry on the Funding for the Treatment of Autism, the Standing Committee on Social Policy in Ontario Legislative Assembly on the Developmental Services Act). She continues to advocate for the creation of public policy that provides appropriate evidence-based services and support for individuals with ASD and other disabilities throughout their lives. She is teaching medical trainees about public health policy advocacy and has supervised several social justice advocacy initiatives with these students.



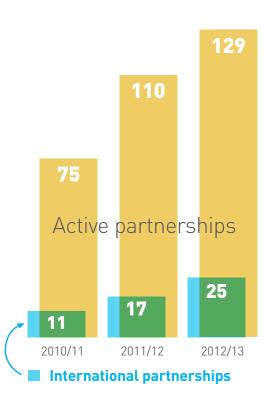
#### Judy Illes, PhD, FRSC, FCAHS

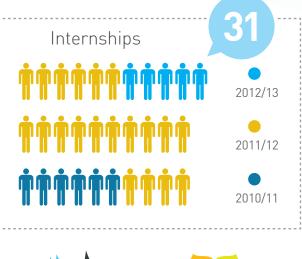
Dr. Judy Illes, Professor of Neurology and Canada Research Chair in Neuroethics at UBC, is Director of the National Core for Neuroethics at UBC, and faculty in the Brain Research Centre at UBC and the Vancouver Coastal Health Research Institute. She also holds affiliate appointments in the School of Population and Public Health and the School of Journalism at UBC, and in the Department of Computer Science and Engineering at the University of Washington in Seattle, WA, USA. She is an elected fellow of the Royal Society of Canada, of the Canadian Academy of Health Sciences, and of the American Association for the Advancement of Science. As a pioneer and eminent scholar in the field of neuroethics, she has made groundbreaking contributions to ethical, social, and policy challenges at the intersection of biomedical ethics and neuroscience, with a specific focus on neurodevelopmental disorders, aging and dementia, addiction and mental health, neuroimaging, stem cells, cross-cultural values, and the commercialization of health care.

### BY THE NUMBERS 2012/2013

This segment of the annual report, as introduced in 2011/2012, will demonstrate growth of the Network and vital statistics that provide insight into impacts discussed in narrative form in the report.











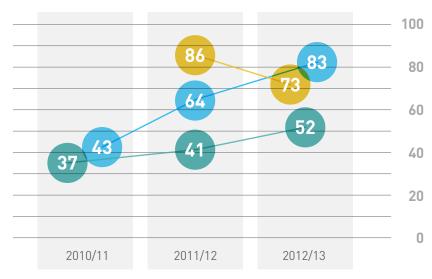
Articles in refereed publications

Patent applications

### Growth of Network research teams

- Project-supported trainees and young professionals
- Network supported investigators
- Network

  Membership
  Applicants





**\$17.3M** 2012/13

**\$18M** 2011/12

Regional representation

Doctoral

of currently supported Trainees and Investigators by NeuroDevNet research projects & fellowships

Sr. Research

		Assistants Candidates			es A	Associates		
City	Associat Techs	-	Master's Candidate		ostdocto Fellows		TRAINE TOTALS	
Halifax	9			3			12	•
Montreal	18	2	1	8	3	4	36	
Ottawa	1			1	1		3	
Kingston			1	2	1	2	6	
Toronto/GTA	9	5	1	8	8		29	
Winnipeg					1		1	
Saskatoon	1		2	1			4	
Edmonton	12	2	3	6	3		26	
Calgary	1		1				2	
Vancouver	11	2	9	8	4	3	37	
Victoria				1			1	
Totals	62	11	18	38	21	7	157	

Undergrad

Network vestigato		Mentors				
	Associate vestigato		FACULTY TOTALS	1		
1	4	1	6	0		
10	2	3	15	0		
	1	1	2	0		
3		1	4	0		
9	4	3	16	0		
1			1	0		
1			1	O		
5	2	1	8	0		
1	2		3	0		
8	6	4	18	0		
2		1	3	0		
41	21	15	77*			

\*Four Network Investigators are also Mentors of NeuroDevNet Fellows

#### Audience engagement social media and website





# RESEARCH PROGRAM UPDATE **AUTISM SPECTRUM DISORDER**

#### Closing the Gap on Identifying the Genetic Roots of Autism

Dr. Stephen Scherer's Toronto lab is one of the epicentres in an international drive to identify the genetic variants associated with autism spectrum disorder (ASD). There, in the MaRS facility in Toronto's University-Hospital Core, the co-lead of NeuroDevNet's autism research group is bringing the world closer to the underlying causes of autism and biologically based tools for diagnosis.

Emboldened by the vast technological resources vested in a joint project with the Beijing Genomics Institute and Autism Speaks that aims to analyze the whole genomes of 10,000 ASD-affected families around the world, Scherer's group ventured the very first whole genome analysis in the disorder drawing on Canadian data. Their study of 32 families produced a startling finding: as many 50 percent of people with ASD may have an identifiable genetic variant that explains some of their symptoms.

"Whole genome analysis (WGA) enabled us to look at the full extent of genetic involvement in ASD for the first time." Scherer says of the \$1 million pilot study supported by NeuroDevNet and the Beijing project partners. He and his colleagues found associations with ASD in four genes not previously linked with the disorder.

High-quality, multi-generational data from Network Investigator Dr. Peter Szatmari and Autism research group Co-Lead Dr. Lonnie Zwaigenbaum "was critical to the study," he adds. "The power was often having multiple affected people in a family, in multiple generations, as well as unaffected kids, to look at segregation. This highlights the unique contributions and capacities of the network."

Scherer believes whole genome analysis has the potential to identify even more genetic variants in ASD than current sequencing strategies. "Our findings have primed many other things coming soon, and many ideas to follow."



### RESEARCH PROGRAM UPDATE AUTISM SPECTRUM DISORDER

#### Who is Likely to have Autism, and How Early can it be Detected?

NeuroDevNet researchers are challenging accepted notions about who is likely to have autism, and how early it is possible to diagnose a child with ASD. In multiple longitudinal studies of highrisk infants—the younger siblings of children with autism—the ASD research group is identifying behaviors that indicate ASD in young children as early as 12 months of age, as well as highlighting that girls may be almost as likely to have the disorder as boys.

"We are defining an early ASD phenotype," says Autism research group co-lead Lonnie Zwaigenbaum. "Autism researchers have been challenged by the lack of objective measures to characterize the broad range of observable characteristics, or traits, related to the disorder."

"If we can intervene in this window of six to eighteen months, it's not inconceivable we'll be able to prevent autism. That would be a remarkable game changer."

Dr. Peter Szatmari, network investigator

In Canada, the typical age of diagnosis is four, while a review conducted by Zwaigenbaum, NeuroDevNet Investigator Dr. Susan Bryson, and Dr. Nancy Garon found robust evidence that ASD can be detected as early as one year. "We're talking about things you can see with your own eyes," says Bryson. "You don't need sophisticated tools. That's the importance of our findings."

It's crucial that frontline physicians become aware of these advances, she adds. "While progress has been made in detecting autism earlier—some based on genetic testing—too many toddlers are being missed. The reasons for that are complex—some GPs may not feel comfortable picking up early signs of ASD. They need to know what questions to ask, and what they should look for."

They should certainly be looking for signs of ASD in girls, as well as boys, especially in families where there is already a child with autism. Prior research pegged boys in the general population as being four times more likely to be diagnosed, while a NeuroDevNet-led team of top Canadian autism researchers found only modest differences between three-year-olds of both genders in terms of prevalence, cognitive and adaptive skills, and the severity of ASD symptoms.

"This raises the possibility that girls with ASD may be underrecognized clinically," says Zwaigenbaum, "or at least that the rates of ASD may be more similar in boys and girls in families where there is already an older child with the disorder."

Unusual use of toys, such as only playing with trucks and cars upside down, or fiddling with, mouthing or dropping them can be a sign of ASD in young children.



High-risk siblings may show autism-like traits as early as six months, according to a cross-Canada study involving both Zwaigenbaum and Peter Szatmari. This is the earliest that autism traits have been identified in children. The study followed 500 children born to families with a history of autism, and found 40 percent of the children had autistic traits at 12 months. Only half of these children went on to be diagnosed with autism at age three.

"The key point of the paper is that many highrisk infants show symptoms by 12 months, but not all go on to a diagnosis of ASD," says Zwaignbaum. "Early social communication symptoms are related to ASD, but are not diagnostic.

"The data suggest that the 'diagnosis' of autism represents a threshold across a continuum of ASD traits seen in relatives of children with ASD." says Szatmari. "If we can intervene in this window of six to eighteen months, it's not inconceivable we'll be able to prevent autism. That would be a remarkable game changer."

Taken together, the findings shed new light on patterns of symptom onset and progression that can assist clinicians in early detection and diagnosis of ASD, according to Zwaigenbaum. "Differences in social engagement and play behaviour are visible long before children with ASD are diagnosed," he adds. "If these differences could be targeted by interventions designed specifically for this age group, we may help at-risk infants get back on track developmentally, and ultimately, reduce disability and enhance quality of life for these children and their families."

# RESEARCH PROGRAM UPDATE CEREBRAL

#### **Collaboration Moves Cerebral Palsy** Research to the Next Level

When NeuroDevNet launched as a network, individual researchers who became part of the cerebral palsy (CP) research team worked mostly in isolation. Communication with provincial cerebral palsy associations was sparse, projects were confined to individual labs, and local CP communities and researchers were not well connected.

In a short period of three years, the cerebral palsy research culture within the Network has shifted decidedly towards collaboration, according to CP research group co-lead Dr. Jerome Yager.

"We used to work alone in silos across the country, but now we're working more cohesively and interacting with communities and cerebral palsy associations more effectively," says Yager, a pediatric neurologist and research scientist from the University of Alberta. "This can only lead to more rapid findings, and a better understanding of how cerebral palsy affects our children and families."

The new model of collaboration has taken many forms, such as the 2012 Edmonton CP in Motion Conference, organized by Dr. Yager. The conference drew a wide array of attendees, from physicians and researchers to students and families living with CP. Presentations from CP in Motion are being assembled for publication in an international journal dedicated to the event.

NeuroDevNet's CP research group presented their cutting-edge work in the field, including Dr. Michael Shevell's leading role in developing the national cerebral palsy registry, Dr. Michael Fehlings' promising use of stem cells to treat white matter brain injury in animal models, and Dr. Steven Miller's supporting, landmark work on the potential of magnesium sulphate to prevent brain injury in the developing fetus.

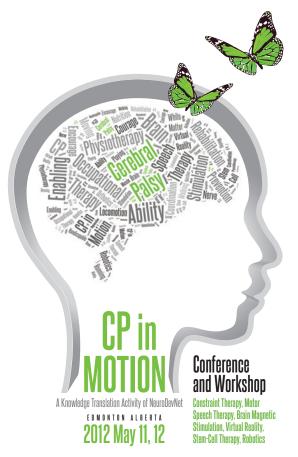
The diversity of the research presented at the conference—and what that means for the future—has enthused Dr. Darcy Fehlings, director of the Child Development Program at the Holland Bloorview Kids Rehabilitation Hospital in Toronto.

"I'm truly excited about having an integrated national neuroscience team that is spanning basic and translational cellular neuroscience, all the way up to working with children and families—having that whole spectrum is really unique and fabulous."

Dr. Darcy Fehlings, co-lead, Cerebral Palsy research group

"I'm truly excited about having an integrated national neuroscience team that is spanning basic and translational cellular neuroscience, all the way up to working with children and families," says Fehlings. "Having that whole spectrum is really unique and fabulous."

Dr. Yager agrees. "Translational medicine is one area where NeuroDevNet has made a big change," he says. "In the previous decade we learned a lot about the brain but hadn't seen a lot of advancement in the treatment of children with CP. We're now starting to see some of the fruits of that knowledge. An excellent example is the use of constraint-induced physiotherapy and the work that Dr. Darcy Fehlings is leading in our group, using exercising and virtual gaming to enhance movement. We're having a greater understanding of a very complex disorder, and I hope to see that grow even further as we look forward."



Vancouver Sun intern and UBC Masters of Journalism Student Katelyn Verstraten reported and co-authored this, and all other stories related to cerebral palsy in this publication.

# RESEARCH PROGRAM UPDATE CEREBRAL PALSY



#### **Neuroimaging Insights on how Magnesium Sulphate** Protects the Infant Brain from Cerebral Palsy

A premature infant, only two weeks old, sleeps in an incubator designed to fit in an MRI scanner. As the baby peacefully rests, the machine bangs and whirls, producing images of the infant's brain that will detect signs of brain injury.

Dr. Steven Miller, a NeuroDevNet network investigator, has been using advanced neuroimaging techniques such as this to examine the effects of magnesium sulphate in preventing brain injury in premature infants.

"We now have this amazing tool to look at the developing brain, and understand the things that we do that are brain protective, like magnesium sulphate," he says. "We can identify new opportunities for brain protection through that."

Brain injuries that occur during pregnancy—such as white matter injuries—can cause neurodevelopmental disorders such as cerebral palsy (CP). Despite advances in medical technology, the high prevalence of CP—it affects 2-3 in 1,000 Canadians—has not decreased. This has motivated researchers, including Dr. Miller and his team, to explore ways to protect the young brain-including treating pregnant mothers with magnesium sulphate.

"With the support of NeuroDevNet we were able to look at a group of babies that were treated with magnesium sulphate," he says. "We saw a dramatically lower rate of white matter injury in the brain scans of the magnesium-treated babies."

Having detected this link, Dr. Miller and his team are seeking an answer to the main question: why? "What is magnesium sulphate doing to the brain to result in the lower rate of cerebral palsy," asks Miller. "I hope that if we understand that, we'll be able to use magnesium sulphate even more effectively."



