



NeuroDevNet

A CANADIAN NETWORK OF CENTRES OF EXCELLENCE

WORKING TOGETHER TO HELP CHILDREN AND FAMILIES



PARTNERSHIP

2013 /14

ANNUAL REPORT





LOGO

NeuroDevNet's spiral logo communicates change, progression and evolution. Its bright multi-coloured palette emphasizes the Network's focus on children. The coloured "stars" are neurons, the building blocks of the brain. Starting from a smaller yellow neuron, denoting hope, the neurons rise in a crescendo that ends with green neurons, signifying health. The fifth annual report aligns with these green neurons in our spiral, conveying health as the culmination of our efforts in the first five-year cycle of NCE funding, and the foundation of our plans as we look towards the future.

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, treatment and prevention.

OBJECTIVES

CAPACITY BUILDING

Train the next generation of experts in disorders of the developing brain

RESEARCH EXCELLENCE

Support and conduct exemplary multi-disciplinary research

KNOWLEDGE TRANSLATION

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

BUSINESS DEVELOPMENT & VALORIZATION

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.

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 disabilities, as well as to their families and caregivers. NeuroDevNet focuses its funding on integrated, team-based, research initiatives related to cause, early diagnosis, and intervention. 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 diagnostics, therapies and changes in policy and practice.



a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA



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Select images of Children on front cover, pages 9, 30, 70, 71 and Autism

Research Project: STACIE TURNER from her series *On the Spectrum*

Portraits of Dr. Daniel Goldowitz and Jim Brookes: MARTIN DEE

Brain images, Cerebral Palsy Project: Courtesy of DR. ADAM KIRTON

Brain images, FASD Research Project: DR. CHRISTIAN BEAULIEU

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Conference, DOHaD Meeting: SUZANNE AHEARNE

Front cover centre image, Hacking for Health: KATELYN VERSTRATEN

Front cover top left image, Researchers and CP Organizations,

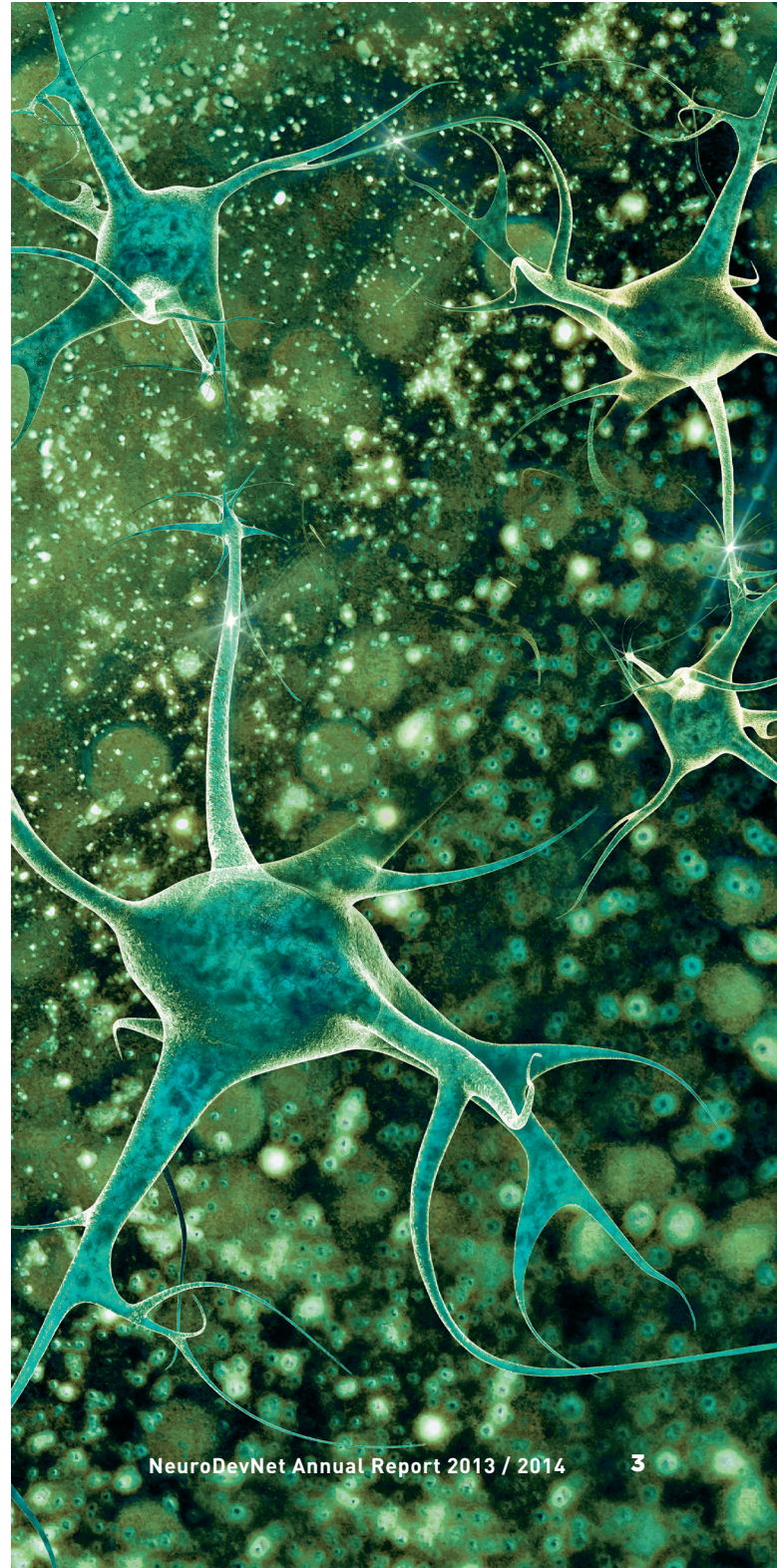
World CP Day and *Jacob's Story*: ANNELIESE POETZ

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COMMENTS

COMMENT FROM THE BOARD CHAIR

As NeuroDevNet's Chair of the Board of Directors, it is with great pleasure that I share with you my personal comment in NeuroDevNet's Annual Report, highlighting the Network's activities and initiatives over the past year.

I joined the NeuroDevNet Board, captivated by its mandate and goals to further capacity for early diagnosis, intervention, and support for families affected by neuro-disabilities. These goals remain compelling, and will contribute to improving the quality of life among the one out of six Canadian children affected by a developmental disorder.

The focus of the first five years on autism, FASD and cerebral palsy has produced tremendous scientific achievements and discoveries that, today, are having the beneficial impacts we set out to make.

I wish to recognize the contribution of the Board of Directors of NeuroDevNet in supporting and furthering our mission. Profound thanks are due to our colleagues Dr. David Phipps and Dr. Judy Illes, who have completed their terms as directors, and have stepped down. Thankfully, both of these colleagues remain deeply involved in the Network, as the respective leads of the KT and Neuroethics Cores.

This past year, the Board was comprised of 15 members who represent a considerable range of experience and expertise, and draw from diverse backgrounds in both the private and public sectors, and academia. This wealth of skill and capacity has produced excellence in the governance, management, and strategy that help guide NeuroDevNet.

Dr. Jerome Yager will become the Network representative on the Board. Dr Yager, based at the University of Alberta is Professor and Director of the Division of Pediatric Neurology and Head of Section, Pediatric Neurosciences in the Department of Pediatrics, and serves as co-lead of NeuroDevNet's CP Project.

Our profound thanks go to each of you, for helping ensure the Network's current successes, and paving the way for a promising future.

I am pleased to report that our scientific leadership of NeuroDevNet remains constant. The network is ably led by Scientific Director Dr. Dan Goldowitz. This year, our Executive Director Nicky Lewis moved to Australia, and was replaced by Jim Brookes, who previously served as the Network's Director of Business Development and valorization champion.

Towards the close of the period covered by this annual report, NeuroDevNet began preparing for a renewal application to the NCE for an additional five years of funding. This application has been guided by the network's strategic plan which the Board finalized a year ago. I am confident of the fine groundwork laid in the first five years of the Network, which is depicted in the success stories included in this publication.



Partnership, which is the theme of this year's report, is crucial to the Network's success, amplifying the impact of our Canadian investment in neurodevelopmental disorders, and realizing national and international impacts and synergies.

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I note just a few of these contributions, and encourage you to peruse in full the stories that showcase the commitment and potential vested in our collaborations. For example, researcher David Nichols was the backbone of our support for the Sinneave Family Foundation in mounting the tremendously successful Second Annual ASD Vocational Conference in Calgary in June 2013.

A few months later, World CP Day in Vancouver galvanized relationships with and between cerebral palsy associations across Canada, and paved the way for participation of Janice Bushfield, Executive Director of the Cerebral Palsy Association in Alberta as one of the parent advocates joining us for our annual Day on the Hill in March 2014.

World Autism Awareness Day brought key ASD organizations, NeuroDevNet among them, together on the steps and in the halls of Parliament in April 2014. A few months later, the Federal Government announced a \$26.4 million, four-year investment in two training programs connecting Canadians with intellectual disabilities particularly autism, with employment. NeuroDevNet was a key presence at the BC gathering of the internationally focused organization, the Developmental Origins of Health and Disease in February 2014.

There is much more to say, but I will leave the highlights of the Network's initiatives in research, training, and knowledge translation to NeuroDevNet's Scientific Director, Dr. Dan Goldowitz.

Hearty congratulations on another year of distinguished achievement. The breadth and depth of the Network's undertakings is truly impressive, and confirms the wisdom of the initial investment in NeuroDevNet. I am truly proud to have led the Board of Directors in helping to support realization of the Network's mandate. NeuroDevNet will have national and international impacts and ultimately change for the better, lives of children with disabilities around the world. ■

A handwritten signature in dark ink, appearing to read "Henri Rothschild".

HENRI ROTHSCHILD

Chair of the Board of Directors, NeuroDevNet

COMMENT FROM THE SCIENTIFIC DIRECTOR

As Scientific Director of NeuroDevNet, I am pleased to share through this, our fifth annual report, significant milestones accomplished by the Network in the realms of research, training, and knowledge translation that emerged during our first funding Cycle.

We have exciting news to share about the activities of our three disorders-focused Demonstration Projects, as well as the contributions of our three service Cores. Each has distinguished itself in unique and impressive ways.

This year we have had a focus on partnership, and its pivotal role in all that we do as a Network.

This year we have had a focus on partnership, and its pivotal role in all that we do as a Network. The successes we recount include the \$1M in support obtained by ASD project co-leads Dr. Lonnie Zwaigenbaum and Dr. Stephen Scherer, to set up a biorepository through a partnership between the Simons Foundation and Autism Speaks (US).

NeuroDevNet and Autism Speaks were also major supporters of Dr. Scherer's discovery of new ASD susceptibility genes, deemed one of the top 100 scientific discoveries of 2013 by *Discover Magazine*. Another major publication was a review article in the *Canadian Medical Association Journal* capturing the state of the science

in autism. An unprecedented collaboration of autism researchers including top investigators in the Network produced this authoritative characterization of predictive genetic testing, early developmental trajectories and treatments in ASD.

Both our cerebral palsy and fetal alcohol spectrum disorders research groups engaged in groundbreaking partnerships with community-based individuals and organizations to produce stunning results. *Jacob's Story*, a compelling play about the challenges of growing up with FASD has played before full houses during three performances in Ontario and will debut in the United States in 2014. The CP Canada Network is a dynamic outgrowth of the coming together of our investigators and cerebral palsy organizations across the country. Together they are working to bring national profile to the most common childhood physical disability that persists in flying below the radar in public awareness and policy.

The partnership between Dr. Adam Kirton and the Heart and Stroke Foundation of Canada will likely influence future Canadian practice guidelines for pediatric stroke, the most common cause of CP. Genetic and imaging insights generated during his highly productive *Opportunities Grant* are moving clinical practice and understanding of CP forward.

Brain imaging is playing an important role in both research and clinical practice within the FASD project. A key element in the internationally regarded cohort of children affected by FASD and typically developing controls, MRI images are an essential component in Glenrose Rehabilitation Hospital's FASD clinical services. The ability to show the brain damage caused by prenatal exposure to alcohol facilitates communication with parents and caregivers, as well as skeptics in the healthcare system that still don't believe alcohol consumption in pregnancy causes harm.

COMMENTS



Martin Dee photography

Animal model work continues to form a crucial bridge to understanding impacts of fetal alcohol exposure in humans. Within the FASD project, cross-pollination between bench researchers and clinicians is deepening understanding of stress and self-regulation in the disorder.

Technology has been an effective mechanism for improving function in NeuroDevNet's experience. Our newest introduction, the *Jooy* App, is a phone- or web-based mechanism for connecting families, caregivers and professionals with adapted leisure activities for youth with physical disabilities. An effective pitch at Montreal's Hacking Health Hackathon brought designers and programmers into collaboration with our CP researchers' first CHILD LeisureNET project.

NeuroDevNet's three Cores of Neuroinformatics, Neuroethics and Knowledge Translation provide the Network with the platforms that bind us together and run throughout all of these projects. They have enhanced new efforts and provided critical perspectives and tools for carrying out Network activities, and pursued insights that had not existed on the Canadian research landscape.

The Neuroinformatics Core has championed extraordinary progress in phenotypic and genomic data collection and analysis as well as establishing national standards for data sharing together with the Ontario Brain Institute. Neuroethics has produced hard-hitting workshops and publications drawing attention to the over-medication of children with neurodisabilities, and the complexities of transitioning from pediatric health care to the adult setting. The KT Core has been of universal assistance in speeding the process of translating NeuroDevNet's work towards impact through our partners, receptors and policy makers.

Several bright lights from our Research Training Program profiled in this report are exemplars of the benefits of the Network's trans-disciplinary approach to training, illustrated by their achievements and insights at each stage along the post-baccalaureate continuum. PhD student Angelina Paolozza, Post-Doctoral student Kieran O'Donnell and former Fellow Kaitlyn McLachlan, attest to the importance of the opportunities they've had, and skills they've acquired, in preparing them for the next step, whether continuing in their studies, or stepping into a new role as a next-generation scientist, clinician or health professional.

Lastly, our events capture our successes in outreach and partner engagement in action.

I close with my appreciation to the excellent researchers in our network, to our hugely dedicated NeuroDevNet staff, our very engaged Board of Directors, and to our highly supportive partners. Our successes would not be possible without the tireless contributions of all of these groups. Our collective efforts — Board, Network, Staff, and partners have been crucial in laying the groundwork for another five years of impressive success. ■

A handwritten signature in black ink, appearing to read 'Daniel Goldowitz'.

DR. DANIEL GOLDOWITZ
Scientific Director, NeuroDevNet

Martin Dee photography



UPDATE

STAFF UPDATE

Jim Brookes Appointed NeuroDevNet Executive Director at Crucial Time of Transition for the Network

Jim Brookes became Executive Director of NeuroDevNet March 12, bringing with him a wealth of experience in senior management in industry, as well as the highly regarded NCE, Mitacs.

In his role, approved by the Network’s Board Executive, Brookes is responsible for overall management and strategic guidance of the NeuroDevNet National Network of Centres of Excellence, as well as its partnership, communications and commercialization initiatives.

“Jim has been a solid and creative member of our leadership team, and essential in strengthening our partnerships and the valorization/commercialization process within the Network,” says Scientific Director Dr. Daniel Goldowitz. “His extensive background in senior management, and dedication to improving the lives of children and families affected by neurodevelopmental disorders provide an ideal combination of experience and perspective as NeuroDevNet completes its first five years and proceeds in its Network renewal process.

“NeuroDevNet has tremendous momentum and promise as we move into the final year of our initial five year funding period,” adds Goldowitz. “Our achievements to date have had the critical driving force of our former ED, Nicky Lewis, who has stepped down as NeuroDevNet’s Executive Director. We are hugely appreciative of Nicky’s formative role in the early years of NeuroDevNet and wish her great success in her senior position in research management with Australia’s Telethon Institute.”

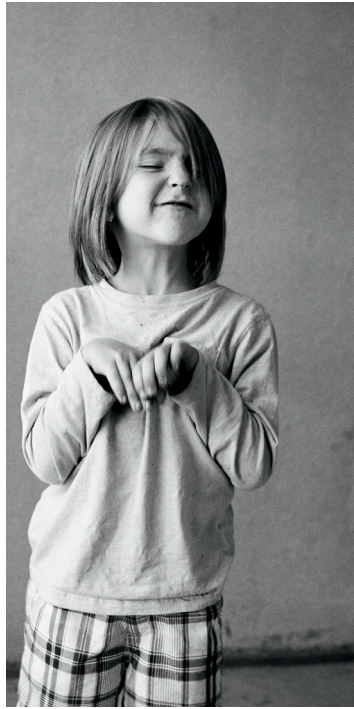
“It is such an honor to take on the Executive Director position as I can think of nothing more important than to support the children and their families in Canada who are impacted by neurodevelopmental disorders,” reflects Brookes. “The NeuroDevNet researchers, partner organizations, and our staff are all incredibly committed to the cause and are an inspiration to work with.”

“... I can think of nothing more important than to support the children and their families in Canada who are impacted by neurodevelopmental disorders.”

Prior to joining Mitacs, Brookes worked in the telecommunications sector for BC Tel, Stentor and TELUS in a variety of senior positions in Business Development, Marketing and General Management. As Vice-President of Local Services at BC Tel/TELUS, he grew a \$2 B market. While with TELUS he also served as Vice-President of Business Transformation.

Brookes has a B.A. and M.A. in Economics from Simon Fraser University and teaches an Economics course at the University of Victoria. He is Chair of the Board of SERENE, a national knowledge translation network in cyber security, and was previously on the Board of the GRAND NCE, a national research network in multi-media.

Brookes has also served on the boards of the Canada FASD Research Network, the Vancouver Symphony and VanDusen Botanical Gardens Association. ■



NUMBERS

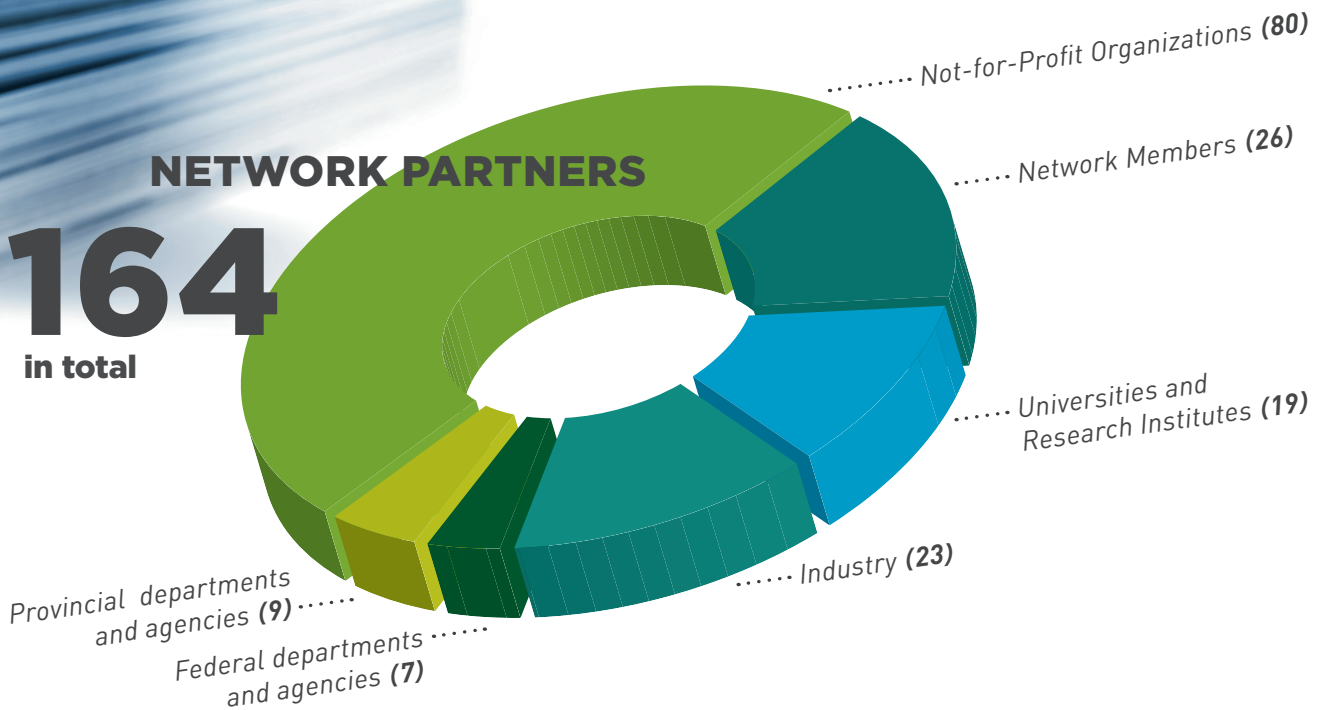
NEURODEVNET BY THE NUMBERS

PUBLICATIONS 2010-2014

168 Total Refereed Publications
114 Produced in Collaboration

NETWORK PARTNERS

164
in total



WEBSITE & SOCIAL MEDIA

141,245 Website views over the past year

41.2% returning, **58.8%** new visitors

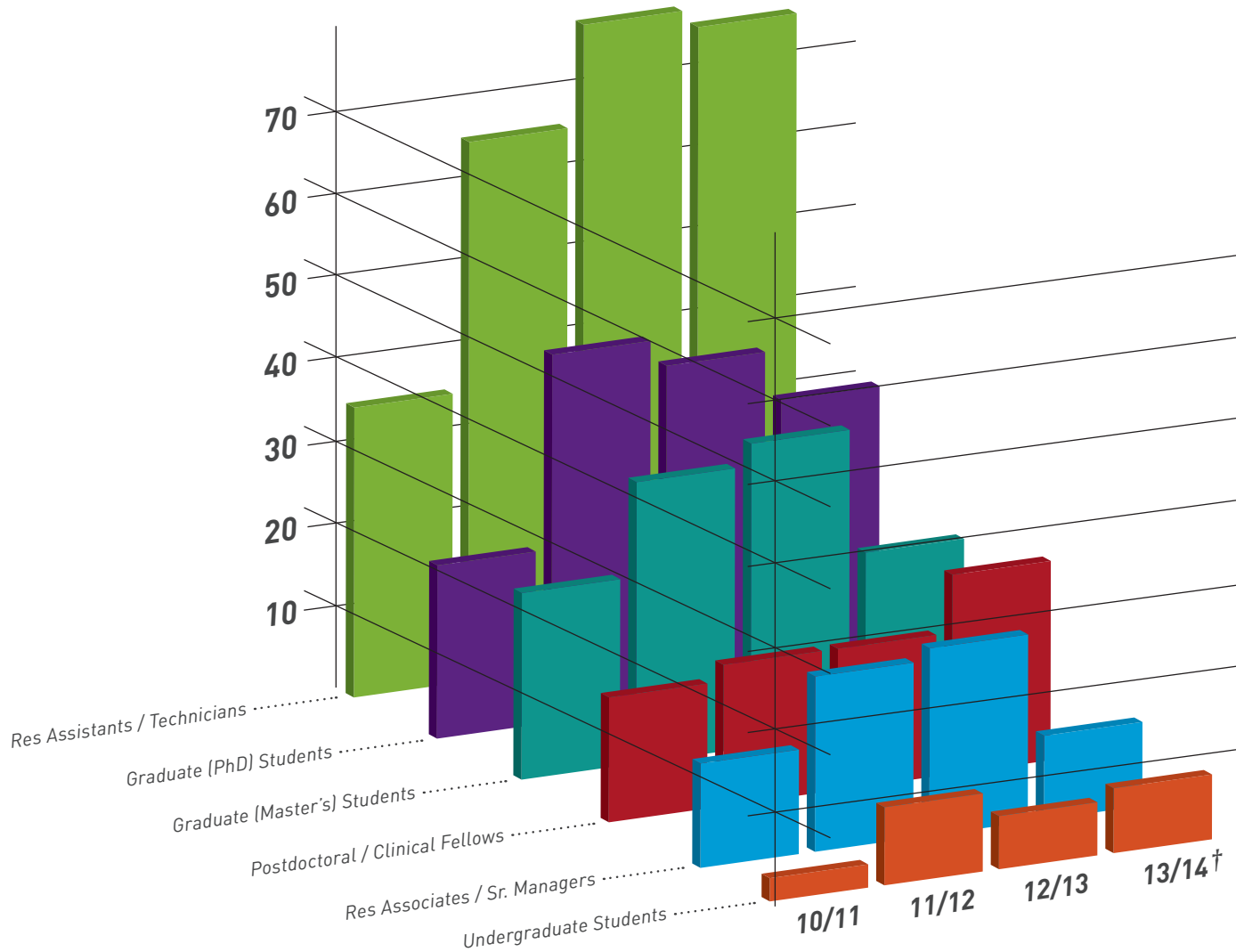
76% people viewing from Canada, **10.28%** from US, **1.77%** from UK

249 Facebook Likes by end of March 2014

728 Twitter Followers by end of March 2014

225 Retweets, **244** Mentions

All TRAINEES and YOUNG PROFESSIONALS involved (Highly Qualified Personnel - HQP)



† FY 2013-14 decrease in Year-4 HQP reflects completion of *Opportunities Initiative* projects

CYCLE I AWARDS - NeuroDevNet Fellowship Program*

	2010/11	2011/12	2012/13	2013/14*
Graduate Students	4	4	6	4
Postdoctoral / Clinical Fellows	1	5	8	4
Total # Awards per year	5	9	14	8

* Fellowships offered vary in length from 1-3 years in duration depending on partnership program, these annual award numbers represent support of 21 individual NeuroDevNet Fellows

4 PATENTS

Four ASD genetic patents were obtained, and three new US formal patent applications were filed. A licensing agreement has been established with Athena Diagnostics.

PROJECTS

AUTISM SPECTRUM DISORDER RESEARCH PROJECT

Autism Biorepository to Shed Light on Heritability and Risk

Researchers in Canada and the US are gaining deeper insights into genetic and environmental factors that increase or decrease risk for autism, through a highly collaborative biorepository.

Spearheaded by NeuroDevNet ASD Research Project lead Dr. Lonnie Zwaigenbaum, the biorepository is a collection of blood samples from parents and children in the *High Risk Baby Siblings* cohort of families where one or more children has an autism diagnosis. The DNA, cell lines and plasma drawn from the samples provide an enduring source of insight into ASD and other developmental outcomes.

“The strategy is to approach families already participating in the *Baby Siblings* studies,” says Zwaigenbaum, “because a lot of information has already been collected [from them]. We can tap into rich behavioural characterizations of the early years of life, and see if genetic differences relate to variation, or phenotypic similarities to older and younger children.

“We’ve been working on this project for the last year and a half,” adds Zwaigenbaum, “so we’re in the process of collecting samples and establishing the biorepository.” The goal is to gather biological samples from about 400 families.

“In talking to families, he continues, “it’s really important to understand how the genetics are expressed across the diversity of autism, and whether assessing them will allow us to predict who is at highest risk. Monitoring siblings has allowed us to move to younger and younger ages to observe the earliest manifestations of autism.”

Multiple partners joined to bring the biorepository into being: Autism Speaks, along with the US-based Simons Foundation for Autism Research are funding the initiative; samples are collected at six North American study sites led by top autism researchers, and are housed at Rutgers University Cell and DNA Repository, the world’s largest facility of its kind.