## RESEARCH PROGRAM CEREBRAL



#### North America's First Cerebral Palsy Registry **Draws International Acclaim**

NeuroDevNet investment has revitalized a small cerebral palsy registry in Quebec, providing the resources to help build it into an internationally acclaimed, trans-Canadian initiative.

Launched in 2000, the Quebec registry was the first of its kind in North America, created with the hope of providing a detailed background on the prevalence, frequency, and spectrum of cerebral palsy in the province. After five successful years, funding ran out and the data was stored.

Five years later, drawing on NeuroDevNet resources and the dedicated leadership of Principal Investigator Dr. Michael Shevell and his colleagues, the registry was re-established and expanded to include data from Greater Toronto and northern Alberta.

Additional funding from the Public Health Agency of Canada enabled further expansion. The registry is now active in six provinces, including southern Alberta, Newfoundland, Nova Scotia and British Columbia.

"It is increasingly recognized as one of the largest registries in the world," says Shevell. "It's also consistently enrolling patients and may be expanding within Canada." Talks are underway about extending the registry to include the Province of Manitoba.

Information from the registry is already being utilized in major studies. A January 2013 study published in Neuroepidemiology provided an estimate of cerebral palsy prevalence in Quebec. In 2012, a paper published in Pediatric Neurology utilized data from the registry to demonstrate that in utero exposure to alcohol or tobacco is not a predictor of cerebral palsy.

"As we hoped, the registry is helping us increase our understanding of CP in Canada," adds Shevell. "We're learning more about geographic distribution and how frequently it occurs, as well as the type, severity, suspected cause and conditions associated with the disorder."

NeuroDevNet registry data is also being consulted and pooled internationally, in EU countries, as well as Australia. Collaborations have deepened as a result.

"We are very fortunate in Quebec that all placentas are examined," says Shevell. "That's not the case in many, many places in the world. And, as a result we're able to cross-link our CP registry data on the pathology of these placentas. They are also interested in looking at this in Australia, so they've invited us to be a part of their group—it's very exciting."

## RESEARCH PROGRAM FETAL ALCOHOL SPECTRUM DISORDER

#### **Comprehensive Understanding** of Brain Damage in FASD Points to **Diagnostic Potential**

The ability to compare brain development, genetics and behaviour between children with FASD and their typically developing peers could set the stage for a major medical advance in diagnosis of neurodevelopmental disorders.

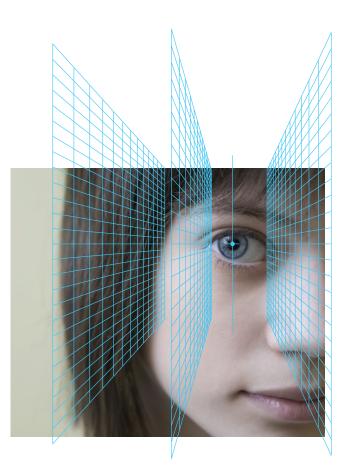
Eye tracking—the measurement of either the point of gaze, or the motion of an eye relative to the head, has, at baseline, given the Network's researchers a potentially powerful and non-invasive tool for assessing brain function. "That's where we are today, not where I think we can go in the future," says James Reynolds, co-lead of the Network's FASD team.

"What we're specifically interested in, is finding out if eye tracking data can be used to model behaviour, and be predictive of different types of brain damage. Can it differentiate children with FASD from typically developing kids, and can the same approach be used to differentiate a child with FASD from one with ASD or ADHD?"

"We generate an enormous amount of information from basic science," adds Reynolds who is based at Queen's University in Kingston, "but we have very few tools that would allow us to translate those data objectively, and evaluate them within a clinical population." That's the potential Reynolds sees in eye tracking. Incorporated into a pioneering database that integrates neurobehavioural information, brain imaging, genetic and epigenetic data, eye tracking helps provide a comprehensive portrait of the 238 children, half with FASD and half typically developing, who are involved in the group's ongoing research.

"I don't believe there's a data set that's as large and comprehensive as this one," says Reynolds. "It's the result of a cross-Canadian study drawing from six different FASD clinics in four provinces."

The uniqueness and the potential of the data have drawn international attention. In the US, the National Institutes of Health has been pursuing similar research, with a similar sample size, but has drawn its findings and study participants from different groups of children. "If we can bring the data sets together," says Reynolds, "that will create the largest data set in FASD anywhere. That would be incredibly powerful—you'd really be able to have confidence on structural brain injury in kids with FASD."







#### Harnessing New Media to Mobilize Information about FASD

Families affected by FASD are incredibly hungry for new knowledge and better understanding of therapies and interventions under development.

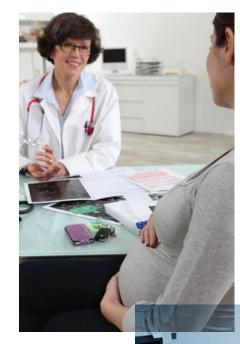
"We know this because of our contact with families for many years," says Joanne Weinberg, co-lead of the FASD research group. "They're looking to NeuroDevNet for information. It's what Elspeth Ross, a parent advocate who attended NeuroDevNet's first meetings with parliamentarians said—'NeuroDevNet represents hope'.'

With this in mind, the FASD research group has entered into a number of new partnerships and collaborations that are specifically aimed at increasing knowledge mobilization among both stakeholders and policy makers. NeuroDevNet's FASD researchers and their work in areas including diagnostic assessment, neurobehavioural characteristics of FASD, interventions, and clinical studies were showcased in a series of webinars produced by the Canadian Association of Pediatric Health Centres (CAPHC), and the Canadian Network for Child and Youth Rehabilitation (CN-CYR), in partnership with the Public Health Agency of Canada. Based on feedback collected by CAPHC, "people from all over the place, a real mix of backgrounds, including teachers and social workers were accessing the webinars," says James Reynolds. "They were feeling a need to get more information about the topics."

A collaboration with the Ontario College of Art and Design is shedding new light on the lived experience of people affected by FASD. Provided with tools and models for data visualization, young artists are drawing from the FASD research group's wide-ranging database, to portray intersections of family relationships, social skills, cognition, geography and behaviour through artistic expression. "They're asking new research questions we wouldn't necessarily ask," adds Reynolds, "and exploring better ways to communicate research findings to stakeholders, whose decisions have tremendous impact." A future exhibit of the works is being planned in collaboration with York University.

Recruitment is underway for the first phase of The Strongest Families Initiative, looking at the accessibility of four web-based pilot modules aimed at supporting families and caregivers dealing with challenging behaviours. The full program, consisting of 11 modules, is expected to take three months to complete, and has been developed in collaboration with the IWK Centre in Nova Scotia, and the Public Health Agency of Canada. "Families don't live next door to treatment centres or support services," adds Joanne Weinberg. "That's why we went this way."

## RESEARCH PROGRAM FETAL ALCOHOL SPECTRUM DISORDER



#### **Cross-pollination within FASD** Research Group Triggers Insights

Multi-disciplinary collaboration within the FASD Research Group is fueling insights into the genetic basis of the vulnerability of the fetal brain to alcohol exposure, as well as the nature and implications of the damage it causes.

Animal studies are tightly linked to clinical research, each informing the other. "It's a very powerful setup for discovery," says Albert Chudley, co-lead of the FASD research group based at the University of Manitoba. "Not just for potential markers for diagnosis, but problems that have some therapeutic implications. We're likely soon to see some payoffs—for example, being able to identify individuals with a genetic or epigenetic (genes being turned on and off by experiences and environment) pattern associated with prenatal alcohol exposure and its effects will allow diagnosis or interventions essentially from birth onwards."

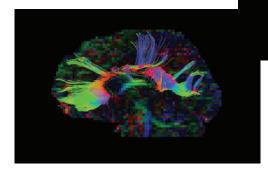
Taking off from the genetics work in the research group's clinical project, Joanne Weinberg and her trainees have examined changes in gene expression—how and to what extent genes are switched on and off in the brains of rats exposed to alcohol before birth. In collaboration with UBC clinical researcher Michael Kobor, they have found that exposure significantly affects the expression of 19 genes involved in key processes critical for normal brain development, including cell death, neurodevelopment, neuronal signaling, and transcriptional regulation.

#### "It's a very powerful setup for discovery."

Dr. Albert Chudley, co-lead FASD Research Group on the close linkage of animal studies and clinical research within the FASD team.

Exciting preliminary data in another study is suggesting a connection between prenatal alcohol exposure, stress hormones, social status, and cognitive function in rats. This research is the basis of a developing collaboration with clinical FASD researchers Carmen Rasmussen, Jacqueline Pei and Kaitlyn McLachlan at the University of Alberta, and Tim Oberlander at UBC, who are examining possible links between cognitive/executive functioning, social and environmental factors in early life and cortisol levels in their sample of children with FASD.

"Stress hormones have very important influences on many systems, including metabolism, nervous system function, and the immune system," says Weinberg. "It's clear that alcohol exposure has implications not only for physiological, behavioural and cognitive functioning later on in life, but also for long-term physical and mental health. What we're hoping is that looking at the regulation of the stress system in kids with FASD can provide a possible biomarker for prenatal alcohol exposure," she adds. "That can inform how we might approach developing interventions."



Images of the corpus callosum, a thick band of nerve fibers that divides the brain into left and right hemispheres in a child with FASD (I) and a typically developing child (r). The FASD-affected brain has fewer connections and structures are not well organized.

#### Biomarkers a Good Tool for Informing Families, but not yet Accepted by Clinicians

Advanced MRI scanning techniques of the brain are enabling researchers to obtain new information about neonatal insults to the brain, but clinicians vary in their acceptance of the scans as a potential prognostic tool.

MRI has long been used to identify white matter damage, but new MRI methods, such as diffusion tensor imaging, are opening the way to establishing biomarkers—such as the distinct hallmarks of the white matter injury seen in CP—that can be used to predict outcomes after newborn hypoxic ischemic injury, or stroke.

Neuroethics Co-Lead Dr. Éric Racine, Associate Researcher Dr. Emily Bell and their collaborators surveyed pediatric neurologists and neonatologists regarding the use of MRI biomarkers for predicting outcomes after newborn hypoxic ischemic injury (stroke). The collaboration with NeuroDevNet's Cerebral Palsy research group revealed that clinicians do not yet agree on the value of advanced MRI biomarkers for prognostication.

"At this point, MRI biomarkers are cutting edge," says Racine. "They are beginning to be introduced in clinical environments." As a result, Racine and colleagues found great variability in terms of access and availability of MRI to clinicians, as well as variability in the time at which children were assessed.

"It's a puzzling issue in our findings that on the one hand, there is variability in access to follow-up MRIs, and some clinicians lack confidence in the reliability of MRI interpretations. On the other hand, physicians are rather enthusiastic about biomarkers for educating family members and for their use in end-of-life decision making. This finding is a bit of a paradox. We're not sure what it means, but we're hoping to sort it out."

Racine says the group has followed up the initial CP research with an interview-based study. "We're interested in why physicians are answering the way they are, and in examining the related ethical implications," says Racine.

The Neuroethics group has also collaborated with NeuroDevNet's FASD investigators on a perspective paper examining the ethical challenges of screening infants for prenatal alcohol exposure. "We're looking at what it might mean to have a biomarker for FASD," says Neuroethics Co-Lead Judy Illes. "A positive finding could potentially criminalize a new mother—you have to think about that up front, not after," she says.

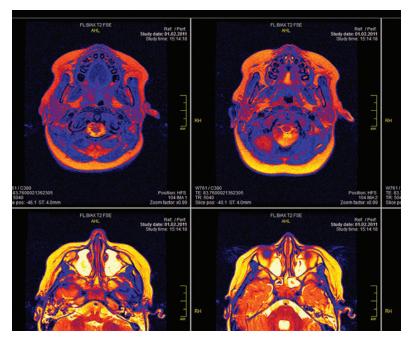
"It's really a special case," agrees Racine, "in terms of analyzing prenatal alcohol exposure and the predictive value of alcohol metabolites. It's not necessarily a diagnosis, but it's a red flag."

Following a 2012 session at NeuroDevNet's annual conference on the value and ethics of biomarkers in FASD. Drs. Bell and Racine together with Dr. Nina Di Pietro from the Vancouver arm of the Neuroethics team, collaborated with FASD experts on a review paper identifying the challenges involved in clinical settings. The work is slated to appear in the Canadian Journal of Neurological Sciences.

"Research on advanced MRI biomarkers is moving very quickly ahead, and at the same time the ethical challenges of using them clinically in new contexts needs to be explored with clinical stakeholders," says Racine.

"We don't yet know what it means for parents. We communicate with them, but we don't necessarily understand what it means from an ethical standpoint to learn about prenatal alcohol exposure on the basis of biomarkers. The next generation of work should be looking at the impact of MRI biomarkers on the values and preferences of the stakeholders—both clinicians, and families."

## ESEARCH PROGRAM



#### When a Brain Scan Bears Bad News, Youth Have a Right to Know

Adolescents deserve a say when a brain scan reveals unanticipated, but potentially clinically significant findings.

NeuroDevNet's Neuroethics group has created a framework that for the first time, takes into account the rights of competent youth to be involved in decisions about disclosure of what are called "incidental findings" or IFs, in neuroimaging studies.

The framework, entitled "Guidance for Consent and Communication," not only seeks to protect the rights of individual youth, it also addresses the burden placed on the researcher, who must otherwise decide whether or not to share information arising from a scan. This is especially challenging if study participants have indicated they don't want to know about anything unexpected.

"What our data suggest is that in youth and adults, plans for disclosures of incidental findings in imaging research needs structure," says Dr. Judy Illes, Co-Lead of the Network's Neuroethics team. "The framework approach tells you how to set up, how to manage, when to tell, who to tell, how to tell, and how you follow up.

"People are now obligated to know about their genetic results. A similar requirement should exist for people who wish to participate in brain imaging when a significant concern arises during the research," adds Illes.