Arriving at this place took years of cultivation. “Dr. Zwaigenbaum generated the seed in everyone’s minds,” says Dr. Alycia Halladay, former director of research for environmental sciences at Autism Speaks in the US. Now chief science officer for the Autism Science Foundation, Halladay recalls “in 2009, Lonnie scoped out the potential uses of a biorepository for the Baby Siblings Research Consortium — especially around gene/environment interactions. As it is known that autism runs in families, this resource will help science discover particular risk markers.”

“As it is known that autism runs in families, this resource will help science discover particular risk markers.” Dr. Alycia Halladay

Through the work of the Baby Sibs Research Consortium, likelihood of an autistic child having a sibling with ASD has since been pegged at 1:5, a much higher rate than the 1:68 reported in the US population.

Halladay also highlights the contributions of Dr. Stephen Scherer, Zwaigenbaum’s co-lead in NeuroDevNet’s Autism Research Project, who is playing a pivotal role in the genetic analysis of the biosamples. The initial round of sample collection was performed entirely in Canada, and included participants in the NeuroDevNet ASD study cohort.



When one child in a family has ASD, siblings are much more likely to share that diagnosis. In this family, the middle daughter has autism.

Stacie Turner photography "On the Spectrum"

Autism Speaks Canada came on board with early support for this work, "because as an organization, we feel that identifying at risk children as early as possible offers families an opportunity to change the trajectory of development with benefits across the spectrum and lifespan," says Executive Director Jill Farber.

"Collaboration has been essential, the biorepository couldn't exist without it," reflects Marta Benedetti, senior scientist with the Simons Foundation's Autism Research Initiative, and a champion of the biorepository. "We jumped in to fund a grant to fill the need for a collection of DNA, to expand on genetic understanding of risk in autism by providing funds for this biorepository. Our ultimate goal, in supporting this along with Autism Speaks [US], is to look at the early developmental signatures of ASDs. We know that this population is at high risk, but we wanted to shed more light on the risk."

Asked if the biorepository was achieving its potential, Benedetti responds, "the biorepository is growing. We are far from reaching an answer to the question about risk addressed in the grant. Yet, the biorepository has been established, and by itself, this is a success." ■

First Full-Genome Sequencing for autism offers promise of earlier diagnosis and improved treatment

The sequencing of the entire genomes of 32 children diagnosed with autism and their families provided a definitive look at genetic variants associated with hallmarks of the disorder — an achievement so dramatic it was deemed one of the top 100 scientific discoveries of 2013.

Half of the families sequenced in the landmark study had inherited, *de novo* and X-linked genetic alterations in four newly identified risk genes, nine known and eight candidate ASD risk genes, as well as in genes associated with fragile X, epilepsy and related conditions. The analysis was conducted by an international team spearheaded by Dr. Stephen Scherer, co-lead of NeuroDevNet’s ASD Research Project.

“Whole genome sequencing offers the ultimate tool to advance the understanding of the genetic architecture of autism,” says Scherer, senior scientist and director of the Centre for Applied Genomics at The Hospital for Sick Children and director of the McLaughlin Centre at the University of Toronto.

Some families had a combination of genes involved in ASD. In addition, risk alterations were found in genes associated with fragile X or related syndromes (CAPRN1 and AFF2), social-cognitive deficits (VIP), epilepsy (SCN2A and KCNQ2) as well as NRXN1 and CHD7, which causes ASD-associated CHARGE syndrome.

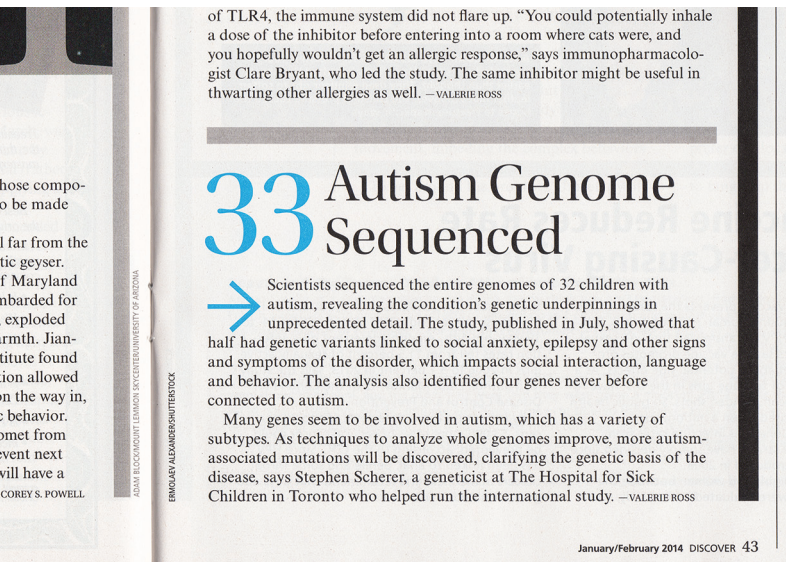


The large proportion of families identified with genetic alterations considered flags for clinical follow up is due, in part to whole genome sequencing’s capacity to comprehensively and uniformly examine regions of the genome that would be missed in other, lower-resolution genome scanning techniques.

“In the future,” says Scherer, “results from whole genome sequencing could highlight potential molecular targets for pharmacological intervention, and pave the way for individualized therapy in autism. It will also allow for earlier diagnosis of some forms of autism, particularly among siblings of children with autism where recurrence is approximately 18 per cent.”

Detection of Clinically Relevant Genetic Variants in Autism Spectrum Disorder by Whole-Genome Sequencing emerged from a \$1 million collaboration of Autism Speaks, SickKids, BGI and Duke University launched in 2011 to generate the world’s largest library of sequenced genomes of individuals with ASD. All participants in the study were unrelated Canadians, drawn from the Autism Speaks Autism Genetic Resource Exchange (AGRE) and NeuroDevNet-funded cohorts.

The study was published July 13, 2013 in *The American Journal of Human Genetics*. ■



Dr. Evdokia Anagnostou, a clinician-researcher based at Holland Bloorview Kids Rehabilitation Hospital, was lead author on the review article.



Holland Bloorview Public Relations

Synopsis of evidence in early diagnosis guiding clinical practice and informing parents

ASD Researchers' state-of-the science collaboration widely embraced

The pace of discovery in autism research is progressing so fast, even experts in the field are challenged to stay on top of the broad range of findings.

Ensuring that pivotal evidence reaches the range of stakeholders concerned with Autism Spectrum Disorders, including front-line clinicians, service and support organizations, and parents can be just as complex.

Aware of this reality, the **Canadian Medical Association Journal (CMAJ)** approached Canadian autism researchers as individuals to produce a review of the state of the science in ASD. "We wanted to summarize the literature and give recommendations based on our assessment of the evidence," says clinician-researcher and study lead author Dr. Evdokia Anagnostou. **Autism spectrum disorder: advances in evidence based practice** "is strictly speaking not a guideline," she adds, "it's evidence based practice parameters — what the clinicians need to look at and think about."

The review, drawing on the expertise of specialists in pediatrics, psychiatry, epidemiology, neurology and genetics from across Canada, outlines the current understanding of ASD and best practices for pediatricians, family doctors and specialist clinics, and identifies resources.

Published January 13, 2014, the paper was immediately spotted by Marg Spoelstra, executive director of Autism Ontario, and was attached to emails sent out by the mother organization and its 25 chapters. Autism Ontario also vigorously promoted the paper via social media, e-blasts, and through its magazine, **Autism Matters**. Autism Ontario has also distributed copies at community-based events.

"The sheer volume of research out there, we in our own professional communities, we can't sort through it," Spoelstra adds. Through her involvement with research networks, she knows and respects every author on **Advances in evidence based practice**. That all of these people can say, 'we together think this is what you need to know, this is what best qualifies for evidence', that to me is an important article for anyone to see — especially Canadians."

"I was thrilled to see it. I breathed a sigh of relief."

Marg Spoelstra

Advances in evidence based practice is amongst the highest-scored articles ever to be published in CMAJ, ranked #45 of 2,439 among downloads for the journal. "People read it carefully," says Anagnostou. "Clinicians are using it as a guideline, and other medical sections have read it as part of a journal club. "I was thrilled to see it," says Spoelstra. "I breathed a sigh of relief".

"This is what I wish researchers would do," reflects Spoelstra. "The paper represents a lot of different work in ASD research. It's very easy to read. The fact that they could say, 'what do we know about this topic, this is where we're going in our understanding about what ASD is, and this is where we should be going in research, for a community searching for 100s of answers? We're grateful." ■

PROJECTS

CEREBRAL PALSY RESEARCH PROJECT

Researchers and CP organizations across Canada align to give cerebral palsy national visibility

It took the power and connectivity of a translational research network to build cohesion within Canada’s cerebral palsy (CP) research community and to foster relationships with CP organizations across the country.

“We have a lot of expertise in cerebral palsy in Canada, but we were all working very separately,” says CP Research Project lead, Dr. Darcy Fehlings. “What the NeuroDevNet umbrella allowed us to do as researchers is to really join forces. From basic and translational researchers to investigators interested in knowledge translation and policy – it was really groundbreaking for us.”

Collaboration, not only within the CP Research Project, but with the broader community of families and advocacy organizations has been a pivotal experience for the team. “Within the [research] project, we had some strong leadership for the importance of seeking family input into how the CP research program was to be designed and run, and the need to build family knowledge on CP – to give back,” says Fehlings.

“It’s important,” she adds, with emphasis, “because it forces you to align your goals in the right direction.”

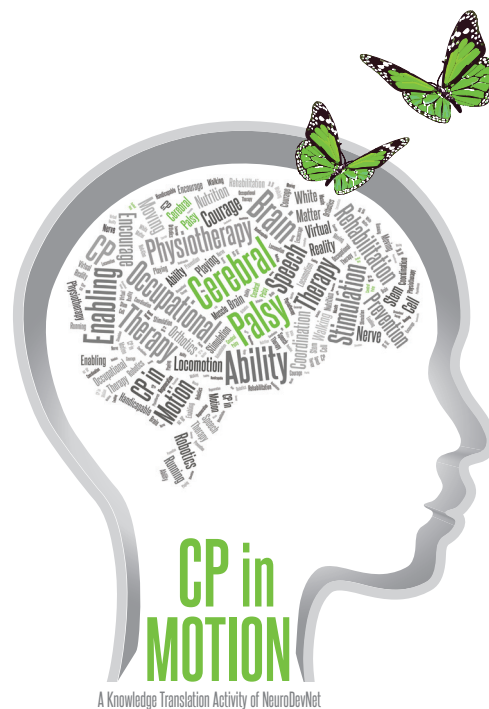
The CP Research Project began that process through events under the title *CP in Motion* or *Kids in Motion*, held in Montreal, Edmonton, Toronto and Vancouver. “At each one, we’ve gotten more powerfully connected with the family groups in the audience, the parents, people with CP, the clinicians, and the researchers who attend,” says Fehlings.

Partnership began to form in earnest when CP organizations from across Canada met with NeuroDevNet on October 2, 2013, World CP Day. Around a conference table in Vancouver B.C., provincial leaders from Alberta, Manitoba, British Columbia, Ontario shared information about the status of CP and CP services in their communities, learned about CP research taking place under NeuroDevNet’s auspices, and explored what could be done together to develop a national presence for CP in Canada. [See story about World CP Day, page 44]

Under the banner of the CP Canada Network, the group has since planned the 2014 Kids in Motion meeting in Halifax, and Janice Bushfield, Executive Director of the CP Association in Alberta, was a key participant in NeuroDevNet’s *Day on the Hill* during Brain Awareness Week 2014. [See story, page 42] “Going to a *Day on the Hill* was a little bit out of our comfort zone,” says Bushfield, “but it was great to meet everybody there.”

“We’re at a real crossroads. We’re never going to move CP forward if we don’t participate.”

Janice Bushfield, CP Association in Alberta





Anneliese Poetz photography

“Without a national organization it’s very hard to get traction,” she adds. “Being a part of NeuroDevNet, it’s a hugely important part of this movement. We’re at a real crossroads. We’re never going to move CP forward if we don’t participate. Ultimately, I think we need a national organization. Our focus for that national body needs to be research, advocacy, and policy change.”

“Right after attending *CP in Motion* in Vancouver, the idea of creating an Advisory Committee lit up my brain,” says Feri Dehdar, Executive Director for the Cerebral Palsy Association of B.C. (CPABC). “Right now, 15 people are sitting on this committee,” including leading CP clinician researchers in BC, other medical professionals, service providers, parents, individuals with CP, and caregivers.

“The Committee serves primarily as a forum to collaborate with the people we feel we can learn from”, she adds, “to better understand the needs of people living with cerebral palsy, and who serve as ambassadors of the CPABC. The Advisory Committee also serves the vital function of informing the Board about the needs and services of people living with cerebral palsy, based on their unique perspectives. This information will assist CPABC in developing new programs and initiatives. The Committee will keep our outreach current and relevant.”

After speaking at length while in Vancouver with Dr. Michael Shevell, who oversees the National CP Registry, David Kron returned to Winnipeg with a mission: to get the registry operational in his province. He succeeded in getting the support of the Board of Directors of the Cerebral Palsy Association of Manitoba, where he works as membership and program director, and the Rehabilitation Centre for Children. “I told them, ‘let’s connect with NeuroDevNet and the registry, because somewhere down the line, something’s going to help, and you’ve got to be ready for it.’”

Asked what sold him on the registry, when there are many competing needs, Kron says, “I’m looking at the long term. It won’t help me, I’m 46 years old. I’m looking at the next generation and the generation after that, and all the things coming down the pipe, like stem cell therapy and transcranial brain stimulation. It’s something real and tangible that affects everybody with CP’s life in the future, and it offers hope.” ■

ABOVE: World CP Day 2013 - NeuroDevNet researchers and heads of cerebral palsy organizations across Canada discuss opportunities to collaborate.

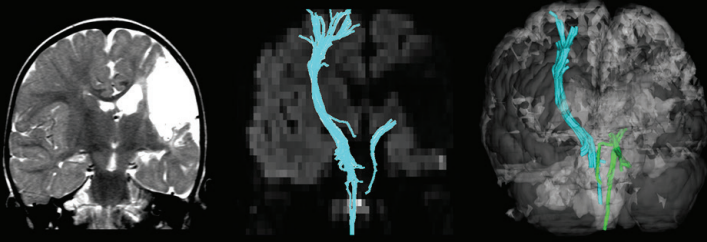


image supplied by Dr. Adam Kirton

Pediatric Stroke Project Seeds Improvements in Clinical Practice

“Pathophysiology of Perinatal Stroke” a NeuroDevNet-funded *Opportunities Initiative*

The risk factors and root causes of strokes that cause cerebral palsy (CP) in pre-term and newborn infants are being probed vigorously from multiple angles within NeuroDevNet’s CP Research Project.

The fundamental groundwork for this approach has been created in Alberta, through the Alberta Perinatal Stroke Project (APSP), and the large cohort of children built under its auspices. Spearheaded by Neurologist Dr. Adam Kirton, and brought into being supported by seed funding from the Network’s *Opportunities Initiative*, the APSP attracted more than 200 families to participate in its research, and laid the groundwork for several studies that continue to explore insights into risk factors gained during this initial phase.

At the time he sought funding, Kirton said, there were few extant studies looking at risk factors for perinatal stroke. He and his team leveraged the *Opportunities* investment to develop the most comprehensive risk factor analysis ever applied to perinatal stroke. Ten research papers and two best practice recommendations have been published, based on the research project and collaborations supported by NeuroDevNet.

Key discoveries reported at the close of 2013 included finding evidence of inflammation among children who had had arterial stroke near the time of birth; Kirton and his team also found through careful case-controlled study that prothrombotic disorders (a tendency to form blood clots that block blood vessels) were relatively rare in full-term children who had venous strokes well before birth, as well as children with arterial stroke either before or soon after birth, in contrast to previous findings.

“This has translated into improved clinical care,” says Kirton. “Our results are establishing new, more accurate age-dependent norms for these tests in children. Two important advances also emerged from this work.”

“Thanks to the progress supported by NeuroDevNet,” adds Kirton, “the APSP was awarded one the first CRIO grants, a \$750,000 award that has helped us expand many of the methods and projects we developed and extend them provincially.” Collaborative Research and Innovation Opportunities (CRIO) Grants are funded by Alberta Innovates – Health Solutions to produce and translate new knowledge into improvements in health and healthcare.

“This will more than double the power of our clinical research network to continue this work while we launch new initiatives.”

Dr. Adam Kirton

“This will more than double the power of our clinical research network to continue this work while we launch new initiatives.”

The knowledge seeded by NeuroDevNet’s early investment and Kirton’s inspiration may also be incorporated into new pediatric stroke guidelines.

Canada does not have formalized pediatric guidelines, per se, but Kirton was a key informant in the production of the Heart and Stroke Foundation of Canada’s 2011 Family Guide to Pediatric Stroke. “We created that,” says Dr. Patrice Lindsay, Director of Best Practices and Performance, Stroke, for the Foundation. “Every family orders 10 copies of it — one for the teacher, one for the family doctor, one for the swim coach...”

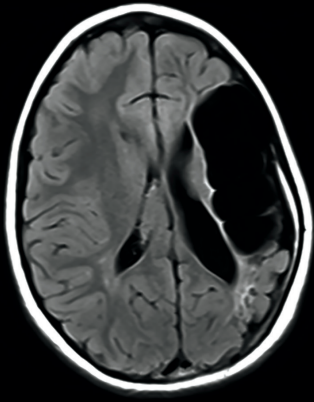


image supplied by Dr. Adam Kirton

"We just reviewed it," Lindsay adds, mentioning the guide is one of the legacies of the Canadian Stroke Network, a former NCE. "Our expert pediatric group found the science hasn't changed enough yet to revise it. We figure our target is within 12-18 months." Collaboration with Britain, whose guidelines are in need of updating, is being explored.

"I can't speak to what content will be changed, but we do an expert review process and identify new and upcoming areas," says Lindsay. "Adam Kirton has been our pediatric best practice chair and our champion. The time he has put into awareness and education has really moved pediatric stroke miles in Canada. It's just risen to a new level under his leadership." ■



TOP: Scans show areas of the brain damaged by stroke in children with cerebral palsy.

ABOVE: An infant in an incubator in the Neonatal Intensive Care Unit. Prematurity increases risk of stroke in very early life.



Hacking for Health Catalyzes CP Researchers' Leisure Activity App Idea

For all children and youth, leisure activity improves quality of life. Developing personal interests, interacting with peers, and increasing skills are universal benefits of recreational and social activities.

But for children and youth with disabilities, there are added benefits of participation, including better coping skills and physical health, and reduced family stress.

"Services that promote functional independence and engagement in activity are most intense in the first five years of a child's life, and then things start to fall off as children grow older," says Dr. Annette Majnemer, Director and Associate Dean School of Physical & Occupational Therapy at McGill University.

While they engage in many leisure activities, children and youth with disabilities face numerous barriers to participation. Research exists that identifies those barriers and ways to overcome them, but few mechanisms exist for translating that knowledge into action.

Together, Dr. Keiko Shikako-Thomas, a postdoctoral fellow at the Canchild Centre for Childhood Disability Research

at McMaster University and Majnemer obtained a grant from the Canadian Institutes for Health Research to support the launch of The Child Health Initiative Limiting Disabilities through Leisure (CHILD LeisureNET). The project aims to mobilize a variety of stakeholders including parents, youth, service providers, researchers and policymakers to increase awareness of existing evidence and collectively find solutions to promote leisure opportunities for children and youth with cerebral palsy, juvenile rheumatoid arthritis, traumatic brain and spinal cord injury, developmental coordination disorder and other physical health conditions.

Jooay is designed to help users find adapted leisure opportunities close to home — on the web, or via a smartphone.

The *Jooay* App, one of the first initiatives emerging from CHILD LeisureNET, is gaining strong interest from families, youth with disabilities, and health professionals. *Jooay* is designed to help users find adapted leisure opportunities close to home — on the web, or via a smartphone.



Katelyn Verstraten photography



The idea for the App came about in an Edith Strauss Knowledge Translation in Rehabilitation Symposium at McGill University. The *Jooay* concept gained the interest of developers after a pitch at the Hacking Health 2014 Hackathon in Montreal, made by Shikako-Thomas and occupational therapy (OT) colleagues. The Montreal-based organization aims to improve healthcare by inviting technology creators and healthcare professionals across Canada to generate low-cost, innovative concepts that can be rapidly prototyped and refined. The OTs joined forces with the tech team who created the user interface, graphics and design for *Jooay*.



Dr. Annette Majnemer,
McGill University



Dr. Keiko Shikako-Thomas,
Canchild Centre for Childhood
Disability Research

"It's an interesting example of integrated KT," observes Shikako-Thomas. "The idea came from the university, based on interviews with youth with cerebral palsy, parents and others, evolved with the participation of public and industry partners, then came back to the university as part of a CHILD LeisureNET research project and is now returning to the community... quite the complete KT cycle!"

"We came up with idea for the app when we heard that access to adapted leisure activities was done through rehabilitation settings, but out in the community, people didn't know where they could go for activities such as adaptive yoga, swimming or camp," says Majnemer. "We've found many families don't know what's already out there in the way of adapted leisure activities in their own communities. We've been told 'we'd love to do it [leisure activity] but we have no idea where to go for it'. We thought, 'that's an easy fix'."

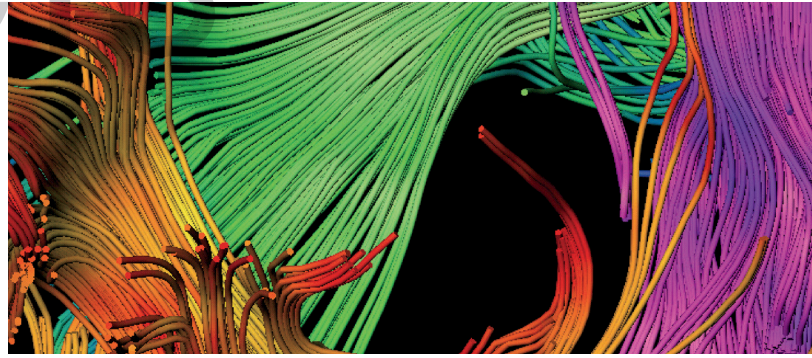
"It takes more money than we thought," she adds, "but we found ways to get a team together, and found out about grants." Both Majnemer and Shikako-Thomas also have renewed appreciation for the difficulty families face in trying to identify leisure opportunities. "It takes time to find out about all these programs within a province," affirms Majnemer.

Jooay's success will depend on user engagement — their additions to *Jooay's* growing database will help keep programs current and information up-to-date, providing the most relevant resources for families' to access leisure.

Despite the challenges, the duo is determined to move forward with *Jooay*. Through stakeholder outreach and Hacking Health, they've found "so many people are engaged and excited — occupational therapists, technologists, kids, and parents" Majnemer adds. "The interactions are really powerful," says Shikako-Thomas. "It's awareness and desire for change, coming together with realistic solutions." ■

PROJECTS

FASD RESEARCH PROJECT



Brain imaging provides crucial insight into links between structural damage and functional capabilities in children with FASD

Dr. Gail Andrew carries a small, colourful image of a brain affected by prenatal alcohol exposure with her wherever she goes.

“There are still a lot of naysayers out there who say alcohol doesn’t cause brain damage,” says Andrew, the Site Lead of Pediatrics and Medical Director of Fetal Alcohol Spectrum Disorders (FASD) Clinical Services, at Glenrose Rehabilitation Hospital and Professor of Clinical Pediatrics at the University of Alberta.

“People say, you can’t see it, therefore it doesn’t exist. I always carry one of those DTI images [a Magnetic Resonance Imaging (MRI) technique called Diffusion Tensor Imaging that is a sensitive measure of abnormalities in white matter structures in the brain].

“I say, prenatal alcohol exposure doesn’t necessarily cause major structural damage such as a Swiss cheese effect or holes in the brain that would be visible on current clinical MRI scans,” adds Andrew. “The brain damage is diffuse. It’s more like you don’t have as many pathways, you’re going to get fewer, or unconnected sparks in the flow of electricity in your light bulb, and it’s not going to work. That’s what’s happening in the brain of an individual affected by prenatal alcohol exposure at the most basic level. The impacts go beyond cognition. They affect the ability of an individual to function in day-to-day life.”

Over the past three years, NeuroDevNet’s FASD research team has generated a large set of experimental brain images including DTI, in addition to comprehensive behavioural, genetic and epigenetic information from a cohort of 238 typically developing children and children with FASD.

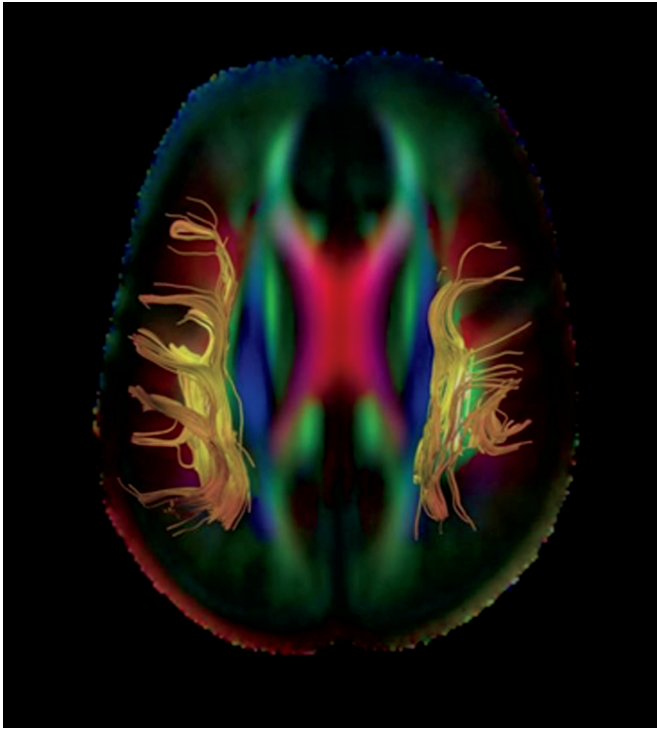
“The goal of the program has been to identify developmental brain differences in children with FASD, as compared to children not exposed to alcohol before birth,” says FASD Research Project co-lead Dr. James Reynolds. “In addition to tracking long-term changes,” adds Reynolds, “our study is addressing relationships between structural brain abnormalities and a child’s cognitive functioning.”

“...caregivers come away with the knowledge that bad parenting is not the reason for their child’s challenging behaviour...”

Dr. Gail Andrew

Four sites have been gathering brain imaging data: at Reynolds’ home institution, Queen’s University, the University of Alberta in Edmonton and the University of Manitoba in Winnipeg, where colleagues Dr. Christian Beaulieu and Dr. Albert Chudley are based, respectively, and the University of British Columbia.

image supplied by Dr. Christian Beaulieu



The Women's and Children's Health Research Institute (WCHRI), also based in Edmonton, has been a key institutional partner in the brain MRI study for FASD, as well as NeuroDevNet's Alberta-based projects in autism spectrum disorder and cerebral palsy. "This has been an excellent partnership," Dr. Sandra T. Davidge, WCHRI's director, wrote in a letter of support.

"The multi-site approach gives us three main advantages," says Beaulieu. "First, is the ability to recruit a larger number of participants much faster into the study. This enables more statistical power for the research, i.e., a better chance of finding something significant. Second, it provides a broader recruitment of individuals from across the country that should better reflect the diversity of the group. Third, it engages more researchers and clinicians into key research projects that they otherwise may not have pursued. Clinicians are so busy, but it's critical to engage them in research to move forward our understanding of this disorder, and to create a pathway for the uptake of our scientific discoveries into clinical practice."