An article on the framework by Illes and Senior Research Fellow Dr. Nina Di Pietro at UBC's National Core for Neuroethics is in press with the Journal of Magnetic Resonance Imaging. The recommendations were highlighted in a 2012 workshop on the management of IFs in brain imaging research, in which the Network's Neuroethics team played a leading role.

Supported by NeuroDevNet and the US National Institutes of Health (NIH), the workshop focused on 1) persisting concerns about the handling of IFs that included problems of standardization, communication, negative effects of incidental findings on participants, and pitfalls of the current interface between research and medicine, and 2) ethical concerns specific to IFs in vulnerable populations, including the potential for exacerbating mental health disorders such as anxiety, diminished capacity of participants, youth and poor access to follow-up care. The "Guideline for Consent and Communication" that emerged from the workshop is part of a trio of developments that are moving the dial forward on incidental findings, according to Illes.

The Canadian and US experts in law, physics, economics, neuroradiology, and neuroimaging who attended the workshops are collaborating on the Guideline, as well as an FAQ for incidental findings, and specific guidance planned for publication by NIH, alongside a forthcoming report by the Presidential Commission on the Study of Bioethical Issues.

"We are hoping for widespread uptake of these new recommendations alongside the important and ongoing discussions about best practices, especially as new ways of acquiring information about the brain from youth emerge, such as combined technologies that use both imaging and genetic testing," says Illes.

## RESEARCH PROGRAM UPDATE **NEUROETHICS**



#### Ethics of Care Examined as Children with **Neurodevelopmental Disorders Transition** to Young Adulthood

Investigators from all three of NeuroDevNet's disorder-focused research groups gathered in Montreal in February 2013 with the Network's Neuroethics team to examine the role of ethics in understanding the experiences of individuals with neurodevelopmental disorders during transition.

Twenty-three researchers joined in developing potential solutions for challenges that included lack of support and lack of understanding of how to navigate the health care system.

"We came up with four general recommendations: one of them was moving from the goal of autonomy to more personalized goals," says Neuroethics Co-Lead, Éric Racine. "You also have to tailor care to the needs and preferences of individuals, acknowledge that better understanding is needed of transitional care, and address negative care provider attitudes to people with neurodevelopmental disorders.

> "This is where we see the potential of incorporating ethics into clinical practice... we can have a transformative impact."

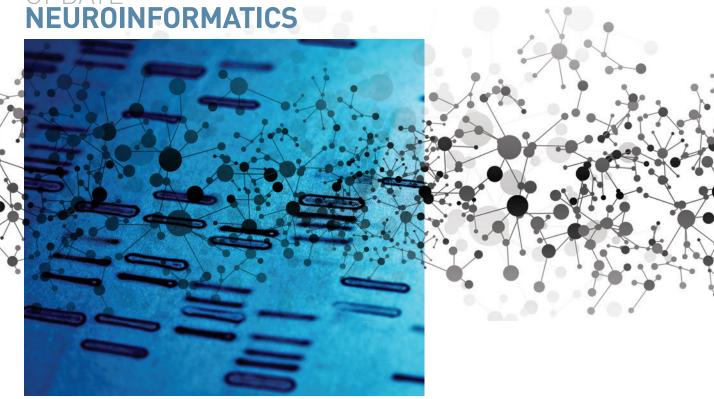
> > Éric Racine, co-lead, Neuroethics research group, on young adults with neurodevelopmental disorders learning to navigate within the health care system

"We don't understand the impact of the whole stage of transition —it's a huge ethical area that can lead to stigma," says Racine. "We're calling for transition programs to incorporate ethics into their general approach. Building this capacity should be the goal of a transition program."

The group has applied for a CIHR Knowledge Synthesis Grant to continue their exploration of ethics in transition. "I would love to do more work in this area," says Racine.

"This is where we see the potential impact of incorporating ethics into clinical practice. We have learned attitudes can have a negative impact on transition. If we offer better support, young adults can be much better prepared to navigate through the system and experience respect for their values. That's highly stimulating from a research perspective," adds Racine, "because we can have a transformative impact."

## RESEARCH PROGRAM UPDATE NEUROINFORMATICS



#### **Neurocarta Database Advances:** Understanding of the Genetic Basis of Neurodevelopmental Disorders

NeuroDevNet's Neuroinformatics team released its massive database linking genes to phenotypes in February, representing a major contribution to understanding the genetic basis of neurodevelopmental disorders as well as improving diagnosis and treatment.

Neurocarta enables tracking and exploring of associations between genes and disorders, allowing researchers to look for candidate genes for any disorder of interest within one consolidated database. Researchers can also enter annotations from their own experiments and analyze them in the context of other researchers' observations.

Currently, the database holds over 40,000 lines of evidence linking more than 8,000 genes to more than 2,000 different disorders. Neurocarta's release and a concurrent 2013 publication in BMC Genomics have triggered interest in partnerships among other disease-based genetics groups, nationally and internationally.

Neuroinformatics Lead Dr. Pavlidis and Project Manager Dr. Elodie Portales-Casamar have been pursuing opportunities to obtain more data and boost the utilization of Neurocarta data in other resources. They are particularly excited about using Neurocarta in collaboration with Scripps Research Institute researchers in San Diego, who publish genetic information to Wikipedia. "We're providing our data on genedisease relationships to increase the quality of the information on genes and diseases in Wikipedia," says Pavlidis.

In addition, Neurocarta is also helping NeuroDevNet FASD researchers choose candidate genes for focused analysis in their genetics project. "That project involves looking for susceptibility genes for damage from prenatal alcohol exposure," adds Pavlidis. "Our role is helping them make the best use of existing information from the scientific literature, and Neurocarta is the platform of choice.

"Neurocarta is a unique resource for neuroscientists working on brain development," says Pavlidis. "Neurocarta's potential is just beginning to be realized and explored."

"Neurocarta is a unique resource for neuroscientists working on brain development its potential is just beginning to be realized and explored."

**Dr. Paul Pavlidis,** lead, Neuroinformatics team

## RESEARCH PROGRAM UPDATE NEUROINFORMATICS



#### **Platform for Complex Data Management Supports Integration of Neuroimaging**

LORIS, the third pillar of data management customized for NeuroDevNet, is now actively supporting analysis for all three of the Network's major research projects.

The most recent information integrated into the web-based data management system was neuroimaging data from the Network's Cerebral Palsy research group. LORIS, which stands for Longitudinal Online Research and Imaging System, was originally developed by Imaging Lead Dr. Alan Evans and his team for the US National Institutes of Mental Health's 10-year study of normal brain development. It is designed to integrate behavioural and imaging information.

Within NeuroDevNet, the platform is currently being used to manage all collected data, and as a query interface for retrieving data in a specific context. "One example is the FASD research group," says Neuroformatics Project Manager Dr. Elodie Portales-Casamar. "They've performed many clinical tests on their cohort. If one is interested in the results of a specific psychometric test where children have performed poorly, LORIS allows you to retrieve the data for that subset. Basically, it allows you to mine your data in the most flexible way possible."

"LORIS extracts, but doesn't extrapolate," adds Dr. Pavlidis. "It supports integration with other analysis tools. It also brings benefits for data integration and sharing, across NeuroDevNet research projects, and with researchers outside the Network."

Following a 2012 publication on LORIS by Dr. Evans's group in Frontiers in Neuroinformatics, the Neuroinformatics team has been involved in show-casing the capacity of the system to increase its use by other researchers.

# RESEARCH PROGRAM UPDATE KNOWLEDGE TRANSLATION



#### Mobilizing NeuroDevNet Findings through Innovative Outreach and **Engagement Strategies**

With one in six Canadian children now considered to have a neurodevelopmental condition, most of Canadian society is in some way touched by the need to improve identification, treatment and prevention of these conditions.

This is the backdrop to NeuroDevNet's strategy for creation, translation and application of knowledge. "As the Knowledge Translation team, in tandem with the Network's new Com-mercialization Committee, we have mobilized NeuroDevNet research and put it into the hands of an increasing range of stakeholders," says NeuroDevNet's Executive Director, Nicky Lewis.

"Some of the ways we've pursued this include our pursuit of policy impact through one-to-one engagement with parliamentarians and key committees and federal ministries, as well as provincial governments and ministries," adds Lewis. "NeuroDevNet's annual Day on the Hill has been tremendously successful in engaging interest and involvement with the Network, and in raising awareness of the NCE program itself."

"Our policy change panel at the Third Annual Brain Development Conference was tremendously successful in bringing highly experienced individuals with nuanced perspective to share insights on tools and strategies for federal and provincial engagement with the NeuroDevNet community," says KT Team Lead Nazeem Muhajarine. Panelists included Sir Albert Aynsley Green, England's first Commissioner for Children to give a keynote presentation, Dr. Sheila Laredo, a parent advocate and researcher, Dr. Isabel Smith, a NeuroDevNet researcher with expertise in autism and knowledge translation, and MP Dr. Kirsty Duncan (Etobicoke North) who has put forward numerous motions and spoken eloquently in connection with the needs of children with neurodevelopmental disabilities.

"NeuroDevNet's annual Day on the Hill has been tremendously successful in engaging interest and involvement with the Network, and in raising awareness of the NCE program itself."

Nicky Lewis, Executive Director

Three days after the conference, Dr. Duncan rose to speak in the House in support of Bill C-44—this was a proposed amendment to the Canada Labour Code aimed at providing employees with the right to take leave when their child is critically ill, passes away or disappears as the result of a crime. "Dr. Duncan stated the bill did not go far enough in supporting children and families affected by life-long conditions such as FASD and autism," says Muhajarine. "Subsequently, we provided background and evidence to Dr. Duncan related to motions she prepared for the House on FASD research and services.'

Creating a more formalized mechanism for engagement has long been an aspiration of the Network. Just taking shape, NeuroDevNet initiated planning and testing of concept for a Community for Brain Development. "The idea is to have an alliance of organizations come together because of their shared interest in brain development, who take joint action to improve the lives of children, especially those with neurodevelopmental disorders," says Chief Development Officer Jim Brookes.

"The community is primarily the brainchild of NeuroDevNet's Scientific Director, Dr. Goldowitz," adds Brookes. "We're very excited by this development."

## RESEARCH PROGRAM UPDATE KNOWLEDGE TRANSLATION

#### **Involving Stakeholders in Research** to Address Knowledge Gaps

Mapping the knowledge, needs and preferences of target audiences for research at the stage when a project is being conceptualized is gaining momentum as a KT strategy.

Persistent gaps between published evidence and clinical practice highlight the need for more engaged KT. As a result, the iKT toolbox was developed as a mechanism for integrating knowledge translation into NeuroDevNet research, and wider application.

An application of the iKT toolbox has been slated for a joint project with the Autism Demonstration Project and the McGill Centre for Genomics and Policy. The intent is to use the toolkit to map community needs and challenges in the area of early identification and intervention onto research funded by NeuroDevNet. The mechanisms to be used include an online quiz that measures understanding of the state of the science and imparts interactive feedback based on the user's grasp of the evidence. A survey to assess research participants' attitudes and expectations from genomics research will also be included.

A second application of the iKT toolbox is under development for NeuroDevNet-funded pre-clinical research on stem cell therapeutics, in partnership with the Cerebral Palsy Demonstration Project and the Stem Cell Network. The intent of this application of the toolbox is to help families interested in stem cell therapies and biomarkers.



ohoto: Katelyn Verstrater

## RESEARCH PROGRAM UPDATE **NEUROGAMES**



#### "Serious Games" are Entertaining and Therapeutic

Video games emerging from a collaboration between NeuroDevNet and the Graphics Animation and New Media NCE (GRAND) are in play and showing market potential.

NeuroGAMe, a NeuroDevNet/GRAND initiative teaming neuroscientists with researchers in computer science has produced three games that engage users with the same look and feel as market videogames, but also embed cardiovascular fitness, or the capacity to focus as part of the gaming experience.

CP Fit n' Fun Exergame, also known as Liberi, combines a customized exergame with a dedicated social network that allows for head-to-head contests—and socializing—over long distances, with the goal of preserving mobility and diminishing isolation among teens with cerebral palsy.

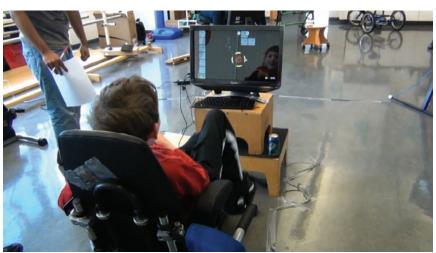
Caribbean Quest, a videogame aimed at younger children, builds capacity to pay attention, recollect, and manipulate objects. The game was initially piloted with children with FASD, and is also being trialed with children with autism through a Mitacs internship. (See Internship story about Andrew Sung, in Training and Education, page 32). A third project, based on a novel biometric feedback system, enables any commercial videogame to be turned into a "brain game." The technology has been piloted with children with FASD, and shows potential for use in other neurodevelopmental disorders.

To date, research involving brain games has focused primarily on the development phase. Further evaluation will be necessary to encourage uptake by the healthcare community. Receptivity and interest are there to be tapped, based on feedback from participants attending Intersection 2012: Advancing Digital and Assistive Technologies for the Brain and Body. The May 15-16 gathering cohosted by NeuroDevNet and GRAND at the University of Victoria drew 60 clinicians, researchers, and representatives of government and industry.

"This is one of the most exciting meetings I've been to because there's so much cross-fertilization," said attendee Lynda Thompson of the Biofeedback Institute of Toronto.

In Liberi, vigorous pedaling on speciallyadapted exercise machines powers customized videogames for kids with cerebral palsy (CP).

Keith Rozendal, 2012 NeuroDevNet/ Vancouver Sun journalism intern contributed reporting to this story.



photos this page: Keith Rozendal

#### RESEARCH PROGRAM UPDATE **NEUROGAMES**

Researcher Chris Bertram's project investigated the effects of interventions that build on the innate strengths of children with FASD. Participants showed improved behaviour and cognitive functioning.