Dr. Andrew, who collaborates with Beaulieu and colleagues, also views the researcher-clinician interaction on the project as a 'basic, bi-directional partnership'. "We as clinicians can offer researchers a lot of good questions. In the other aspect, it's a vehicle of knowledge translation, back, in my case, to share directly with families."

One of the things imaging offers is perspective. When Andrew does clinical briefings with families using brain images, caregivers come away with the knowledge that bad parenting is not the reason for their child's challenging behaviour, and the understanding the child is doing the best he or she can, because they can actually see the brain damage that underlies the behaviour.

Images also demonstrate the possibility of change. Brain images captured years apart, even in the absence of specific therapies for FASD show "the brain does appear to be maturing in the correct direction," says Beaulieu, "but it appears to be starting off with a delay."

Going forward, imaging will continue to be one of the important tools the FASD Research Project will use in investigating biomarkers — physical signs of the disorder — to aid in early diagnosis.

"I think we are only just beginning to see the impact of our investment in neuroimaging for bettering our understanding of FASD as a brain-based disorder," says Reynolds. "Because the information we have generated is so comprehensive, we are starting to link specific neurobehavioural problems in children with FASD to specific anomalies in brain structure. That's the type of information clinicians can use to communicate with families, and to think about intervention strategies that will have the greatest benefit for these kids." ■

Suzanne Ahearne photography



Talking science about FASD — trainees take award-winning outreach curriculum to teens and teachers

In April 2013, NeuroDevNet trainees Tamara Bodnar and Parker Holman won the Let’s Talk Science CIHR-Synapse award for their work translating their animal-model research on FASD from the lab to Vancouver high school classrooms.

“We were both involved in Let’s Talk Science [a national science outreach program] at UBC that pairs a grad student with a K-12 teacher. We met with teachers and told them about the experiments we wanted to do. It’s not necessarily expected that we would have our own agenda.”

But Bodnar and Holman did: “we wanted to present prenatal alcohol exposure in a way that would get high school students that might be starting to drink, engaged,” says Bodnar. “We didn’t want to do a health class telling them why they shouldn’t drink — we wanted them to utilize online resources, develop hypotheses, and test them — to see what the effects of alcohol are on developing organisms without our having to tell them.”

“Some of the activity came out of frustration that when you talk about doing animal model research, people have strong opinions,” reflects Holman. “How then do you talk about that, in a way that’s respectful?” A few conversations with NeuroDevNet’s KT Core provided insight, and an offer to fund experiment kits to be used in classrooms.

Dr. Kathy Sulik, a professor at the University of North Carolina who met Bodnar and Holman through the Research Society on Alcohol’s FASD Study Project, offered “a whole pile of resources,” Holman continues. “We took that health-focused curricula — the activity component was pretty much done — and we just made all the material relevant to grade 8 cells and organ systems, and grade 9 meiosis/mitosis cell division topics, and built the effects of alcohol on developing organisms in as a viewpoint.”

Learning took place all around. Xuan Ngo, their primary teacher partner from Let’s Talk Science and subsequent teachers had to adapt to the students having a clear concept of what they wanted to teach and how it fit the curriculum. Student feedback indicated the experiments defined the experience. “One said, ‘It will stay in my brain now, because I saw it,’” says Bodnar.

“For me,” she adds, “the biggest thing was how to discuss our research with the public.” Holman was surprised at how interested the students were in the effects of adult exposure to alcohol.

Asked about next steps, they started thinking about teaching the teachers. “Tammy and I wanted to have greater impact,” Holman adds.

Suzanne Ahearne photography





“We wanted to present prenatal alcohol exposure in a way that would get high school students that might be starting to drink, engaged...” Tamara Bodnar, PhD Student

OPPOSITE PAGE, TOP: Science Teacher Xuan Ngo, Holman and Bodnar’s original teacher partner, also participated in their professional development workshop.

OPPOSITE PAGE, BOTTOM: Supervisor Dr. Joanne Weinberg and a teacher at the workshop discuss neuroanatomy.

LEFT: Taking FASD from the lab to the classroom: award-winning trainees Tamara Bodnar and Parker Holman.

A conversation between Sandy Whol, an acclaimed former science teacher who now works for Genome BC, and Dr. Joanne Weinberg, Holman and Bodnar’s PhD supervisor, led to an overture to the BC Science Teachers Association. A Professional Development Day activity was soon under development.

The February 2014 offering quickly filled to capacity via online signup. Twenty-six teachers — fellow scientists, as Holman addressed them, gathered in a large, ultra-modern lab in UBC’s Life Sciences complex. Untethered from chalk boards and PowerPoints, they slid with seeming relish into the role of learners — having shed a certain hesitance once Holman mentioned his own years as a public school teacher.

Allies had once again stepped out of the woodwork to support Bodnar and Holman’s outreach. The Rankin Lab at UBC donated worms (*C. elegans*) - that cost \$11 a vial and \$50 to ship - for free. Xuan Ngo, under whose auspices the first student class took place at Hamber High School, had signed up as a participant. The entire science department of Sullivan Heights Secondary in Surrey attended.

A focus of the workshop was developing ideas for translating the experiments to classroom topics in developmental biology and reproduction. The teacher scientists seemed to thoroughly enjoy themselves, whether poking sheep brains while discussing neuroanatomy with Dr. Weinberg, or examining worms or brine shrimp eggs under microscopes. Those who submitted evaluation forms gave all the activities high marks.

A number of teachers expressed their appreciation for the inclusion of current research findings into their experience, and information packages. “I loved the idea that we would receive materials to use in the classroom,” wrote one, “because it is so hard to find time to develop new activities. We rarely have time to get together and plan.” ■



Animal model research provides essential insights in the search for diagnostic biomarkers for FASD

The FASD Research Project is evaluating multiple potential screening tools in the search for effective early diagnosis of prenatal exposure to alcohol.

Along with eye tracking, and brain imaging, genetics, epigenetics (gene Expression) and cortisol — stress hormone levels — are all being linked to databases of clinical records to identify children affected by FASD.

The inclusion of cortisol in this array stems from animal model research conducted in Dr. Joanne Weinberg's lab at the University of British Columbia. "In a rat model, it's possible to examine biological, social and environmental factors and how they associate with patterns of gene expression in FASD — all under tightly controlled circumstances," says Weinberg, one of the co-leads of the FASD Research Project.

"Dysregulation in the stress response system is a powerful finding in the animal model," she adds, "and has important implications for vulnerability to health problems in later life. We're now looking at this in children with FASD. Jacqueline Pei and Carmen Rasmussen, two of our NeuroDevNet colleagues, have submitted a proposal to look at cortisol as a marker of self-regulation and arousal in children with FASD."

"In the rat model, we have the power to test interventions and look at changes in behaviour as well as in the brain," Weinberg continues. "Thus we can uncover underlying brain mechanisms of different intervention strategies, which in turn can provide valuable information for clinicians working with children with FASD." ■

KNOWLEDGE TRANSLATION

Social Media Workshop mobilizes NeuroDevNet trainees' #KT capacity

The KT (Knowledge Translation) Core opened activity the first day of NeuroDevNet's annual research conference in Vancouver with a half-day workshop taught collaboratively with York University's KMb Unit. "More than 60 trainees attended," says Anneliese Poetz, KT Manager.

Poetz presented on planning integrated KT, which is initiated when research is being conceptualized, and end-of-grant KT, while Krista Jensen, KMb Officer at York University, home to the KT Core, gave an overview of the use of social media as a KT tool.

"From our perspective," adds Poetz, "Knowledge Mobilization and Knowledge Translation refer to the same thing: actions toward enhancing uptake of research findings into policy and practice. We provided trainees with practical tools they could take home, as well as hands-on exercises to learn how to apply KT principles to their own research programs." [See Story about the Fourth Annual Brain Development Conference, page 38]

Prior to the event, trainees were asked to complete a needs assessment to help tailor the event to their interests. Pre-and post-event feedback elicited data about trainees' capacity to engage in KT, and level of knowledge about topics covered in the workshop. "The results were significant," says Poetz. "We were able to quantify an average 28% increase in knowledge about KT as a result of this event."

"Future KT training events will likely follow a similar format for delivery and evaluation," says KT lead David Phipps, and will continue to address information and development needs for trainees and researchers in the Network. "The KT Core is also planning to support the development of training programs for clinicians and other practitioners, to facilitate implementation of NeuroDevNet research, and new Federal and Provincial guidelines that have been informed by our researchers." ■

Suzanne Ahearne, photography



Trainees enjoy creating a KT strategy at the 4th Annual Brain Development Conference.

Social Media provided as a tool for stakeholder Engagement

NeuroDevNet Communications has been using social media (Facebook, Youtube and Twitter, @neurodevnet) for about a year and a half, successfully raising awareness of the Network with a broadening range of stakeholders in Canada and internationally. Led by the KT Core, social media tools are now being used to actively engage with these stakeholders and to reach into communities of interest.

“Social media provides a cost-effective opportunity to engage with stakeholders we might not otherwise have the opportunity to meet,” says KT Lead David Phipps. The KT Core has created profiles on Slideshare, LinkedIn, Facebook and Twitter, @neurodevnetKT. “These are important tools for dissemination of research and evidence but KT goes beyond dissemination and uses social media to support the implementation of research evidence into new products, policies and practices that can have an impact on the lives of children with neurodevelopmental disorders.”


Sharing the KT Cores ResearchSnapshots with selected practitioners and policymakers via LinkedIn has provided feedback that helps improve understanding of how these KT Products could be used, for example:

‘I would use these snapshots in the future. We do a lot of in-service training on FASD for organizations in our city. Any type of research will help us give up to date information.’

KATERINA JANSEN, Aboriginal FASD caseworker,
John Howard Society of Alberta

‘I did review the (ResearchSnapshots) and thought they were fantastic! As the head of communications for a Network of FASD services and supports, we could absolutely post these on our website and link to Facebook and Twitter. We also produce a monthly newsletter where it would be great to include a current research section! And lastly it would be great to include these as a part of the trainings that I provide to community and social service agencies, which average two per week.’

LISA ROGOZINSKY, FASD Prevention Conversation facilitator,
Edmonton and area Fetal Alcohol Network Society



Eye Tracking Shows Promise as Screening Tool for Children With FASD

What is this research about?

Prenatal alcohol exposure (PAE) affects the developing brain. Children with fetal alcohol spectrum disorder (FASD) experience a variety of issues resulting from fetal exposure to alcohol. These issues may be cognitive or behavioural. Learning, memory, attention, and movement can also be affected. Eye movement and psychometric tests assess working memory and visuospatial processing. Visuospatial skills allow objects to be seen and relationships between these objects to be assessed. Working memory is the ability to temporarily store and change information. Eye movement tests involve a series of saccades, which are rapid eye movements that bring new visual targets onto the fovea of the retina.

This study looked to examine the relationship between measures of working memory and visuospatial skills in children with FASD, PAE, and typically developing children. The children with PAE had alcohol exposure but were believed to not be affected enough to have a diagnosis at that time. This was done through the use of eye movement tasks and standardized psychometric tests.

What did the researchers do?

Children and adolescents aged 5 to 17 years diagnosed with FASD (71), PAE (20), and typically developing children (111) were studied. Participants were asked not to take their medication on test day to stop any conflicting results. They were seated in a dark, quiet room in a stable chair. Participants


What you need to know:


The developing brain is affected by prenatal alcohol exposure (PAE). Working memory and visuospatial deficit are major problems for those with fetal alcohol spectrum disorder (FASD). Psychometric tests and eye movement control tasks assess cognitive function. These tests show overlapping brain regions that are damaged by PAE.


completed a psychometric test battery and a series of saccadic eye movement tasks.

Participants completed 3 eye movement tasks. In the prosaccade and antisaccade task, trials started with the illumination of a central fixation point (FP). The FP disappeared after a delay and a target appeared to the left or right of the central FP. Participants had to look left or right to the correct location. They were told to look towards the target (prosaccade) or away from the target (antisaccade). In the memory-guided saccade task, participants looked steadily at the central FP while 2 targets appeared one after the other. After the FP disappeared, they had to make saccades to the remembered locations in the order they appeared.

Psychometric tests assess multiple areas of functioning. One subtest measured the ability to judge line orientation (visuospatial ability). Another measured the child's ability to sort cards into categories. The working memory test battery (WMTB) assesses working memory with subtests measuring visual and verbal working memory.







“This engagement opens up possibilities for future collaborations and partnerships as we reach out to stakeholders who may not have otherwise heard about the work being done within NeuroDevNet,” says KT Manager Poetz.

The KT Core has also begun producing videos highlighting research and training in the Network, including perspectives of partners and research participants where possible. “Promoting and sharing these videos through our online networks and through collaboration with NeuroDevNet communications has been effective,” says Poetz, “one of our videos received over 400 views within 2 weeks of posting.

“At the end of each video, we invite viewers to visit our website and ‘join the conversation’ on social media,” she adds. “In other words, we cross-promote our work in a targeted manner through various forms of media. The videos are not only useful for explaining to our diverse stakeholders what our research is about, but they are a valuable tool for showcasing our work to potential partners and collaborators.” ■

NEUROETHICS

The Precautionary Principle

If in doubt... leave them out?

"With the dramatic increase in off-label prescriptions of antipsychotic medications in pediatrics, the lack of monitoring, and uncertainties about effectiveness and safety," says NeuroDevNet Post-Doctoral Fellow Dr. Nina Di Pietro, "we need to better understand the risks and benefits of these medications before deciding to use them on such a broad level."

Enter the Peter Wall Institute for Advanced Studies and its sponsorship with NeuroDevNet of a workshop to respond to this need. On the table: identification of research priorities, and collaborations towards fulfilling them. The experts attending: pediatricians, epidemiologists, neurologists, psychiatrists, general practitioners, ethicists and pharmacologists.

"The Institute's Exploratory Workshops provide an opportunity for researchers to explore a significant research topic in depth," says Bernadette Mah, Program Manager at the Institute. "The use of antipsychotics in children and youth was an important topic to address due to concerns raised in the medical community and by the public about their increased — and potentially inappropriate — use."



Since the workshops, the participants have been busy. They formed the Canadian Working Group on the Use of Antipsychotics for Children and a subcommittee at UBC to discuss policy initiatives, published an op-ed in the *Vancouver Sun* on November 27, 2013, summarizing the issues highlighted in the workshop and a commentary in the Canadian Medical Association Journal. They are also in the process of publishing a book, "The Science and Ethics of Off-Label Antipsychotic Use in Children and Youth" through Elsevier that will be available in early 2015.

"We're looking at approaches and solutions for youth that acknowledge medical, social, economic and political views and the way these complementary sectors influence prescribing practices," says Judy Illes, Professor of Neurology and Co-Lead of NeuroDevNet's Neuroethics Core, based at UBC. "The diversity and insights of the participants at the workshop allowed us to pin down multiple perspectives and avenues that can improve the prescribing and monitoring process. We really advocate a multi-pronged approach." ■



Making the Jump

Transitioning from paediatric health care to the adult system shouldn't have to be a leap of faith.

Children with neurodevelopmental disorders who transition into the adult health care system have both overlapping and distinct needs and goals compared to children with chronic illnesses.

While all youth with health challenges may find the transition difficult, those with neurodevelopmental disabilities may especially feel that their own views are not respected or taken into account in the adult setting. This was just one of the issues discussed at the *Ethics in Transition in Neurodevelopmental Disorders* workshop organized by Drs. Eric Racine and Emily Bell of the Neuroethics Core.

"Youth with neurodevelopmental disorders may feel abandoned in the autonomous, inflexible adult system," says Bell. "So we wanted to understand from an ethics perspective what's important to them."

The discussions revealed that full independence is not every young adult's goal, so a good transition looks different depending on the individual. Some people prefer to retain the family-centred approach of the pediatric system. Key recommendations from the working group included the respect of preferences of stakeholders and revising the target outcomes of transition programs.

ABOVE: Investigators from across the Network, collaborators and representatives of partner organizations met to discuss issues that arise in the transition to adult health care.

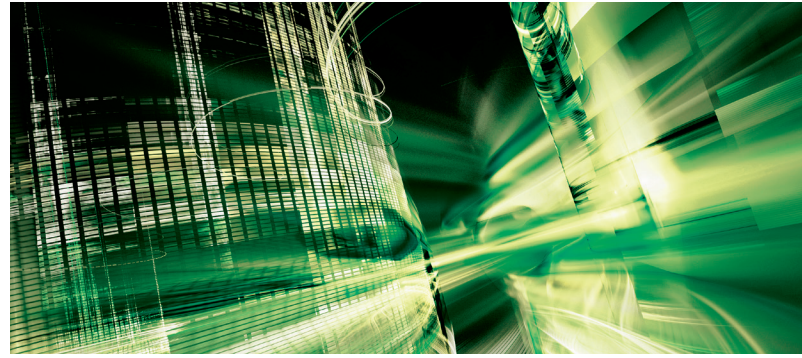
"Health care transition is complex and interwoven with other life transitions. There are ethical issues such as autonomy, choice, best interests, health care systems' priorities and recognition of all patients as individuals at every stage. These issues can be even more challenging when there is a neurological disorder," says Dr. Miriam Kaufmann, physician at the Hospital for Sick Children, expert in developing transition programs for youth and collaborator in future work.

The workshop helped participants set directions for future work, which led to a publication, "Ethics challenges of transition from paediatric to adult health care services for young adults with neurodevelopmental disabilities" in *Paediatrics & Child Health*. Next steps involve interviewing patients and developing manuals and resources to evaluate a new model of transition for these youth that focuses on their values and needs. ■



Stacie Turner photography "On the Spectrum"

NEUROINFORMATICS



A Culture of Sharing

Today's research model is renouncing data hoarding in favour of open access. NeuroDevNet is right on point.

Where once researchers kept their data close to their proverbial chests, there is now more interest in openness and the benefits it brings, such as accountability, public access to publicly funded research and the greater possibilities that come from sharing — assuming data collection has been harmonized first.

"Data-sharing is being recognized as important," says Paul Pavlidis, lead of the Neuroinformatics Core and UBC Professor in the Department of Psychiatry. "One of our partners, the Ontario Brain Institute (OBI), already requires investigators to share, and some of those same researchers are in NeuroDevNet. With the strong support of our Scientific Advisory Board, the timing was right."

Currently under development, NeuroDevNet's data-sharing policy will require researchers to make their data available to others within a reasonable time frame and will be acknowledged for doing the work. While the OBI's policy is structured so that researchers return the data to the Institute for dissemination or reuse, NeuroDevNet will provide data management frameworks for projects and facilitate data-sharing. However, researchers will be responsible for hosting their data and developing data-sharing plans that are compatible with the policy.

"A central repository like the OBI's is very resource-intensive," says Elodie Portales-Casamar, past manager of the Core. "While some data may reside within NeuroDevNet, we will help researchers who don't have infrastructure to set up their own."

The Core's team is collaborating with Maelstrom Research to use its software to create a public portal for the research. The portal will contain a list of projects and basic information such as the type of data collected, the cohort, the goals of the study, and original researcher's contact information to actually obtain the data.

"The portal gives us another opportunity to let researchers and the public learn more about the science while it is still going on."

Dr. Paul Pavlidis

"Mostly, researchers hear about new data through publications or presentations at conferences," says Pavlidis. "The portal gives us another opportunity to let researchers and the public learn more about the science while it is still going on." ■



Data Harmonization

An essential approach in the age of big data.

Research should not live in a bubble. To be effective, it must be shared. But first, it must be harmonized.

The Neuroinformatics Core is pursuing harmonization by developing a platform that will make NeuroDevNet projects more compatible — and comparable with each other as well as work done by the rest of the neuroscience research community. In keeping with its efforts to share not just data, but also knowledge and solutions, the Core is collaborating neuroinformatics staff at the Ontario Brain Institute (OBI).

A workshop brought researchers from the two organizations together with researchers from other networks and consortia to talk about harmonization and how to make it work within neuroscience, according to Elodie Portales-Casamar, former manager of the Neuroinformatics Core, who helped organize the gathering. “It reflects the collaborative field where we all face the same issues and find it efficient to work on them together rather than in isolation.”

A key contribution from OBI has been valuable insight on common data elements. These are a small set of items such as gender, year of birth, ethnicity, medications that every project should collect — needed or not — to make the rest of the data useful for other studies.

“Gone will be the days when researchers collect data on their laptops and keep it there in their labs, in silos,” says Shiva Amiri, Informatics and Analytics Manager at OBI. “Now, we have the computing power to collate data from multiple projects into huge datasets and work from much larger sample sizes. This will increase the speed and accuracy of research.”

“Having standards improves the quality of data and our ability to recheck results in the future,” says Neuroinformatics Core lead Paul Pavlidis. “Most excitingly, it increases the potential to find commonalities across neurodevelopmental disabilities by making the data more comparable. But even less ambitious uses, like being able to share data on normally developing subjects, could be incredibly useful.”

“It reflects the collaborative field where we all face the same issues and find it efficient to work on them together rather than in isolation.”

Dr. Elodie Portales-Casamar

Data harmonization and standardization can only happen if the process does not place too much of a burden on investigators, and data sharing and integration can raise additional ethical issues that need to be addressed. By developing a harmonization framework for NeuroDevNet, the Neuroinformatics Core is helping ensure network research has the greatest possible impact. ■

TRAINING AND EDUCATION

What's it like to be a NeuroDevNet Trainee? A Doctoral Student and Post-Doctoral Fellows reflect on their experiences.

Angelina Paolozza

Doctoral candidate delves into all aspects of FASD diagnosis as a NeuroDevNet trainee.

At last year's Brain Awareness Day at Queen's University, PhD student Angelina Paolozza strapped an EEG headband on some Grade 5 students in James Reynolds's lab to demonstrate how their brainwaves work.

"We place one electrode to the front of the brain and explain how brainwaves work," she says. "Then we have a competition to see who can concentrate the hardest and make the barrel on the computer screen blow up, followed by another to see who can remain calm longest watching an orb float."

"When we do these demonstrations, parents can see in real time what makes their child concentrate or get distracted from homework," says Paolozza. "Kids don't understand what helps them and what doesn't. If you can show them, that's really useful to everybody."

Teachers are fascinated by the device for the same reason. Getting direct biofeedback on what works or doesn't in the classroom would be gold. Unfortunately, since the headband is hooked up to a laptop or iPhone, it is not appropriate for the classroom.



"It could be a distraction to other kids," says Paolozza. "We anticipate that parents will use it at home, figure out what works and tell the teacher so they can apply it in the classroom."

A different version of the headband — this time with 20 electrodes — will be part of Paolozza's postdoc on children with FASD. The objective will be to measure brain activity continuously for 24 hours to search for increased brain excitability which may cause some of the cognitive, behavioural and sleep problems these children face.

As a NeuroDevNet trainee, Paolozza was a member of the research team in a multi-site study of deficits in children with FASD, performing eye-tracking and psychometric tests. More recently, she became involved with the imaging arm of that study, correlating the data gathered to the integrity of white matter in the brain — learning to operate the scanner and performing all the imaging herself.

"Thanks to NeuroDevNet, I've acquired a comprehensive set of experimental skills and techniques," says Paolozza. "They have allowed me to forge ahead with my studies and gain increased recognition for someone so early in their career." ■



“The goal of the Fellowship is to lay a strong foundation for career progression. I certainly got that and more.”

Kieran O’Donnell

“The key benefits to Fellowships are multiple opportunities to meet people in different fields of work.”

Attending NeuroDevNet’s annual meeting (and associated workshops on knowledge translation) and the quarterly meetings of the Canadian Institute for Advanced Research (CIFAR) Child and Brain Development Program as part of his Fellowship exposed Kieran O’Donnell to synergy between the two agencies, a wide range of disciplines and leading figures in epigenetics and how it relates to early life experience.

All this O’Donnell put to good use back in Michael Meaney’s epigenetics lab at the Douglas Hospital Research Centre in Montreal, where his project examined an early perinatal parenting intervention with known clinical benefits to see if it might be associated with long-term biological changes in the child. In this case, the “children” were 27 years old.

“This was a high-risk study, without precedent, that allowed us to generate some of the first data on how early interventions influence epigenetic processes,” says O’Donnell. “The data will now be used to develop a larger program of research to test the biological mechanisms that link psychosocial interventions to improved child outcomes.”

Collaborating with his other mentor, NeuroDevNet investigator Mike Kobor, across the country at UBC and researchers in Singapore gave O’Donnell a first-hand taste of being part of an international multi-disciplinary team — an experience he believes is especially beneficial for young researchers in their careers as projects become more multi-disciplinary. And, even more beneficial for him, and his aspirations to an assistant professorship.

“The goal of the Fellowship is to lay a strong foundation for career progression,” says O’Donnell. “I certainly got that — and more.” ■



“My fellowship is exactly what NeuroDevNet planned for the program...It was a once-in-a-lifetime opportunity for me.”

Kaitlyn McLachlan

NeuroDevNet’s focus on interdisciplinarity and cross-network mentorship paves the way to employment.

Kaitlyn McLachlan’s Fellowship at the University of Alberta/UBC allowed the young researcher to bring together the pieces of a larger puzzle that may otherwise have remained untouched.

Combining data sources and expertise on environmental adversity and her background in psychology with Dr. Joanne Weinberg’s research on biological markers of self-regulation, the team’s objective was to better understand how early life experiences influence outcomes in children with FASD. The result is a manuscript currently under peer review.

“The role of environmental adversity is still an unturned stone,” says McLachlan, “and hard to evaluate without very large datasets. We couldn’t have done this without collaborating across sites and disciplines.”

McLachlan credits the Fellowship as a rare opportunity to train to become more diversified and competitive in the job market. Her new job at St. Joseph’s HealthCare Hamilton is in clinical practice with a research focus and an academic appointment at McMaster University. She will be using her new training in neurodevelopmental disability to help better understand patients’ behaviour.

“My fellowship is exactly what NeuroDevNet planned for the program,” says McLachlan. “It has a huge interdisciplinary component with collaboration between investigators and institutions. As well, it was a once-in-a-lifetime opportunity for me. What graduate in clinical psychology gets to study neurodevelopment, physiological markers of stress, brain imaging, and get this level of support? It wouldn’t happen anywhere else. You’d have to choose!” ■

image from Toronto Star



TORONTO STAR



THE VANCOUVER SUN

Hot Off the Press

Vancouver Sun intern **Katelyn Verstraten** parlays her skill and experience into an offer at the *Toronto Star*.

Sitting at her desk as a journalism intern in the middle of the busy *Vancouver Sun* newsroom, Katelyn Verstraten could have felt overwhelmed. That didn't happen.

"The news team at the *Vancouver Sun* treated me like one of its own and built my confidence," she says. "I felt like a real journalist, which was very powerful when I still had a year left in my Master's program."

The third intern placed by NeuroDevNet's Neuroethics Core with the *Vancouver Sun* from UBC's School of Journalism, Verstraten focused on reporting about neurodevelopmental disorders for the metropolitan daily over a four-month period. Previous interns have reported on autism and FASD.

"We've been very pleased with the quality of the NeuroDevNet interns," says Fazil Mihar, a former associate editor at the *Sun*, and now working as assistant deputy minister in charge of the new Oil and Strategic Initiatives Division within the B.C. Government. "We felt the internships helped raise awareness of autism and other neurodisabilities among our readers. We were fulfilling our role to highlight challenges/problems faced by segments of society that don't have a voice."

"This program is a perfect combination of science and society, research and writing on ethics and children, and academic mentoring and practical experience," adds Neuroethics Lead Dr. Judy Illes, who initiated the internship program.