Kids pilot submarines over coral reefs or direct scuba-based trash collection in mini-games that are part of Caribbean Quest. Piloted as an intervention for FASD, the game has also been trialed in the Sooke School District on Vancouver Island as an intervention for students with autism.

### TRAINING AND **EDUCATION**

#### **NeuroDevNet Trainees Right on "TrAC"**

NeuroDevNet's vision for trainees goes far beyond the lab bench. Their input is sought on program and project developments that are fundamental to the future of the Network.

TrAC, the Network's Training and Advisory Committee, is the brainchild of Training and Education Programs Manager Douglas Swanson, who has sought participation from trainees in all areas of the NeuroDevNet community. The first iteration, established in 2012, has six members, including Master's and Doctoral students, Postdoctoral Fellows, as well as new junior faculty members.

"My goal is for this team to serve as an action committee," says Swanson. "We would like their input on how our programs have served their needs, for example what they've learned from us, what's been good, and what hasn't. This is really helpful for developing our programs."

This level of involvement reflects the Network's reciprocal commitment to its trainees, according to David Eisenstat, the Chair of the Research Training Committee. "NeuroDevNet has a duty to train the next generation of highly qualified personnel to investigate brain development and its associated neurodevelopmental clinical disorders," he says, a duty that is taken seriously. Funded trainees are required to have a co-mentor in addition to their primary supervisor—in most cases, the mentor is from a different academic department, institution or university, says Eisenstat.

Exposure and immersion in multi-investigator-driven research and interdisciplinary neuroscience is the future of translational research in this field," Eisenstat adds. "NeuroDevNet training initiatives are at the leading edge in preparing future investigators to function in teams across disciplines, and traditional academic silos."

"Exposure and immersion in multi-investigator-driven research and interdisciplinary neuroscience is the future of translational research in this field."

Dr. David Eisenstat, Chair of the Research Training Committee, NeuroDevNet

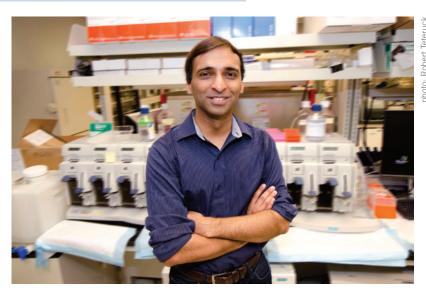


The TrAC team is keen to dive in, taking an advisory role on all trainee-oriented aspects of the September 2013 Annual Brain Development Conference. Swanson says their advice has been invaluable. For example, "the Training Committee gave us good positive feedback on how to improve the poster session for this year," says Swanson. "In 2013, we'll be implementing a more structured approach to the poster evaluation."

Looking forward, Swanson plans to recruit four more members for next year's committee. TrAC will be a twoyear commitment, with old and new members working together for optimal success—not just for the committee, but the Network's trainee experience as a whole.

"As NeuroDevNet approaches Network renewal, we will have a cohort of trainees who have been fostered by the overarching goals of NeuroDevNet, mentored by investigators and multi-disciplinary teams, and invited to Network sponsored workshops, Brain Camps and the annual Brain Development meetings" adds Eisenstat. "Our next iteration of the Network can only be enhanced by direct trainee involvement in advising the Research Trainee Committee regarding existing and new training initiatives."

#### **TRAINING AND EDUCATION**



Anath Lionel, PhD candidate and graduate fellow

#### 2012-2013 Fellowship Highlights

NeuroDevNet's fellowship award winners are leading the way in their respective fields. Two graduate and two post-doctoral awards are offered each year and the competition is fierce-less than 10 per cent of the applicants are successful. Trainees that are selected as Fellows participate in a co-mentorship training plan spanning multiple fields, introducing them to areas of research they may not have previously considered.

Douglas Swanson, NeuroDevNet's Training and Education Programs Manager, says the competition is very intense, and all applicants go through a lengthy evaluation period.

"First and foremost they're looking at scientific and academic excellence," says Swanson. "You can see the cream—the top performers—really shine in these applications."

PhD candidate and graduate fellow Anath Lionel is one of these top performers. His work in the lab of NeuroDevNet investigator Dr. Steve Scherer from The Hospital for Sick Children and the University of Toronto has focused on the discovery of new genetic markers of neurodevelopmental disorders such as schizophrenia, autism, and attention deficit hyperactivity disorder. He has also worked on the genetic overlap between these disorders and recently published a study identifying that mutations in gephyrin, a gene that plays a key role in the developing brain, are part of the genetic story behind autism, schizophrenia, and epilepsy.

Post-doctoral fellow Jill Zwicker is funded in partnership with the Michael Smith Foundation for Health Research. Under the guidance of her co-supervisors, Dr. Steven Miller and Dr. Ruth Grunau, Zwicker's work focuses on early brain development in premature infants and assessment of motor skills throughout childhood. Premature infants are significantly more likely to have developmental coordination disorder, or DCD, and their struggles with many ordinary tasks can persist into adolescence. Zwicker and her team use brain-imaging techniques to study brain development of premature infants at risk of DCD.

Funding from NeuroDevNet for the past two years has allowed both Zwicker and Lionel to focus on their research. Looking forward, Lionel plans to complete his PhD, and hopes to continue working on the genetics of neurodevelopmental disorders—something he is passionate about.

"Research is not always easy—it has its ups and downs," says Lionel. "But when you actually make a scientific discovery with direct implications in the clinical setting—that's really fulfilling."

Zwicker has recently been appointed as an Assistant Professor in the Department of Occupational Science and Occupational Therapy at UBC and will continue her research program focused on brain development and motor impairment. She plans to use neuroimaging to determine the effectiveness of rehabilitation interventions for children with DCD and other motor conditions.

"I would like to thank the NeuroDevNet community for their support and mentorship during my fellowship," adds Zwicker. "I look forward to continued involvement in NeuroDevNet as a faculty member."



Jill Zwicker, postdoctoral fellow

#### **TRAINING AND EDUCATION**



#### Webinar Series Draws Researchers, Clinicians and Parents

NeuroDevNet's 2012-13 webinar series attracted frontline clinicians and trainees from across North America.

Highlighting current research on cerebral palsy, autism, and fetal alcohol spectrum disorder, the first two 90-minute sessions showcased advances in neuroinformatics and neuroimaging.

In October 2012, Dr. Anita Bandrowski (UC San Diego) led the "Neuroscience Information Framework," and in March 2013, Network Investigator Dr. Christian Beaulieu (University of Alberta) and NeuroDevNet trainee Angeline Paolozza (Queen's University) hosted "Brain Structure and Behavioral Outcome Studies in Fetal Alcohol Spectrum Disorder."

"The goal of the webinar series is to inform the NeuroDevNet community about the diverse work of researchers within and outside our Network," says Douglas Swanson, NeuroDevNet's training and education programs manager, who organized and convened the webinars.

"We're also trying to attract trainees that may not have experience in these areas," adds Swanson. "We want to give them exposure to different areas of research, different ways of thinking about this research, and expanding opportunities for sharing and collaboration."

"Showcasing important applications to our investigators stimulates participants to think about novel approaches to their individual research projects and provides access to leading researchers, some outside the network," says Dr. David Eisenstat, Chair of NeuroDevNet's Research and Training Committee. "These webinars can only lead to new collaborations and

The webinar series is the newest iteration of innovative approaches to training introduced by Swanson. Last year, he piloted NeuroDevNet 101, a web-based course that received enthusiastic reviews.

"The entire NeuroDevNet community has benefitted tremendously from these educational opportunities provided by scientists both internal and external to the Network," says Eisenstat.

Recent sessions have drawn parents, educators, NeuroDevNet trainees, and community workers focusing on CP, autism, and FASD. According to Swanson, many of the participants become actively involved in the discussions, enthusiastically contributing their insights and experiences.

"Receiving that input from the community is a great thing," says Swanson. "It really shows the researchers who are presenting that their work is being listened to."

The first "season" of the webinar series continued through June 2013, and featured presentations from NeuroDevNet Network investigators on "Hypothermia in Prevention of Perinatal Brain Injury" (Drs. Jerome Yager and Pia Wintermark) and "Non-invasive Brain Stimulation Therapeutic Applications" (Dr. Adam Kirton). These presentations are available for viewing on NeuroDevNet's webinar website.





#### Social Skills Training Success in **Geneva Centre for Autism Internship**

An Australian social skills training group program piloted at the Geneva Centre for Autism in Toronto received an evaluation boost from Mitacs intern Suzanne Robinson and her supervisor, Autism Chair Dr. Jonathan Weiss.

The Secret Agent Society is a well-regarded Australian program that involves children, parents and teachers in teaching and reinforcing social skills for high functioning youth diagnosed with Autism Spectrum Disorders.

In the Geneva Centre pilot, six children, aged 8-12 who were struggling with social skills and had a history of being bullied participated in nine two-hour group sessions and follow-up. Parent support sessions and teacher tip sheets, phone calls and staff involvement ran alongside the children's group activities.

"This was a fantastic program," says Robinson, who is simultaneously working on a Master of Arts degree and a health diploma at York University. "It was very comprehensive and user-friendly. The kids were really engaged by the fun and interactive features like walkie talkies, and active games."

In their assessments of the program, "the children sometimes had a hard time articulating what they learned from the group, but their parents gave passionate testimonials on the changes they have witnessed," says Robinson. "For example, one parent said for the first time, their child has made friends, talked on the phone, made play dates and calmed anxieties." One child told her he was having an easier time controlling his anger.

Robinson collected this information as part of her data analysis on parent, youth and teacher reports before and after the program. Her final report incorporates additional information gathered from family members and teachers. "Now, we plan on meeting with staff from the Geneva Centre to discuss the results and future planning for the Secret Agents Society (SAS) Program."

"Doing this group taught me valuable strategies to keep youth engaged and help solidify concepts," says Robinson. "I hope to continue running group programs like SAS with children and families."

"The internship was the perfect way to help Suzanne develop stronger applied research skills and connections with community employers," says Weiss. "The process also allowed us to assist the community partner in evaluating the pilot of a novel intervention that may greatly assist youth with ASD and their parents."

Robinson's Mitacs internship is one of three funded by the Alberta-based Ability Hub during the 2012-2013 academic year. Two of the internships focused on evaluating potential interventions for ASD, and one was aimed at developing resources to educate professionals interacting with children about the impact of early traumatic experiences on the developing brain.

Characters from the computer game version of Secret Agent Society -Solving the Mystery of Social Encounters.



### **TRAINING AND EDUCATION**INTERNSHIPS

#### Mitacs Internship Investigates Potential of a Computer Game Intervention in Autism

Caribbean Quest, a computer game created to strengthen focus and working memory in young students with FASD is showing promise in children with Autism Spectrum Disorder.

University of Victoria PhD student Andrew Sung and his supervisor, Dr. Sarah Macoun, launched a pilot study of the intervention with 21 participants aged 8-12 within the Sooke School District on Vancouver Island. Initial findings found improvements on certain cognitive tests of attention, and parents reported gains in executive functioning, social skills and attention.

"Rating scales completed by teachers, on our first analysis, did not indicate the same pattern of improvements seen in parent rating scales," says Macoun, who is only beginning analysis of the complex data gathered with Sung, a PhD student in Educational Psychology.

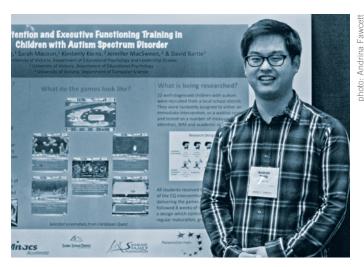
Although distinctly different neurodevelopmental disorders, FASD and ASD share some common features, including problems with attention, executive functioning and working memory. These issues show up as difficulty with planning and emotional control, as well as struggles with multi-step activities such as mathematical calculations.

University of Victoria researcher Dr. Kim Kerns initially developed Caribbean Quest for research in children aged 8-12 with FASD. In Sung and Macoun's study, children of the same age, affected by ASD, were segmented into two groups that ran from January through June 2013. "Most of the children who participated absolutely loved it," says Macoun.

"Our district sought this internship because we were interested in supporting the high number of students with ASD within our district in any way possible," says Veronika Kurucz, ASD Curriculum Coordinator in the Student Support Services Department for the Sooke School District. Between 10 to 12 percent of the students in the district have an ASD diagnosis. Dr. Macoun worked in the Sooke District for a number of years, and knew a number of the students, "which we felt would be beneficial," Kurucz adds.

"These interventions are new," observes Macoun, "and we are trying to understand important factors such as how much intervention is enough, how many times a child should play, the types of metacognitive strategies to include, and the best ways to facilitate improvements when playing the game.

"We're interested in finding out if the parents had a positive impression bias, or if there were really genuine improvements they were picking up," says Macoun. "Teacher return rates on surveys assessing behaviour were not as high as parent return rates, so the next step will be to gather qualitative information, and in September, Andrew will hopefully go out and interview school staff about which children seemed to benefit most from the intervention and in which ways."





Andrew Sung, PhD student, University of Victoria



### **TRAINING AND EDUCATION**INTERNSHIPS



#### Assessing Knowledge Gaps on Impacts of Early Childhood Trauma in Justice & Child Welfare Communities

How much is known about the impact of maltreatment on a child's developing brain? Maddison Spenrath, a student in the Master's program in Population and Public Health at the University of British Columbia, researched the topic as a participant in a joint NeuroDevNet-Mitacs internship with the Ability Hub in Calgary. Her project, entitled "With the Child in Mind - Brain Development and Best Interests Decisions," was aimed at developing resources to educate justice, legal and other professionals interacting with children about the impact of early childhood trauma on the developing brain.