Verstraten wrote five articles on cerebral palsy during her internship, each one focusing a different lens — such as rural health care and transition to the adult system — on the disability. She also travelled to the Netherlands to report on the health care system there. By the time the internship was over, she had built an enviable portfolio of clippings that she used to apply to the *Globe & Mail's* BC bureau and to the *Toronto Star* for other internships.

Successful in her application to the *Star*, Verstraten was asked to stay on after completing her internship. But the lure of freelancing in Canada and abroad was irresistible. Now, she'll have an opportunity to explore ideas on the shape of her career as a health journalist and to follow up on other stories on cerebral palsy in an international context.

"The internship at the *Vancouver Sun*/NeuroDevNet set me apart from my peers for two reasons," she says. "It defined the general shape of my career and provided an amazing opportunity. It was an invaluable experience. I don't think I could have gone on to the *Star* without it." ■

EVENTS





Amazing speakers — high caliber presentations — the Fourth Annual Brain Development Conference

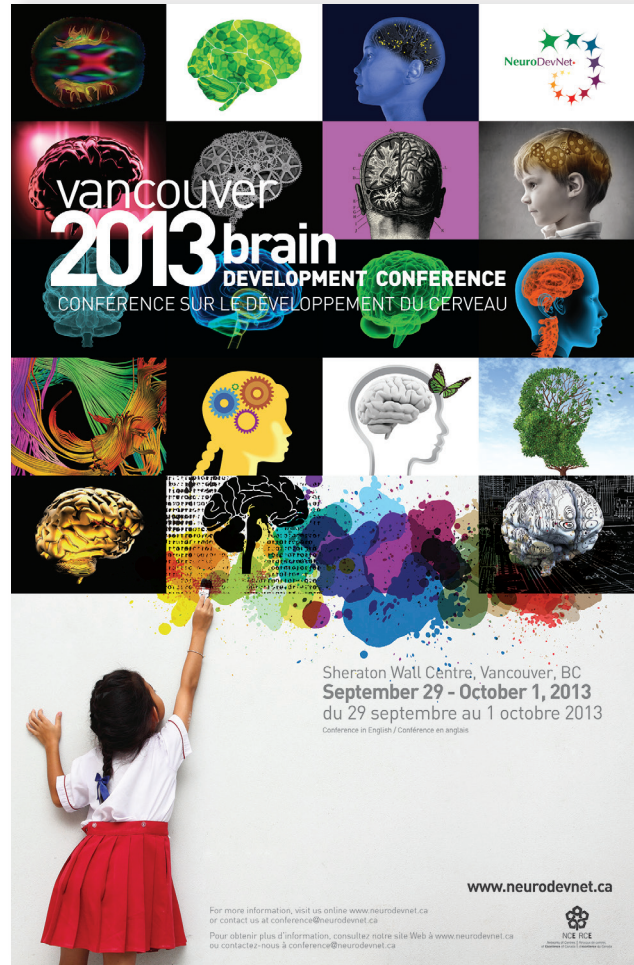
Canada's sole conference dedicated to the developing brain took 200 delegates on a journey to the frontiers of knowledge Sept. 29-Oct. 1, 2013 in Vancouver B.C.

Researchers, clinicians and trainees were treated to cutting edge insights on diagnosis and treatment of neurodisabilities and raved about the three-day program that included sessions on novel therapeutics, the continuum from neurodevelopmental disorders to neurodegeneration, and lessons for the bench about going commercial with promising findings.

"Extremely interesting, engaging, and informative," wrote one attendee.

Five plenary sessions engaged delegates in the implications of early childhood trauma, the importance of promoting executive functioning in children, neuroimaging insights into the teen brain, and the annual Fraser Mustard Lecture, given by Dr. Neal Halfon, Director of the UCLA Centre for Healthier Children, Families and Communities in memory of a champion of neurodevelopmental research.

Trainees enjoyed a pre-conference workshop dedicated to the Art of Knowledge Mobilization and Social Media, giving top marks to a presentation by the KT Core Manager Anneliese Poetz and Krista Jensen of York University's Knowledge Mobilization Unit (See Story, page 27)



A true highlight of the conference was "Putting Words to Silence," a presentation by Ian Brown, reporter for the *Globe and Mail*. In a style that has been described as "unflinching and uncompromising," Brown transfixed the audience with the story of his son, Walker, who has a rare genetic disorder called cardiofaciocutaneous syndrome, and the family's struggles in raising a child with cognitive capacity of a two-year-old, who can't talk, or swallow, and tends to hit himself in the head.

"His experiences brought the issues to life," wrote a second attendee. "One of the most excellent speakers I have ever come across," added another. ■

Suzanne Ahearnne photography this page



LEFT: Speaker Ian Brown transfixed the audience with the story of his son, Walker.

BOTTOM LEFT: Dr. Neal Halfon gave the Fraser Mustard Lecture.

BOTTOM RIGHT: Dr. Eric Chudler spoke about neuroscience education and outreach.

“His experiences brought the issues to life. One of the most excellent speakers I have ever come across.”





FASD play showcases real life, with transformative impacts on its audiences

***Jacob's Story* — and the terrible, awful, no good, very bad thing that happens to some kids**, is a play that takes audiences on an emotional roller coaster ride akin to what kids and families affected by fetal alcohol spectrum disorder (FASD) experience every day. NeuroDevNet's FASD Research Project participated in the development and mounting of *Jacob's Story*, a melding of the growing understanding of the disorder from a research perspective and the lived experience of one young man, whose life story represents many families' and individuals' journeys with FASD.

Jacob's Story follows a young boy with FASD named Jacob. Although he is a character in the play, Jacob has this representative capacity because the issues he faces are those that confront every child, adolescent, and adult living with FASD.

Len Whalen, the author and director of *Jacob's Story*, emphasizes that there are barriers that prevent people in the education system from understanding individuals with FASD. "I felt the reason that was happening was, people were looking at numbers, so my suggestion was, 'what about introducing the emotions and people through a play?'"

Moving the play from idea to a reality came about following a conversation between Whalen and NeuroDevNet Research Associate Sue Kobus. Kobus also serves as Research Coordinator of Kingston's FASD Action Network, a group of interested health and social service providers, parents, and other community members that promote awareness of FASD. The combination of Whalen's experience in education and theatre together with Kobus' organizational skills and connections to the community turned out to be an ideal partnership. The two connected with Dr. James Reynolds of Queens University, team lead for NeuroDevNet's FASD Project. Reynolds immediately saw an opportunity to maximize the impact of research involving families affected by FASD.

"There are so many areas of life where these kids intersect with trained professionals that can impact them positively," says Reynolds. "Unfortunately, in many cases, that point of contact can result in negative consequences."

The play premiered in February 2014 at the Domino Theatre in Kingston, Ontario. Following the performance, Dr. Reynolds and NeuroDevNet hosted an hour long discussion with the audience, comprised of teachers, families, researchers, community and public health agencies, clinicians, and correctional officers.

“You can’t go back and teach a class the same after you see that show,” she says. “It touches your heart and practice.” Roberta Laplante, teacher

Ms. Roberta Laplante, an elementary school teacher had a “Jacob” in her Grade 2 classroom last year. In 15 years of teaching, she had never seen a student who would yell, scream, and roll on the floor without self-control, until a child with FASD arrived in her classroom. Seeing *Jacob’s Story* completely changed her teaching approach, prompting her to create an entirely different experience for her student in the classroom.

“You can’t go back and teach a class the same after you see that show,” she says. “It touches your heart and practice,” said Laplante.

It was after reading the KT ResearchSnapshots and reference materials handed out at the play that Laplante realized the behaviours she saw in her student were signs of FASD. She started making small, but impactful changes in her teaching style; first, she provided her student a quiet area in the classroom as a refuge for when she felt overwhelmed. Instead of giving consequences and sending the girl to the principal, Laplante used strategies that built on trust and relationships. She encouraged her student to discuss her problems and the difficulties.

The results, she says, were phenomenal. Her student is now able to recognize when she needs time to herself, she improved her reading skills, and made many friends in the classroom.

“It was all through seeing *Jacob’s Story* and understanding what it must be like for these kids,” adds Laplante. “I thought about how it must be like to not have any self-regulation. To not being able to handle it and melt down every five seconds and have nobody like you. That was a reality. So it’s just really simple things that we can do. As a teacher, we can make their lives so much easier and let them have success.” ■



Anneliese Poetz photography

LEFT: The audience engages with playwright Len Whalen (centre, in white shirt), who plays the father, and Daniel Pauley (r), who plays Jacob, following a performance.

TOP: Cathy Griffen, who plays the mother in *Jacob’s Story*, with members of the audience.

ABOVE: Dr. James Reynolds answers questions from the audience about FASD.

Cynthia Munster photography



Stakeholder consultation produced a new “ask” for Federal engagement ...

Day on the Hill 2014: new allies — new asks

NeuroDevNet’s annual visit to parliamentarians in Ottawa saw seasoned participants from the Network join new partners from the parent and advocacy communities in speaking to the importance of supporting children with neurodisabilities and their families.

Shelley MacKewn, a parent of a young child with FASD, Valerie Temple, a developmental psychologist with Surrey Place Centre in Toronto, Janice Bushfield, executive director of the Cerebral Palsy Association in Alberta, and parent of a young adult with CP, Esther Rhee, National Program Director, Autism Speaks Canada, and Frank Gavin of the Canadian Family Advisory Network, and parent of a young adult with autism joined NeuroDevNet Board Member Patrick Lafferty, and NeuroDevNet administration and staff in rounds of visits with MPs and Senators.

In-person discussion, particularly with MPs Mike Lake (Edmonton-Mill Woods-Beaumont), David Wilks (Kootenay-Columbia) and Andrew Saxton (North Vancouver), in combination with growing connection with the broad range of stakeholders produced a new “ask” for Federal engagement: support for funded chairs in neurodevelopment.



A Federal/CIHR-NGO collaboration including NeuroDevNet began supporting Dr. Jonathan Weiss as the very successful Chair in Autism Spectrum Disorders Treatment and Care Research two years ago, and is serving as a model for further discussion of additional chairs.

In 2014, as in each of NeuroDevNet’s two previous Days on the Hill, a cross-aisle afternoon reception was generously hosted by Senator Jim Munson and his staff. MP Mike Lake and Sen. Yonah Martin offered welcoming remarks.

So successful was the outing, a second visit to the Hill was set for early October, 2014. ■



“...it was very grounding to realize the work I was doing was relevant in a much larger context...” Dr. Timothy Oberlander



DOHaD examines future avenues for developmental research and greater connectivity in Canada

Researchers met in Vancouver in February 2014 to continue Canadian strength in the study of the Developmental Origins of Health and Disease (DOHaD).

DOHaD, an international organization promoting this integrated approach to studying life-course diseases from their earliest origins, convened the Vancouver gathering with NeuroDevNet sponsorship, in order to recognize strides made in the developmental domain in recent years, as well as identify opportunities for future investigation and application to public health policy.

In addition to network-building, objectives included integrating an evolutionary and ecological approach into DOHaD research and identification of new areas of investigation where Canadians could take an international leadership role in partnership with other jurisdictions.

“From NeuroDevNet perspective, it is a natural fit — for lots of reasons,” says NeuroDevNet Scientific Director Dr. Daniel Goldowitz, who gave one of the keynote presentations.

Dr. Timothy Oberlander, a UBC-based researcher/clinician affiliated with the Network shared enthusiasm for the gathering and its focus. Presenting his recent findings on prevalence of autism in babies born to women taking SSRIs during pregnancy, Oberlander found “it was very grounding to realize the work I was doing was relevant in a much larger context. I could see what I was doing from a different perspective that could eventually be translated into a language that was accessible to other researchers and policymakers.” ■





Enabling kids with cerebral palsy to do what they love — World CP Day 2013

World Cerebral Palsy Day is a global innovation project to change the world for people living with cerebral palsy (CP) and their families. Launched in Australia, it is designed to gather ideas from people around the world and make the best of those ideas a reality.

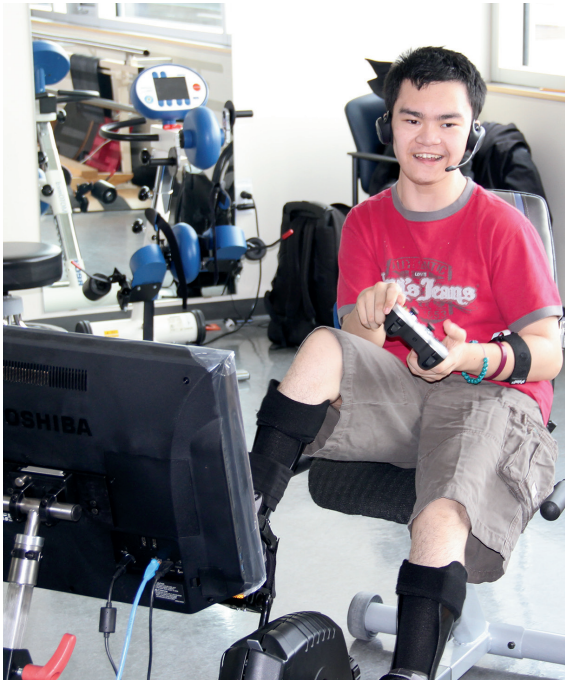
NeuroDevNet celebrated the occasion on October 2, 2013 with a landmark gathering of CP organizations across Canada, who together explored potential avenues of partnership and collaboration. A new national entity, The CP Canada Network, was formed, uniting organizations coast-to-coast with researchers dedicated to raising the profile of cerebral palsy on a national level. (See story about CP Canada Network and some of the outcomes of the meeting with CP organizations on page 16)

The half-day event also showcased a live demonstration of NeuroDevNet CP lead Dr. Darcy Fehlings' *Liberi Exergame*, that features customized multiplayer videogames powered by pedaling an adapted stationary bicycle. With funding from NeuroDevNet and the GRAND NCE, the *Exergame* was conceived to encourage youth with CP to exercise and virtually connect with their peers.