Spenrath's project identified gaps in knowledge among these professionals, whose daily work involves deciding the fate of children within family and criminal courts. "There is an urgent need to develop educational resources to implement the best practice possible," says Spenrath. "Bringing the science of trauma and early brain development to these stakeholders in an accessible form may foster greater understanding of how crucial their decisions are to a child's well-being."

As part of her gap analysis, Spenrath along with her supervisor, Dr. Laura Ghali of the Ability Hub and the University of Calgary, developed a survey she distributed to a focus group she facilitated. The group comprised of legal and judicial professionals, also discussed the most effective ways of sharing information on maltreatment and brain development. A revised web-based survey, based on input from the focus group, was mailed to a sample of judges and lawyers in Alberta as well as attendees from a 2009 symposium bearing the same title as Ms. Spenrath's project.

Spenrath's internship was the second phase of a larger project aimed at providing courtrooms across Canada with current knowledge regarding child development issues. The first phase, which took place in 2009-10, involved the development of curriculum and a learning website, as well as the 2009 symposium. Data analysis is currently underway. The last phase of the project will focus on the distribution of resources across Canada, and aims to reach other audiences such as professionals working with children.

Working together with the Ability Hub will contribute to the goal of improved recognition and interventions for children with neurodevelopmental disorders in the child welfare and family court systems, says NeuroDevNet's Director of Development, Jim Brookes.

# INTERNATIONAL PROMINENCE



#### First Traineeship Exchange Program with India a Productive Collaboration

Dr. Muralidharan Kesavan will develop a new program in mood disorders at NIMHANS, an Institute of National Importance in the areas of mental health and neurosciences, in Bangalore, India, drawing on knowledge and experience gained during a NeuroDevNet co-funded visiting professorship.

Hosted jointly by the Network, UBC's Department of Psychiatry, and the Mood Disorders Foundation, Kesavan had a tremendously productive year in Vancouver, between July 2012 and June 2013.

An Associate Professor in the Department of Psychiatry at NIMHANS, Kesavan authored four papers that were either published or under review in peer-reviewed journals, including the Journal of Affective Disorders, Journal of Psychiatric Research and the British Journal of Psychiatry. He also made significant progress on four additional papers in varying stages of development.

"During my time at UBC, I acquired experience in neurocognition and in administering rating scales in mood disorders," says Kesavan. "I also developed an interest in bipolar disorder, and have since started work on a biomarker protocol for identifying individuals at high risk of developing bipolar disorder."

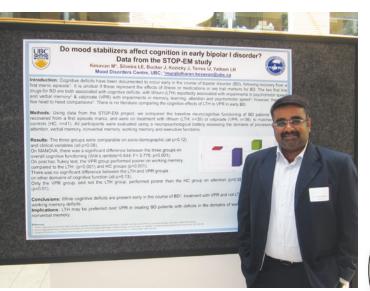
Kesavan has also initiated a project investigating cortical inhibition in unipolar and bipolar depression using TMS-EEG. While in Vancouver, he received training in how to program deep brain stimulation equipment in treatmentresistant depression for an ongoing study at the UBC Mood Disorders Centre.

"My focus now is to start a special clinic for mood disorders within NIMHANS, in collaboration with colleagues here

and at UBC" he says, "and to pursue research in the areas I explored during my sabbatical.

"I'm also interested in looking at the grey area between schizophrenia and mood disorders. An initiative called B-SNIP is already underway in the US, and there is an urgent need to initiative the same in our Institute, to lead the way in exploring this concept in developing countries.

"I hope the connections made during my visit will be the first of many opportunities for collaboration between programs at NIMHANS, NeuroDevNet and UBC," concludes Kesavan.



Dr. Muralidharan Kesavan, Associate Professor, Department of Psychiatry, NIMHANS





#### NeuroDevNet and US Researchers Explore Genetic **Basis of Cerebral Palsy**

North America's first cerebral palsy registry team is partnering with a group from the Children's Hospital of Philadelphia to examine genetic factors and their relationship to CP.

While the United States does not have its own cerebral palsy (CP) registry, Children's Hospital of Philadelphia (CHoP) has a large biobank of patient blood samples—around 800 of which were drawn from patients thought to have cerebral palsy. Before beginning to look for genetic markers of CP in the blood samples, CHoP invited members of the CP registry team, led by Dr. Michael Shevell, former principal investigator of NeuroDevNet's CP group, to determine if all the blood samples came from patients who actually had cerebral palsy or not.

Dr. Shevell and his colleagues analyzed CHoP's patient records, characterizing the phenotypes—or physical appearance—of patients from whom the blood samples were drawn. About 50 per cent of the patients assumed to have cerebral palsy did not.

"We were able to improve characterization of the phenotypes," says Dr. Shevell. "And what we determined was a lot of their patients didn't really have cerebral palsy. This was very helpful to them, because genetic studies are only as good as how well you classify the patients clinically."

NeuroDevNet's CP registry team and their CHoP partners will continue to collaborate on the project, hoping to identify genetic markers of cerebral palsy in the patient blood samples. The ongoing work is being funded via a \$100 thousand grant from the Cerebral Palsy International Research Foundation. Dr. Shevell (McGill) and Dr. John Connolly (CHoP) are principal investigators on the project.

## FEATURED THEMES: INTERNATIONAL PROMINENCE

#### FASD dataset attracts international interest

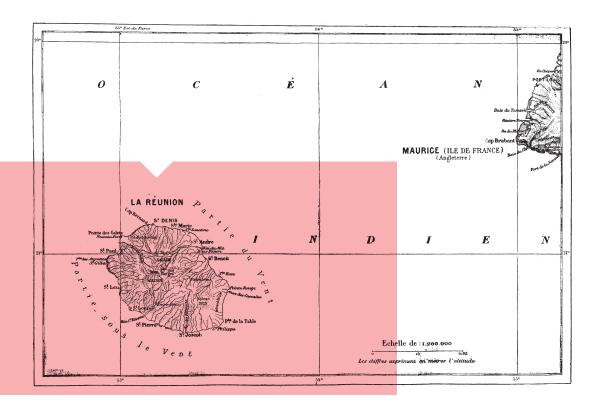
NeuroDevNet FASD researchers and their French counterparts await approval from the French Government on a promising epigenetics collaboration on Reunion Island.

This small island is an overseas department of France located in the Indian Ocean, between Mauritius and Madagascar. About five percent of the pregnancies among the ethnically diverse population of 700,000 involve alcohol exposure.

High levels of alcoholism, a stable population, and the commitment of local authorities to intervene to prevent FASD make the collaboration highly desirable. "We're trying to find a particular pattern of epigenetic abnormality that may predict vulnerability or protection to prenatal alcohol exposure," says Albert Chudley, co-lead of NeuroDevNet's FASD research group.

French researchers have data from about 200 people affected by FASD, including islanders of European Caucasians, Chinese, South Asians, Africans, and Creole backgrounds. A comparison with NeuroDevNet's data, drawn from the Canadian population would yield valuable insights, Chudley says. "If we find similar patterns and variants involving FASD, that's very powerful from a genetic point of view. We may also find different patterns—that's the real reason why we're interested."

Approval at a governmental level has been slow to come, but both groups of researchers continue to pursue their vision of educational exchange, and development of new programs for diagnosis and research platforms. Chudley says the project is worth waiting for. "We applied for some funding from Genome Canada—there's good potential down the road for commercialization."



## FEATURED THEMES: COLLABORATION AND PARTNERSHIPS



#### NeuroDevNet ASD researchers lead international autism research conference

Toronto was the centre of the world in autism research in May 2012. The International Meeting for Autism Research (IMFAR) was organized and led by NeuroDevNet ASD research group leads Dr. Stephen Scherer and Dr. Lonnie Zwaigenbaum.

IMFAR is noted for cutting edge research, and Scherer opened the Tonroto meeting saying that much of the information to be presented was unpublished, but certainly would lead to publication.

"This makes it very exciting," wrote a blogger for Seattle Children's Hospital, "but it also forces us to buffer our excitement and understand that so much of this research is in its early

Close to 2,000 people attended IMFAR, from all over the world, including Ethiopia, Albania, India, and Taiwan.

"In selecting a theme for the 11the year of IMFAR," says Scherer, "the goal was to look forward 10 years and see where autism science will be in 10 years. That guided the selection process for the speakers and presenters."

NeuroDevNet and the Sinneave Family Foundation co-funded the IMFAR pre-conference. a community-oriented half-day event that showcased findings later presented during the main conference, including evidence on the role of oxytocin in the development of social reciprocity, and social and career outcomes among young adults with ASD post-high school.

#### "This makes it very exciting, but it also forces us to buffer our excitement and understand that so much of this research is in its early stages."

David Eaton, ARNP, posting about IMFAR 2012 on the Seattle Children's Hospital Research Foundation's "The Autism Blog"

Themes of the main conference included discovery, treatment, and dissemination while subthemes included behavioral science, application of drugs, gender bias—the 1:4 ratio of females to males among those diagnosed with ASD, and genetic implications for ASD research relative to biomarkers and therapeutics.

Among the best-attended sessions were six presentations focusing on updates to the DSM-5 criteria for ASD. In one, Dr. Sue Swedo, who chaired the DSM Neurodevelopmental group charged with reaching consensus on the disorder, presented revisions and offered reassurance to individuals in the Asperger's community who feared the disappearance of their identity with the new criteria. Swedo is Chief Pediatrics & Developmental Neuroscience Branch at the US National Institutes of Mental Health.

A booth hosted by NeuroDevNet brought hundreds of new contacts to the Network and engaged funded trainees in representing the Network to their peers.



#### **Neuroinformatics Group Plays Leadership Role** in International Engagement

NeuroDevNet is helping move Canadian neuroscience forward through its support for national participation in a key global neuroinformatics initiative.

The Network co-hosted a joint satellite workshop at the May 2012 Canadian Association for Neuroscience Meeting with the International NeuroInformatics Coordinating Facility (INCF), based in Stockholm. "The aim was to help build the Canadian neuroinformatics community, and determine whether there was a desire to join the INCF," says Dr. Portales-Casamar.

Citing "obvious synergies between neuroinformatics work in Canada and the aims of the INCF," the 60 scientists attending the meeting expressed strong support for the idea of building towards an INCF national node.

"The sooner Canada contributes to, adopts and can access the rapidly developing neuroscience standards, tools and data sources around the world for which INCF acts as a portal and clearing house," Dr. Stephen Strother, an investigator at the Rotman Institute, commented in a report on the workshop, "the faster Canadian neuroscience research is likely to progress."

Dr. Pavlidis and his team are working on it. "Besides growing the network, we are forming partnerships with other organizations that have an interest in neuroinformatics. It's highly relevant to NeuroDevNet's mission. Among the initiatives under way, we're trying to lead Canada towards increasing standardization of data collection and representation practices," says Pavlidis, "which would reduce research costs and increase rates of knowledge translation."

# FEATURED THEMES: TRANSLATIONAL SCIENCE

#### TORONTO STAR



#### NeuroDevNet researchers mobilize ASD findings in two national newspaper series

Lack of services and funding to support families with autistic children in Ontario reached a crisis point in 2012, triggering two national newspapers to run major series focusing on the disorder.

Seven NeuroDevNet investigators were key sources in The Toronto Star's popular series, "The Autism Project," a multimedia examination of life on the autism spectrum that launched in November 2012.

The series began with a video feature on Dr. Stephen Scherer's work in "Field of Genes," while Dr. Lonnie Zwaigenbaum, his co-lead in NeuroDevNet's Autism Research Group, appeared along with investigator Dr. Wendy Roberts in "Talking with the Experts." Dr. Roberts was also interviewed for a later article, "Teens with Autism Face Uncertain Fate."

Dr. Zwaigenbaum and Dr. Susan Bryson discussed a program for young children pre-diagnosis in "Study Tests Early Intervention for Toddlerss showing Signs of Autism while they Wait for Assessment," while Dr. Bryson offered perspective in "Mothers with ASD ask why scientists are missing girls." Dr. Mayada Elsabbagh commented on "The Odyssey to Get Your Child Diagnosed and Treated." Dr. Evdokia Anagnostou was interviewed for "Decoding the Autistic Brain," and framed the evidence in a blog exploring the existence of an autism epidemic. Dr. David Nicholas highlighted the attributes of the most successful employment programs for people with ASD in "A Worker With Autism May be Your Best Employee," and Dr. Peter Szatmari declared no waitlist for autism services was acceptable in "Children face up to four-year wait for therapy."

Three months later, the Ottawa Citizen ran an in-depth series examining current research, treatment, and innovations in ASD in a North American context. Reporter Pauline Tam conducted a year-long investigation culminating in an eight-part series including interviews with Stephen Scherer, Wendy Roberts, Peter Szatmari, Evdokia Anagnostou and Lonnie Zwaigenbaum, who discussed the evolving understanding and latest scientific evidence of autism, and future

Together the two series put a spotlight on gaps in policy and social services for ASD in Ontario, and highlighted the personal and societal costs of unmet needs. Public outcry led Ontario's Ombudsman to launch an investigation into services for adults with autism and other developmental disabilities and two years after first promising to do so, Ontario's Children and Youth Services Minister publicly committed to streamline autism services and created a special panel of experts to guide the province's next steps. Three NeuroDevNet-affiliated researchers are currently serving on the panel.



Image from Toronto Star article The Autism Project: Children face up to four-year wait for therapy



Image from Toronto Star article The Autism Project: Study tests early intervention for toddlers showing signs of autism while they wait for assessment



Image from Toronto Star article The Autism Project: Mothers with ASD ask why scientists are missing girls

## FEATURED THEMES: TRANSLATIONAL SCIENCE



#### **Autism Treatment and Care Chair**

Dr. Jonathan Weiss and his 12-year-old client with autism were supposed to be finishing up a successful course of therapy to teach the boy effective ways of managing his school-associated anxiety and stress.

Instead, the session awakened career-changing awareness in the young researcher, who last November was awarded a national Chair in Autism Treatment and Care, co-funded by NeuroDevNet, CIHR, and key national organizations focused on ASD.

"In therapy, we were focused on triggers around separating from his parents, hearing the school bell in the car on the way to school," says Weiss. "Then, he told me, 'I'll practice relaxation strategies, breathing, and positive statements—everything that I learned, and then I'll go outside and the bully will still be there. When he pushes me down, I'll practice my relaxation strategies'."

'Bullying. We didn't pay attention to that initially," says Weiss. "That was a wakeup call for me. Together, we realized the work we had to do involved more than he and I. We had to bring the family and school into the conversation. The stressors weren't just on his shoulders, or his family's. We had to develop new tools, and ways of working."

One of the first things Weiss did was seek out advice from researchers at PREVNet, a York University based NCE focused on bullying prevention. "They had some resources on their site that we were able to adapt for the child, his family and the school in their unique situation," he says.

The PREVNet collaboration has served as an important model for the work Weiss has subsequently pursued as the Chair in Autism Treatment and Care. In January, he convened a meeting of stakeholders form across the county to discuss research priorities around mental health and autism.

"There were a number of immediate next steps—one was to launch an ASD mental health blog," says Weiss. "The second immediate outcome was the forming of new collaborations between the research chair and a number of stakeholders who are doing excellent work around ASD and mental health already." Weiss highlights new and growing partnerships and research projects—that have emerged since the meeting with organizations as diverse as the Toronto Catholic School Board and the Social Skills Training Institute in Australia.

"We have to be very aware of good science happening in other jurisdictions—other provinces and other nations—we can learn from that, too. Bullying is just one example of the issues that we'll be looking at,"

Weiss adds, as he moves forward with his agenda of developing and adapting treatments to provide effective responses to mental health issues in youth with ASD.

"One outcome we would like to see is evidence-based practice around a whole myriad of potential stressors. It's complex work, and it will take a lot of collaboration."

Partners funding Jonathan Weiss' Chair include Canadian Institutes of Health Research, Health Canada, NeuroDevNet, Autism Speaks Canada, the Canadian Autism Spectrum Disorders Alliance, the Sinneave Family Foundation, and the Spectrum of Hope Autism Foundation.

For more information about Dr. Weiss and his work as the Autism Chair, visit his blog at: http://asdmentalhealth.blog.yorku.ca/2013/02/the-asd-mental-health-blog-is-now-live/dr-jonathan-weiss/ and the Chair website at: http://asdmentalhealth.ca

## FEATURED THEMES: TRANSLATIONAL SCIENCE



An Affymetrix Cytoscan HD—an array used routinely in NeuroDevNet's genetic studies. The technology can detect small changes in the genome in patients with many disorders, including autism.

#### NeuroDevNet research translates into autism diagnostic tool

Dr. Stephen Scherer's collaboration with Population Diagnostics, Inc. (PDx) has provided the groundwork for a new generation of early detection diagnostic tests for autism.

Scherer's breakthrough findings on copy number variation (CNVs) has led to two patents that describe a method of comparing CNVs in people diagnosed with autism, to participants in research trials acting as healthy controls. CNVs are a type of genetic variant that can disrupt, delete, or generate multiple copies of a gene.

Two other patents related to Scherer's research in autism genetics have also been obtained. Collaboration with industry lent great advantages to Scherer's research. PDx's technical contributions—the ability to discern harmless copy number variations in genes from those that contribute to disorders—meant that "we were able to effectively interpret the genome at a higher resolution than had been obtained by previously utilized microarrays," he says.

"This focused our attention on smaller variants associated with autism," Scherer adds. "We were able to confirm variants in genes that we and others have previously discovered, using alternate methods and are pleased to have uncovered an abundance of novel variants."

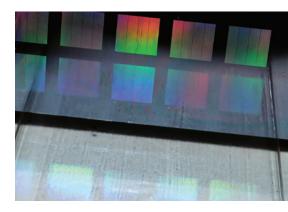
In addition to discovering sixteen novel genes associated with autism (many implicated in neurodevelopment), the collaborative research highlights the general importance of analyzing genomes specifically for CNVs. According to a PDx press release, more refined analysis of the data collected from autism patients in the initial research is underway, and is revealing additional small CNVs in novel autism genes as well as novel variants in previously known autism genes.

Scherer and PDx's joint discoveries underscore that the genetic landscape for autism involves numerous genes that contain many low frequency genetic variants that have a large effect, according to Dr. Peggy Eis, Chief Technology Officer at Population Diagnostics.

"Collectively," she says, "these newly discovered genes from our collaboration with SickKids, along with novel genes from our finer-scale analysis that will be reported in a future paper, represent a significant portion of the unexplained genetic contribution to autism, and greatly contribute to our understanding of the underlying genetic causes of autism. We are excited about the opportunity to accelerate their clinical use in diagnostic tests, as potential drug targets and as genetic biomarkers in therapeutics development".

Scherer has also filed three new US Formal patent applications for other discoveries.

A gene expression array from Ilumina used to detect gene activation in neurodevelopmental disorders and other conditions.



## FEATURED THEMES: **TRANSLATIONAL**

NeuroDevNet's Top Ten:



Facilitating Initiatives with Commercial Potential NeuroDevNet research has produced a number of initiatives with strong commercial

potential. Expert consultation, in the form of the Network's new eight-member Commercialization Committee is helping shape strategy and focus for bringing ten priority projects to the marketplace.

Founded in 2013, the group is spearheaded by the Network's Chief Development Officer, Jim Brookes, and is comprised of individuals with extensive involvement in industry/ university commercialization programs. "The committee highlighted that these ten initiatives have strong valorization potential which means strong potential for societal impact for industry, as well as not-for-profit and government organizations," says Brookes. "We've moving forward at a good pace, with developments this year related to each of our top prospects."

For example, says Brookes, four Autism gene discovery patents obtained are already contributing to improved autism diagnostic capabilities. "Our Autism research group filed three new US Formal Applications relating to those patents."

Applications for patents are also under development, looking at the electrical activity of the brain for a home-based seizure monitoring system that can detect epilepsy-related brain states.

"Research emerging from our FASD group utilizing eye tracking equipment manufactured by a Canadian company, SR Research, is already demonstrating a high degree of effectiveness in identifying children with FASD and other neurobehavioural disorders," says Brookes. "This could lead to new markets for the company's products and the potential of a new screening protocol for FASD. (See FASD Research Group story, "Comprehensive understanding of brain damage in FASD points to diagnostic potential", p. 16)

"In just our first 3 years as a Network we have made substantial strides in that translation from bench to bed—and even curbside in some cases... the best is yet to come."

Dr. Daniel Goldowitz, Scientific Director, NeuroDevNet on the Network's progress in commercialization of research findings

Computer games being evaluated by several different research groups show promise as therapeutic tools. One game, Caribbean Quest, is showing promise in developing executive functioning and working memory in children with FASD, autism and ADHD. Preliminary data generated via a MITACS Internship supervised by Dr. Sarah Macoun has shown cognitive benefits in a group of about 20 school children with autism in a Vancouver Island school district (see story, p. 32).

snug vest

# FEATURED THEMES: TRANSLATIONAL SCIENCE NeuroDevNet's Top Ten - continued









CP Fit n' Fun, an exergame based on pedaling a modified stationary bicycle to power an interactive videogame, improves both fitness and socialization in youth with cerebral palsy. "Professors Darcy Fehlings and Nicholas Graham are exploring the opportunity for a start-up company," says Brookes. An app for modulating anxiety is also being evaluated, via interns placed with a company partner, the Westcoast Child Development Group. "We're expecting the app to launch via the Apple store in 2013,"

Anxiety and stress in children with autism are targeted by an inflatable vest that applies calming pressure. NeuroDevNet placed a 2011 intern who conducted a pilot study for Squeezease Therapy, the start-up company that developed the vest. "We've gone on to help connect Squeezease with autism organizations, including Autism Speaks in the US, that can promote their inflatable vest and potentially support further development," says Brookes.

Prevention research is another strong element in NeuroDevNet's commercialization portfolio. Within the Cerebral Palsy research group, animal studies have shown that consuming antioxidantrich broccoli sprouts produces significantly more resilient brains in rats. "Our group is looking at ways of scientifically pro-viding evidence for natural health products as forms of preventive therapy," says Dr. Jerome Yager, co-lead of the CP research group. "This is often lacking in the nutraceutical world. The science will enable us to bring these alternative, but effective therapies to the consumer."

Research is improving the existing methods of detecting fetal acidemia—a known contributor to prenatal brain injury—using mathematical algorithms that interpret ultrasound or abdominal ECGderived fetal heart rate data. An intern placed by NeuroDevNet is assisting in a related animal study that supplements fetal heart rate data with data from EEG probes applied to the head of the fetus during labour. "This group is using similar methods in animal testing to detect fetal inflammation, which is another known contributor to pre-natal brain injury," says Brookes.

"The Commercialization Committee is mindful of the needs and challenges experienced by children and families affected by a neurodevelopmental disorder," adds Brookes. "They know it is hugely important that university innovations that could help these children are made available to them in the most effective manner possible—and not left at the lab bench."

Dr. Dan Goldowitz, Neuro Dev Net's Scientific Director agrees. "In just our first 3 years as a Network we have made substantial strides in that translation from bench to bed—and even curbside in some cases. Whether it has been a genetic test for autism that is now available or a computer game that is being explored in BC, the best is yet to come".







Day on the Hill 2013

## **EVENTS:** DAY ON THE HILL 2013



#### Day on the Hill 2013

NeuroDevNet's second annual Day on the Hill in Ottawa raised the profile of neurodevelopmental disorders and cultivated momentum for the Network's initiatives.

One of the primary objectives of this year's visit during Brain Awareness Week was to interest members of the House of Commons Standing Committee on Health (HESA) in conducting a study on the status of Canadian children with neurodevelopmental disorders, and in making recommendations to improve outcomes.

Three teams of delegates, including NeuroDevNet Board members, parent advocates, researchers, and staff from Network headquarters also met with members of the House of Commons Standing Committee on Industry, Science, and Technology (INDU), to familiarize the parliamentarians with the NCE program, and NeuroDevNet's accomplishments and intentions.

Twenty one-on-one meetings in all were held, followed by an evening reception hosted by Senators Jim Munson and Yonah Martin. The senators were joined by MP Mike Lake in offering welcoming remarks to approximately 75 guests, including MPs, Senators, parliamentary staff members and representatives from national organizations such as the Networks of Centres of Excellence of Canada, the Public Health Agency of Canada, and the Canadian Institutes of Health Research.

Despite an intensive schedule and unexpected snow, participants were enthusiastic about the experience.

"It was very worthwhile to make the time to talk about the important work that NeuroDevNet is doing in increasing communication across disabilities, across areas of research, and clinical and parental expertise across Canada," said Deborah Pugh, Executive Director of ACT Autism Community Training, a community service organization based in British Columbia who was one of the delegates.

"It was very worthwhile to make the time to talk about the important work that NeuroDevNet is doing in increasing communication across disabilities, across areas of research, and clinical and parental expertise across Canada."

> **Deborah Pugh,** Executive Director of ACT Autism Community Training, a community service organization based in British Columbia on NeuroDevNet's Day on the Hill

"All in all, it was a wonderful experience," wrote Brenda Boylan, in an email following Day on the Hill. Boylan was a parent participant on one of the NeuroDevNet teams, and brought her adopted son, Isaiah, who has FASD to the reception. Initially reluctant to join in, she came away inspired to speak out publicly, and raise awareness of the disorder and its impacts. Isaiah Boylan went to school the following day and told his teachers he'd been rubbing shoulders with two senators. "It's things like this that open the door for more discussion on FASD," said Brenda Boylan, "and it helps my son understand and feel empowered by the big role he has, getting the message out there."

# EVENTS: WICKFEST



Wickfest photos by Dave Holland, Doug Swanson, and Anthony Santelices

#### NeuroDevNet sheds light on the teen brain at Wickfest

A large and popular youth hockey tournament might seem like an unusual setting for brain development outreach, but NeuroDevNet's debut at Wickfest in November 2012 was a slapshot. Invited by Olympian Hayley Wickenheiser, network staff and trainees shared information about the developing brain with hundreds of girls aged 9-16 and their parents—mainly through play.

Traumatic brain injury (TBI) is the most common association between the brain and hockey, but NeuroDevNet participated in Ms. Wickenheiser's annual tournament with the intention of showing that brain development is important to everyone.

NeuroDevNet-funded researchers who have developed computer-based games and devices for therapeutic purposes stepped up to showcase how increased focus, improved proprioception—knowing where you are in space—and eye-hand coordination can improve your game even if you're a top youth athlete.



Researcher Chris Bertram (r) from the University of the Fraser Valley, with Olympian Hayley Wickenheiser. Bertram turned the assumption that video games are bad for your brain on its head with Wickfest presentation on re-wiring the brain with video games.



#### **WICKFEST** HIGHLIGHTS

Brian Christie from the University of Victoria enabled the young players to compete head-to-head with Hayley. The Olympian turned in a remarkably high score on a device called a Neurotracker that uses new multiple object tracking software to improve player eye-brain co-ordination and performance.



Software designed to improve focus—"just concentrate and blow up that barrel of dynamite on the computer screen as quickly as you can"—was also a big hit, emerging from FASD research group co-lead James Reynolds' lab at Queen's University.

Kim Kerns from the University of Victoria presented a workshop about the interaction of the motor system and the brain. Her Caribbean Quest game proved popular with young Wickfesters, along with other activities aimed at increasing capacity to focus and self-regulate.





Brian Christie demonstrates use of the Neurotracker for Hayley Wickenheiser before she tries it for the first time.

# EVENTS: WINTER INSTITUTE 2013

#### Winter Institute 2013

No classroom or lab can match the unique environment of the Biennial Winter Institute, a traineefocused conference in Banff, Alberta that brings together prominent international researchers and graduate level students from across Canada with a shared interest in neurodevelopmental disorders.

Co-sponsored by NeuroDevNet, Calgary's The Ability Hub, and CIHR funding of the Quebec-based Autism Research Training (ART) Program, the Winter Institute is focused on the overlap between Autism Spectrum Disorder and other neurodevelopmental disorders. NeuroDevNet and ART trainees attend as part of their multidisciplinary understanding of brain and behaviour.

This year's event took place March 6-9, with an international faculty of 24 presenters addressing an expanded range of conditions, including FASD and ADHD, as well as cross-cutting issues that present

in a range of neurodevelopmental conditions, such as sleep disorders, the search for biomarkers as a tool for early identification, changes in criteria for neurodevelopmental disorders in the DSM-5, and the potential of computer-based games as therapeutics. To see the full program, visit https://imfar.confex.com/imfar/2012/webprogram/start.html.

Diversity was also seen in this year's trainee population. Half of the 46 students were enrolled in the ART program, and most were affiliated with NeuroDevNet. Other participants included NeuroDevNet trainees specializing in FASD and cerebral palsy, members of the networks' trainee advisory committee, and students working with NeuroDevNet's Knowledge Translation team.

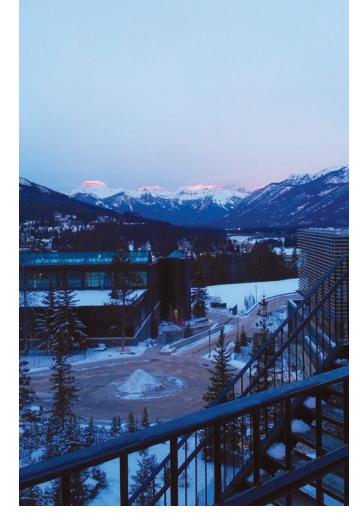
"As a NeuroDevNet trainee involved in the FASD demonstration project, I appreciated the format, the integration of trainees, broader relevance, the breadth of topics discussed, learning from and about ASD, and the chance to participate in a well-established training and research program. I would recommend this to other trainees in neurodevelopmental research." - Comment from a participant

The program featured traditional opportunities such as poster sessions to present and network, as well as breakout groups focused on research management and professional skills: effective mentorship, grant management, management of a research team, interdisciplinary collaboration and achieving tenure and promotion.

Trainees also applauded the rare opportunity to meet parent ambassadors from the Calgary-based Ability Hub as well as self-advocate Chris Macintosh, an adult with ASD from Victoria.

"In the Rockies, under the roof of this hothouse, future opportunities for interdisciplinary collaboration and many fruitful discussions emerged," says Dr. Doug Swanson, NeuroDevNet's Training and Education Manager.





# FINANCIAL STATEMENTS FOR THE YEARS ENDED MARCH 31, 2013 AND 2012



1822 West 2nd Avenue, Vancouver, BC, Canada V6J 1H9 P 604 732 1466 F 604 732 3133 E info@hay-watson.bc.ca

#### INDEPENDENT AUDITOR'S REPORT

To the Directors of NeuroDevelopment Network, Inc.

We have audited the financial statements of the NeuroDevelopment Network, Inc. (the "Network"), which comprise the statement of financial position as at March 31, 2013 and 2012, and statements of operations and fund balances 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 generally accepted accounting principles, 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.

In our opinion, the financial statements present fairly, in all material respects, the financial position of the Network as at March 31, 2013 and 2012, and its financial performance and its cash flows for the years then ended in accordance with Accounting Standards for Not-for-Profit Organizations.

Lay + Watson

Hay & Watson **Chartered Accountants** Vancouver. British Columbia June 5. 2013

# FINANCIAL STATEMENTS FOR THE YEARS ENDED MARCH 31, 2013 and 2012 NeuroDevelopment Network, Inc.

#### **STATEMENTS OF** FINANCIAL POSITION

	March 31, 2013 \$	March 31, 2012 \$	April 1, 2011 \$
ASSETS			
Current assets			
Cash - restricted	836,382	2,238,435	2,079,394
Cash - unrestricted	109,286	51,842	7,065
Unspent research grants paid to			
participating institutions	801,435	815,902	1,340,611
Prepaid expenses	6,478	18,003	10,714
	1,753,581	3,124,182	3,437,784
Equipment (note 4)	-	4,497	8,996
	1,753,581	3,128,679	3,446,780
LIABILITIES			
Current liabilities			
Accounts payable and accrued liabilities	200,713	196,836	228,419
Deferred contributions (note 5)	1,442,083	2,874,004	3,200,800
Deferred capital contributions (note 5)		4,497	8,996
	1,642,796	3,075,337	3,438,215
Net assets	110,785	53,342	8,565
	1,753,581	3,128,679	3,446,780

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

APPROVED BY THE BOARD OF DIRECTORS

Henri Rothschild, Chair, Board of Directors

Gary Wechsler, Chair, Finance and Audit Committee

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#### **STATEMENTS OF OPERATIONS AND CHANGES IN NET ASSETS** Years Ended March 31, 2013 and 2012

	2013 \$	2012 \$
Receipts Grant from NCE (note 5)	5,491,921	4,299,133
Other sources of funds	5,491,921 80,954	4,299,133 76,620
Amortization of deferred capital contributions (note 5)	4,497	4,499
Affior tization of deferred capital contributions (note 3)	4,477	4,477
	5,577,372	4,380,252
Expenditures		
Communications	80,192	35,049
Amortization	4,497	4,499
Insurance	7,382	10,125
Miscellaneous	_	1,043
Networking	255,095	184,238
Professional and consulting fees	82,100	121,998
Research and training (note 6)	4,343,773	3,179,180
Salaries and benefits	606,152	565,750
Supplies and office costs	25,614	52,495
Travel and meetings	115,124	181,098
	5,519,929	4,335,475
Excess of receipts over expenditures	57,443	44,777
Net assets, beginning of year	53,342	8,565
Net assets, end of year	110,785	53,342

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

# FINANCIAL STATEMENTS FOR THE YEARS ENDED MARCH 31, 2013 and 2012 NeuroDevelopment Network, Inc.

#### **STATEMENTS OF CASH FLOWS** Vears Ended March 31, 2013 and 2012

Years Ended March 31, 2013 and 2012	2013 \$	2012 \$
Cash flows from (used in) operating activities		
Excess of receipts over expenditures  Non-cash items	57,443	44,777
Amortization Changes in non-cash working capital items	4,497	4,499
Unspent research grants	14,467	524,709
Prepaid expenses	11,525	(7,289)
Accounts payable and accrued liabilities	3,877	(31,583)
Deferred contributions	(1,436,418)	(331,295)
	[1,344,609]	203,818
Increase in cash	[1,344,609]	203,818
Cash, beginning of year	2,290,277	2,086,459
Cash, end of year	945,668	2,290,277
Cash composed of:		
Cash – restricted	836,382	2,238,435
Cash – unrestricted	109,286	51,842
	945,668	2,290,277

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

#### **YEARS ENDED MARCH 31, 2013 and 2012** NeuroDevelopment Network, Inc.

#### 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.

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.

These financial statements include only the contributions received by NeuroDevNet from the NCE program, its host institution and others, 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 Accounting Standards for Not-for-Profit Organizations ("ASNPO"), using the deferral method of accounting for contributions.

The Network adopted ASNPO on April 1, 2012, with a transition date of April 1, 2011. Under Section 1501 First-time Adoption by Not-for-Profit Organizations, the standards are applied retrospectively at the transition date with all adjustments to assets and liabilities taken to net assets unless certain exemptions are applied. None of the exemptions which could be applied on the transition to ASNPO were applicable to the Network.

ASNPO employs a conceptual framework similar to Canadian GAAP. Adoption of ASNPO has not changed the Network's statements of financial positions at March 31, 2012 and April 1, 2011 and statements of operations and changes in net assets and cash flows for the year ended March 31, 2012.

#### **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.

# **NOTES TO THE**FINANCIAL STATEMENTS

#### YEARS ENDED MARCH 31, 2013 and 2012 NeuroDevelopment Network, Inc.

#### 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.

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 equipment.

#### Cash - Restricted and Unrestricted

Grant funds received from NCE are considered restricted cash and are administered by UBC, the Network's host institution. Other funds are administered by the Network and are considered unrestricted cash.

#### **Financial Assets and Liabilities**

The Network has adopted the provisions of Section 3856, Financial Instruments, of the Canadian Institute of Chartered Accountants ("CICA") Handbook, as they apply to not-for profit organizations.

The standards require that all financial assets and liabilities be measured at fair value with the exception of investments held to maturity, loans and receivables and other liabilities, which are measured at amortized cost. Cash is measured at fair value using Level 1 inputs. Accounts payable and accrued liabilities are measured at amortized cost. As at March 31, 2013, the recorded amounts approximate fair values.

The Network classifies and discloses fair value measurements based on a three-level hierarchy:

- Level 1 inputs are unadjusted quoted prices in active markets for identifiable assets or liabilities;
- Level 2 inputs other than quoted prices in Level 1 that are observable for the asset or liability, either directly or indirectly; and
- Level 3 inputs for the asset or liability that are not based on observable market data.

#### Unspent Research Grants at Participating Institutions

Research grants paid to the participating institutions are deferred on the statements of financial position until the participating institution incurs eligible research costs, at which time they are recognized as research and training expenditures.

#### **YEARS ENDED MARCH 31, 2013 and 2012** NeuroDevelopment Network, Inc.

#### 3. SIGNIFICANT ACCOUNTING POLICIES (continued)

#### **Equipment**

Equipment is recorded at cost and amortized on a straight-line basis over its estimated useful life of three years.

#### **Recognition of Receipts**

Under the terms of the NCE agreement, the funding received from the NCE 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 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 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 UBC (note 4) and other organizations are not included in these financial statements.

#### **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. Benefit security for employees is improved by the plan maintaining a contingency reserve. The contingency reserve recommended by the plan's actuary and approved by the pension board and Canada Revenue Agency is 40% of liabilities. Contributions to the plan made during the year amounted \$29,813 (2012 - \$26,782).

#### **Income Taxes**

NeuroDevNet, as a non-profit organization, is not subject to Federal or Provincial income taxes.

#### 4. EQUIPMENT

			March 31, 2013 \$	March 31, 2012 \$	April 1, 2011 \$
	Cost \$	Accumulated amortization \$	Net book value \$	Net book value \$	Net book value \$
Computers	13,495	13,495	-	4,497	8,996

# **NOTES TO THE**FINANCIAL STATEMENTS

#### YEARS ENDED MARCH 31, 2013 and 2012 NeuroDevelopment Network, Inc.

#### 5. **DEFERRED CONTRIBUTIONS**

#### **Deferred Contributions Relating to Expenditures of Future Periods**

	March 31, 2013 \$	March 31, 2012 \$	April 1, 2011 \$
Balance - Beginning of year	2,874,004	3,200,800	1,755,229
Contributions received during the year			
Grant from CIHR	2,364,000	2,292,000	3,453,500
Grant from NSERC	576,000	527,000	302,500
Grant from SSHRC	1,000,000	1,000,000	400,000
Grant from Host Institution	20,000	20,000	20,000
Grants from other organizations	100,000	133,337	50,000
	6,934,004	7,173,137	5,981,229
Amounts recognized as receipts during the year	(5,491,921)	[4,299,133]	(2,773,943)
Amounts applied toward furniture and equipment purchased during the year	-	-	[6,486]
Balance - End of year	1,442,083	2,874,004	3,200,800

#### **Deferred Capital Contributions Relating to Equipment**

	March 31, 2013	March 31, 2012	April 1, 2011
	\$	\$	\$
Balance - Beginning of year	4,497	8,996	7,009
Allocation of deferred contributions	-	-	6,486
Amounts amortized to revenue	(4,497)	(4,499)	[4,499]
Balance - End of year	-	4,497	8,996

#### YEARS ENDED MARCH 31, 2013 and 2012 NeuroDevelopment Network, Inc.

#### 6. EXPENSES

NeuroDevNet advances funds to researchers at their host institutions. Funds are held in trust by the institutions and as expenses are incurred they are expensed by NeuroDevNet. During 2013, the expenses for research and training totalled \$4,343,773 including \$3,571,119 of expenses incurred from funds transferred to institutions for research. An additional \$772,654 of expenses was incurred and expensed by the administrative centre for miscellaneous research and training programs.

	Balance April 1, 2012	Current Year Grant	Current Year Expenditure	Balance March 31, 2013
	\$	\$	\$	\$
Institution - Master grants				
Holland Bloorview	35,131	160,500	178,338	17,293
Hospital for Sick Children	92,947	506,250	477,339	121,858
IWK Health Centre	70,207	57,600	73,702	54,105
McGill University	171,038	820,758	750,246	241,550
McMaster University	0	38,500	38,500	0
Montreal Heart Institute	0	50,000	50,000	0
Queen's University	16,413	331,837	325,113	23,137
University Health Network	0	106,000	106,000	0
University of Alberta	31,655	422,832	323,073	131,414
University of British Columbia	242,208	846,854	973,970	115,092
University of Calgary	8,414	70,657	79,071	0
University of Manitoba	10,992	20,000	26,780	4,212
University of Montreal	0	64,559	64,559	0
University of Saskatchewan	102,431	0	58,143	44,288
University of the Fraser Valley	0	29,055	29,055	0
University of Victoria	34,466	31,250	17,230	48,486
	815,902	3,556,652	3,571,119	801,435
Other research and training			772,654	
Total research and training			4,343,773	

# NOTES TO THE FINANCIAL STATEMENTS

#### **YEARS ENDED MARCH 31, 2013 and 2012** NeuroDevelopment Network, Inc.

#### 7. RELATED PARTY TRANSACTIONS AND ECONOMIC DEPENDENCE

#### **Grants from the NCE Network**

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 for the five years ending on December 23, 2014. These contributions are scheduled to be received as follows:

Fiscal Year	NSERC	SSHRC	CIHR	Total	
2009 – 2010	\$ 733,865	\$ 1,151,500	\$ 28,500	\$ 1,913,865	
2010 – 2011	302,500	400,000	3,453,500	4,156,000	
2011 – 2012	527,000	1,000,000	2,292,000	3,819,000	
2012 – 2013	576,000	1,000,000	2,364,000	3,940,000	
2013 – 2014	530,000	1,000,000	2,296,000	3,826,000	
2014 – 2015	-	-	1,917,135	1,917,135	
Total Funding	\$ 2,669,365	\$ 4,551,500	\$ 12,351,135	\$ 19,572,000	

The annual contributions will be released subject to:

- 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.

The funding of \$3,940,000 has been received for 2012/13 (\$3,819,000 in 2011/12) and has been reflected in these financial statements.

#### **Grant from Host Institution**

The Network Agreement between NeuroDevNet and UBC provides a cash grant of \$200,000 over 5 years to December 23, 2014 as well as in-kind support. Gifts in kind are not recorded in the financial statements and include legal service coordination; payroll, purchasing, and grant management; and management of intellectual property, IT support and web hosting services.

**YEARS ENDED MARCH 31, 2013 and 2012** NeuroDevelopment Network, Inc.

#### 8. RISK MANAGEMENT

NeuroDevNet's activities expose it to a variety of 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. This risk arises mainly from its cash. The Network considers this risk to be limited on its cash as these are on deposit at insured financial institutions.

#### **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's interest rate risk is expected to be minimal as its cash are in short-term highly liquid instruments.

#### **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.

#### 9. 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 the requirements of the funders providing grants for research and to safeguard its ability to continue as a going concern in order 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.

# PARTNERS

Our partnerships with industry, government, and not-for-profit organizations help us translate research to inform basic science and produce the best clinical outcomes possible for children and families affected by neurodevelopmental disorders.

#### **Network Members**

Dalhousie University

Holland Bloorview Kids Rehabilitation Hospital Institut de recherches cliniques de Montréal (IRCM)

IWK Health Centre Foundation (Halifax)

McGill University

McMaster University

Montreal Heart Institute

Queen's University

Ryerson University

Simon Fraser University

The University of Toronto

The Hospital for Sick Children

Université de Montréal

Université du Québec à Montréal

University Health Network (Ontario)

University of Alberta

University of British Columbia

University of Calgary

University of Lethbridge

University of Manitoba

University of Saskatchewan

University of the Fraser Valley

University of Victoria

University of Western Ontario

York University

### Universities and Research Institutions

Canadian Centre for Behavioral Neuroscience

Croatian Institute for Brain Research (CIBR)

Laval University

McGill University

San Diego State University

Simon Fraser University

The Hotchkiss Brain Institute - University of Calgary

University of California, Los Angeles

University of Ottawa

University of Pittsburg

University of Zagreb

Vancouver Coastal Health Research Institute

Vanderbilt University

United Nations University

Nipissing University - Muskoka Campus

OCAD University

University of Iowa College of Medicine

Hôpital Sainte-Justine

Karolinska Institutet

McLaughlin Centre (University of Toronto)

#### Industry

Cerner Corporation

Vancouver Sun

Electronic Arts

Ideas for independent living Inc.

Woods Homes

NeuroChip

**Bionetics** 

Squeezease Therapy Inc.

Westcoast Child Development Group

Premier Technology

**TELUS Communications Company** 

PeriGen (Canada) Inc.

GE Healthcare

Kasian Architecture

REDCap (Research Electronic Data Capture) Software

Parents Magazine

Health Nexus

Cedar Lane Labs

#### **PARTNERS**

#### Federal departments and agencies

Networks of Centres of Excellence

National Institutes of Health (NIH)

Public Health Agency of Canada

Canadian Institutes of Health Research (CIHR)

Institute of Human Development, Child and

Youth Health (IHDCYH)

National Research Council (NRC)

Department of Foreign Affairs and International

Trade (DEFAIT)

#### **Provincial departments** and agencies

Alberta Innovates

Centre for Molecular Medicine and Therapeutics

The Child & Family Research Institute

Mount Sinai Hospital

Nova Scotia Department of Health & Wellness

Régie de l'assurance maladie du Québec

The Commission d'accès à l'information

du Québec (CAI)

WCHRI Clinical Research Informatics Centre

The Michael Smith Foundation for Health

Research (MSFHR)

Women's Health Research Institute

BC Women's Hospital & Health Centre

Alberta Perinatal Stroke Project (APSP)

BC Ministry of Health

#### **Not-for-Profit Organizations**

Australia Federal CP Register

ACT - Autism Community Training

Autism Research Training (ART) Program

Autism Speaks Canada

Baby Siblings Research Consortium

Brain Canada

Canadian Association of Paediatric Hospitals (CAPHC)

Canadian Epigenetics, Environment and Health Research Consortium (CEEHRC)

CanAssist

Canada FASD Research Network (CanFASD)

Canada-Israel FASD Consortium

Canadian Association of NeuroScience

Canadian Autism Spectrum Disorders (ASD) Alliance

Canadian Child Health Clinician Scientist Program (CCHCSP)

Children's Hospital of Philadelphia (CHOP)

Canadian Physiotherapy Association

Children's Hospital of Philadelphia (CHOP)

Commission d'accès à l'information du Québec

Computational Approaches in Neuroscience Action Control

& Transformations (CAN-ACT).

CP International Research Foundation

Early Intervention Services of York Region

Enhancing the Scientific Study of Early Autism (ESSEA)

Fondation Père Favron

Graphics Animation And New Media (GRAND) NCE

Institute for Ethics, History and Theory of Medicine, University of Munich

Institute of Neurosciences, Mental Health and Addiction (INMHA)

International Autism Genome Project

International Neuroinformatics Coordinating Facility (INCF)

Neurological Health Charities Canada (NHCC)

Manitoba Cerebral Palsy Association

March of Dimes

Maternal Infant Child and Youth Research Network (MICYRN)

National Institute of Mental Health and Neuro Sciences (NIMHANS)

Norlien Foundation

Ontario Brain Institute

Ontario Science Centre/Café Scientifique

Partners in Research (PIR) / Virtual Research on Call (VROC)

Research Foundation of the Cerebral Palsy Alliance (Australia)

R. Howard Webster Foundation

Shailah Interactive

Simons Foundation Autism Research Initiative

Stem Cell Network

THREE TO BE

Union of Ontario Indians

# RESEARCHERS

#### **Network Investigators**

Evdokia Anagnostou John Andersen Christian Beaulieu Armando Bertone Chris Bertram Susan Bryson Brian Christie Albert Chudley

Ann Marie Craig Marie-Pierre Dubé

Alan Evans Darcy Fehlings Michael Fehlings Eric Fombonne Daniel Goldowitz Geoffrey Hall Ghassan Hamarneh Krista Hvde

Grace Iarocci Judy Illes Patricia Janssen Shannon Johnson Elizabeth Kellev Kim Kerns Adam Kirton Michael Kobor

Annette Majnemer Marco Marra Michael Meaney Fiona Miller Steven Miller Pat Mirenda

Nazeem Muhajarine Tim Oberlander Paul Pavlidis Alan Peterson Éric Racine

Carmen Rasmussen Lisa-Anne Rasmussen

James Reynolds Wendy Roberts Stephen Scherer Stephen Scott Michael Shevell Isabelle Soulieres Heidi Sveistrup Peter Szatmari Joanne Weinberg Daryl Wilson Pia Wintermark Jerome Yager

Lonnie Zwaigenbaum Jonathan Weiss

#### **Associate Investigators**

May Abou Zahra Yasser Ad-Dab'bagh Dana Anaby Linda Andersen Gail Andrew Daniel Ansari Anthony Bailey Michal Begin Nathalie Berube Elaine Biddiss Gunnar Blohm Francois Bolduc Virginia Bourget Signe Bray Richard Brown Michael Brudno David Buckley Jacob Burack Catherine Cameron Peter Carlen Sterling Clarren Michael Colicos Melanie Couture Suzanne Curtin Deborah Dewey Graziella Di Cristo Adele Diamond

David Eisenstat Margaret Fahnestock Tiago Falk Bridget Fernandez Martin Frasch Jan Friedman Liisa Galea

Veronica Ghazarian Helly Goez Ruth Grunau Richard Hawkes Gina Harrison Geoffrey Hicks Liisa Holsti Mary Jane Hornaas Osman Ipsiroglu

Suzanne Johnson K.S Joseph Bhushan Kapur Kathy Keiver

Muralidharan Kesavan

Louise Koclas Bryan Kolb Sri Krishnan Deborah Kurrasch Céline Lamarre Nancy Lanphear Anna Lehman Nicole Letourneau

Stephen Lomber Christine Loock Jan Lutke Karon MacLean Frank MacMaster Krisztina Malisza Adam McCrimmin Audrey McFarlane Gerlinde Metz Fiona Miller Kishore Mulpuri Doug Munoz Diane Munz Andras Nagy David Nicholas Sarah Nikkel Ipek Oruk Lucy Osborne Maryam Oskoui Nicole Pigeon Quentin Pittman Marco Prado Peter Rosenbaum

Mojgan Rastegar **Urs Ribary** Bryan Richardson A. Jane Roskams Dawa Samdup James Sanders Guillaume Sebire Sidney Segalowitz Isabel Smith Garth Smith Veronica Smith Laurie Snider Marla Sokolowski Isabelle Soulieres Kaye Spratt Greg Stanisz Pat Stroman Jane Summers

Larry Unsworth Tracy Vaillancourt Esias van Rensburg Alexander Velumian John Vincent Naznin Virji-Babul Joanne Volden Charlotte Waddell Wyeth Wasserman Rosanna Weksberg Ellen Wood Virginia Wright

Jaynie Yang

Margot Taylor

Hasan Uludag

#### RESEARCHERS

#### **Network Trainees**

Shawn Andrews Kimberly Armstrong Jacalyn Guy Gillian Hanley Carl Jackson Danielle Levac Anath Lionel Ann-Marie Nader Keiran O'Donnel Kathryn Rancourt Susan Walker Farah Zahir Jill Zwicker

#### **Associate Trainees**

Megan Alexander Pamela Arstikaitis Quentin Ballev Omer Bar Yosef Lauren Baugh Emily Bell Terry Bennett Tamara Bodnar Heather Brown Susanne Brummelte Rebecca Cheung Isabelle Chouinard Jennifer Corrigan Colleen Curtis Charles de Leeuw Kennedy Denys Nina Di Pietro Krissy Doyle-Thomas Kelly Drummond Eric Duku Miriam Elfert Linda Ellis Stuart Falkner Trehani Fonseka Nicholas Foster Debra Fulton

Sara Furlano Stelios Georgiades Satvinder Ghotra

Allyson Graham Simone Griffin Layla Hall Ameer Hamza Kasey Hemington

Hamilton Hernandes

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Kathryn Vaillancourt Sari Van Delft Sari Van Delft Jillian Vinall Lucie Wade

Susan Walker Hong Weng Louise Whiteley Jared Wilcox Loriann Williams Katherine Wyper Ye Yang Dongming Zhou

#### **Initial Investigators**

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Suzanne Lewis Catherine Limperopoulos Bruce McNaughton Michael Meaney Freda Miller Tim O'Connor Catherine Rankin Stuart Shanker Moshe Szyf Derek van der Kooy Daniel Weeks Janet Werker

Ian Wishaw

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#### Auditors

Hay & Watson, Chartered Accountants

#### Legal Counsel

Borden Ladner Gervais LLP, Vancouver, BC

Lucyna Lach, Associate Professor, McGill University Nicola Lewis, Executive Director, NeuroDevNet (ex-officio)

#### **Staff**

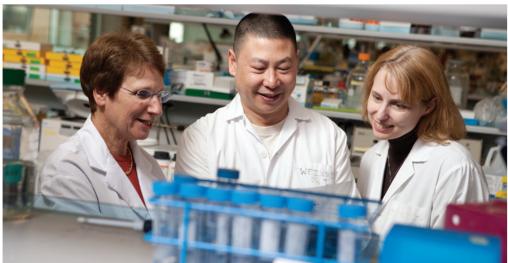
Bethany Becker, Communications Manager Jim Brookes, Chief Development Officer Darlene Cripps Senior Administrator Bruno Grazzioto, Finance Administrator Kirsten Lawrie Senior Administrator Anthony Santelices, Project Coordinator Douglas Swanson, Training and Education Manager Christine Tang-Ayushi, Administrative





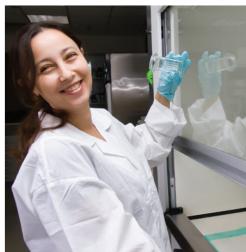


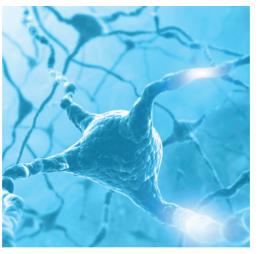




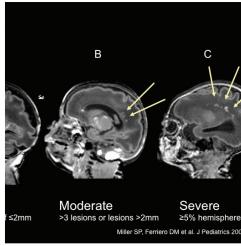




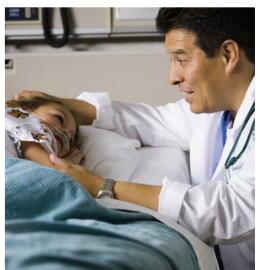
















# MAKING AN IMPACT

#### ANNUAL REPORT 2012 2013

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#### NeuroDevNet

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