CTV Toronto covered the demonstration on its evening newscast, which pitted 13-year-old Wesley Magee-Saxton of Toronto against Colin Huppee, also 13, who lives in Maple Ridge, B.C. The two had a lively competition via headsets that enabled conversation as the game unfolded, and pedaled away intently with their online game displayed on large screens in each setting. "This research allows us to do what we love — play video games — and get exercise at the same time," says Wesley, "AKA, killing two birds with one stone."

In the aftermath of World CP Day, CP Canada Network engaged with MP Kirsty Duncan, (Etobicoke North, Lib.) who spoke in the House about the status of cerebral palsy in Canada on March 25, informed by input from the fledgling organization. The group also submitted a petition to the Government of Canada regarding the need for a national strategy for CP. ■

With funding from NeuroDevNet and the GRAND NCE, the *Exergame* was conceived to encourage youth with CP to exercise and virtually connect with their peers.



FAR LEFT: Representatives of CP organizations across Canada and NeuroDevNet researchers join Colin Huppee and his father (right, in hat, back row) following Colin's live demonstration of the *Exergame*.

ABOVE: 13-year-old Wesley Magee-Saxton of Toronto demonstrates *Liberi Exergame* in a virtual challenge against Colin Huppee of Maple Ridge, B.C. seen in real time via the screen in the background.

LEFT: Combining fun and fitness with the *Liberi Exergame*.

BELOW: During a breakout discussion, researchers and heads of cerebral palsy organizations discuss information needs in the CP community.





In the world of employment disability just a matter of degree and context

Emotion and inspiration ran high at “What Will It Take? Advancing Vocational Opportunities for Persons with Autism Spectrum Disorders,” a joint conference hosted in June 2013 by the Sinneave Family Foundation, Autism Speaks Canada, and NeuroDevNet.

The Calgary gathering was the second event backed by the Sinneave Family Foundation, one of NeuroDevNet’s most significant partners. As with the previous year in Toronto, the conference featured a dynamic program with leading international speakers at the forefront of creating meaningful employment opportunities for people on the autism spectrum.

“What will it take in 20 years for 80 percent of people on the autism spectrum to be engaged in meaningful employment activities, and be members functioning members of our society,” Tom Collins, President of the Sinneave Family Foundation asked the audience of more than 200 diverse professionals with an interest in the topic, teens and adults with autism, parents, and employers. “What will it take so that in high school, we prepare people with autism for life as adults in our society? What will it take for them to be welcome and included, and experience success in post-secondary education?”

With those challenges, a dynamic program commenced, showcasing successful ventures already employing workers with disabilities in the United States and Canada, as well as experts in vocational placement for people with autism who are actively engaged in the preparatory challenges Collins addressed.

Presenters included:

Randy Lewis, who shared the story of the transformation of the distribution centres workforce for Walgreens, the largest drug retailing chain in the US. As the father of a teenage son with autism, he was inspired to create an inclusive environment with opportunities for people with physical and cognitive disabilities.

Mark Wafer, Tim Hortons Franchise owner and progressive employer, exposed the roots of the 30 percent employment rate among people with disabilities: misperception. Myths are the greatest barriers to unemployment among the disabled, he contended. People with disabilities can’t work as safely, require extra supervision, lack innovation, and have lower productivity. In reality, Wafer’s experience with disabled employees on-the-job has been exactly the opposite.

photos by The Ability Hub

“I knew we were in for a ride we’d never taken before. You know every person is different. You know every person is worthy, that everybody has a role. But nothing compares to making another person successful.” Randy Lewis, Walgreens

“Why is this important?” queried Tom Collins. “We’re past the point of employment as a social good in western society. The Federal government has put \$250 million into helping people with disabilities find meaningful employment, because by their own estimates there are almost 800,000 disabled Canadians who are capable of working but are unemployed. They are a hidden workforce. It’s a matter of economic reality to find ways to engage people.”

“There is a momentum of awareness and action supporting individuals with disabilities into employment building across Canada,” Collins adds. “Conferences and events hosted by national organizations are playing an important role in improving the employment futures of individuals with ASD.”

The momentum has continued to gather, supported by many across the Country and by the efforts of the Sinneave Family Foundation, and its partnership with Autism Speaks Canada. Subsequent developments include the November 2013 Federal request for an employment-related proposal from the two organizations. A month later, a proposal was submitted.

In February 2014 the Federal Government announced \$11.4 million in funding for CommunityWorks Canada sponsored by The Sinneave Family Foundation and Autism Speaks, and \$15 Million for Ready, Willing, and Able sponsored by Canadian Association for Community Living towards employment initiatives for youth and young adults with autism.

The Sinneave Family Foundation has begun planning a major conference aimed at educators and their role in preparing youth on the autism spectrum for the challenges of adult life to take place in October 2016 in Edmonton, Alberta. ■



LEFT: Tom Collins, President of the Sinneave Family Foundation, opens “What Will it Take?,” the Foundation’s second conference dedicated to vocational opportunities for people on the autism spectrum.

TOP: Tom Jackman (centre with mike), speaks about his experiences appearing in the film “Autism Grows Up,” following its premier, as Director Rob Kelly (l) and Network Investigator David Nicholas look on.

ABOVE: Keynote speaker Mark Wafer connects with attendees at a reception following the conference.

NETWORK

NETWORK INFORMATION

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
Memorial University of Newfoundland
Montreal Heart Institute
Queen's University
Ryerson University
Simon Fraser University
The Hospital for Sick Children
The University of Toronto McLaughlin Centre
Université de Montréal
Université du Québec à Montréal
University Health Network (Ontario)
University of Alberta
University of British Columbia
University of Calgary (The Hotchkiss Brain Institute)
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 Institutes

Alberta Child and Family Research Institute
(University of Calgary)
Canadian Centre for Behavioral Neuroscience
(University of Lethbridge)
Child and Family Research Institute
(University of British Columbia)
Croatian Institute for Brain Research (CIBR)
Hôpital Sainte-Justine
Karolinska Institutet
Laval University
Nipissing University - Muskoka Campus
OCAD University
San Diego State University
United Nations University
University of California, Los Angeles
University of Iowa College of Medicine
University of Ottawa
University of Pittsburgh
University of Zagreb
Vancouver Coastal Health Research Institute
Vanderbilt University
Women and Children's Health Research Institute
(University of Alberta)

Industry

Ambulatory Monitoring Inc.
 Avertus
 Bionetics
 Cedarlane Labs
 Cerner Corporation
 Electronic Arts
 GE Healthcare
 Health Nexus
 Ideas for independent living Inc.
 Kasian Architecture
 NeuroChip
 Parents Magazine
 PeriGen (Canada) Ltd.
 Pfizer
 Premier Technologies Solutions
 REDCap (**R**esearch **E**lectronic **D**ata **C**apture)
 SR Research Eyelink
 Squeezease Therapy Inc.
 TELUS Communications Company
 Teva Pharmaceutical Industries Ltd.
 Vancouver Sun
 Westcoast Child Development Group Inc.
 Wood's Homes

Federal departments and agencies

Canadian Institutes of Health Research (CIHR)
 Department of Foreign Affairs and International Trade
 (DFAIT)
 Institute of Human Development, Child and Youth Health
 (IHDCYH)
 National Institutes of Health (NIH) (USA)
 National Research Council (NRC)
 Networks of Centres of Excellence
 Public Health Agency of Canada

Provincial departments and agencies

Alberta Innovates: Health Solutions
 Alberta Perinatal Stroke Project (APSP)
 BC Ministry of Health
 BC Ministry of Children and Family Development
 Commission d'accès à l'information du Québec (CAI)
 Michael Smith Foundation for Health Research (MSFHR)
 Nova Scotia Department of Health & Wellness
 Régie de l'assurance maladie du Québec
 Ontario Ministry of Economic Development & Innovation

NETWORK INFORMATION continued

Not-for-Profit Organizations

The Ability Hub
 Alberta Children's Hospital
 Allergen
 Alva Foundation
 The Asante Centre
 Australian Cerebral Palsy Register
 Autism Community Training Society
 Autism Genome Project
 Autism Research Training (ART) Program
 Autism Speaks Canada
 Baby Siblings Research Consortium
 BC Women's Hospital & Health Centre
 Brain Canada
 British Council
 Alberta Children's Hospital
 Canada FASD Research Network (CanFASD)
 Canada-Israel International Fetal Alcohol Consortium
 Canadian Association of NeuroScience
 Canadian Association of Paediatric Hospitals (CAPHC)
 Canadian Autism Spectrum Disorders Alliance (CASDA)
 Canadian Child Health Clinician Scientist Program (CCHCSP)
 Canadian Epigenetics, Environment and Health Research Consortium (CEEHRC)
 Canadian Foundation for Innovation (CFI)
 Canadian Institute for Advanced Research
 Canadian Physiotherapy Association
 CanAssist
 CellCAN
 Centre de Réadaptation Marie Enfant (CRME)
 The Centre for Mindfulness Studies
 Centre for Molecular Medicine and Therapeutics
 Centre for Ontario Data Exploration (CODE)
 Childhood Cerebral Palsy Integrated Discovery Net (CP-Net)
 The Children's Hospital of Philadelphia (CHOP)
 Commission d'accès à l'information du Québec
 Community Living British Columbia
 Computational Approaches in Neuroscience
 Action Control & Transformations (CAN-ACT)
 Cerebral Palsy International Research Foundation
 Early Intervention Services of York Region
 Enhancing the Scientific Study of Early Autism (ESSEA)
 Fondation Père Favron
 Genome Canada
 Glenrose Rehabilitation Hospital
 Graphics Animation And New Media (GRAND) NCE
 Health Sciences Centre Foundation
 Integrated Services for Autism and Neurodevelopmental Disorders (ISAND)
 Institute for Ethics, History and Theory of Medicine, University of Munich
 Institute of Neurosciences, Mental Health and Addiction (INMHA)
 International Neuroinformatics Coordinating Facility (INCF)
 MAB-Mackay Centre
 Cerebral Palsy Association of Manitoba
 March of Dimes
 Maternal Infant Child and Youth Research Network (MICYRN)
 Mitacs
 Monarch House
 Montreal Children's Hospital
 Mount Sinai Hospital
 National Institute of Mental Health and Neuro Sciences (NIMHANS)
 Neurological Health Charities Canada (NHCC)
 Norlien Foundation
 Ontario Brain Institute
 Ontario Science Centre / Café Scientifique
 Partners in Research (PIR) / Virtual Research on Call (VROC)
 Peter Wall Institute for Advanced Studies
 Promoting Relationships and Eliminating Violence Network (PREVNet)
 Province of Ontario Neurodevelopmental Disorders (POND)
 R. Howard Webster Foundation
 Research Institute of the Cerebral Palsy Research Alliance In Australia
 Shailah Interactive
 SickKids Foundation
 Simons Foundation Autism Research Initiative
 Sinneave Family Foundation
 Stem Cell Network
 Stollery Children's Hospital Foundation
 THREE TO BE
 TIDE-BC
 Translating Emergency Knowledge for Kids (TREKK)
 Trudeau Fellowship
 Union of Ontario Indians
 WCHRI Clinical Research Informatics Centre
 Women's Health Research Institute

Network Investigators

Evdokia Anagnostou
 John C. Andersen
 Christian Beaulieu
 Armando Bertone
 Chris P. Bertram
 Jessica Brian
 Susan Bryson
 Brian Ross Christie
 Albert E. Chudley
 Evelyn Constantin
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 Marie-Pierre Dubé
 Ruth Eckstein Grunau
 Alan Evans
 Darcy Lynn Fehlings
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 Éric Fombonne
 Daniel Goldowitz
 Geoffrey B. Hall
 Ghassan Hamarneh
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 Krista Hyde
 Grace Iarocci
 Judy Illes
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 Shannon A. Johnson
 Elizabeth Kelley
 Kimberly Kerns
 Adam Kirton

Michael Kobor
 Annette Majnemer
 Marco Marra
 Michael Meaney
 Fiona Miller
 Steven Miller
 Pat Mirenda
 David Nicholas
 Tim F. Oberlander
 Maryam Oskoui
 Paul Pavlidis
 Jacqueline Pei
 Alan C. Peterson
 David Phipps
 Éric Racine
 Carmen Rasmussen
 James Reynolds
 Wendy Roberts
 Stephen Scherer
 Stephen H. Scott
 Michael Shevell
 Isabel Smith
 Isabelle Soulières
 Heidi Sveistrup
 Peter Szatmari
 Joanne Volden
 Joanne Weinberg
 Daryl Wilson
 Pia Wintermark
 Jerome Yager
 Lonnie Zwaigenbaum

Senior Network Research Staff

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 Emily Bell
 Matthew Caverley
 Wendy Comeau
 Lynn Dagenais
 Nina C. Di Pietro
 Courtney Green
 Jennifer Howe
 Sue Kobus
 Kathleen O'Grady
 Anneliese Poetz
 Elodie Portales-Casamar
 Christine Rogers
 Eleanor Seymour
 Lauren Switzer
 Carol Wilson

NETWORK INFORMATION continued

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Elaine Biddiss
Gunnar Blohm
François Bolduc
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Michael Brudno
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Jacob A. Burack
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Suzanne Curtin
Deborah Dewey
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Bhushan M. Kapur

Kathy Keiver
Muralidharan Kesavan
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Mojgan Rastegar
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Peter L. Rosenbaum
Jane Roskams
Dawa Samdup
James Sanders
Sidney J. Segalowitz

Garth Smith
Veronica Smith
Laurie Snider
Marla Sokolowski
Kaye Spratt
Greg Stanis
Sylvia Stockler
Pat Stroman
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Heidi Sveistrup
Anne R. Synnes
Margot J. Taylor
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Joanne Volden
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Lucie Wade
Jaynie F. Yang

Network Trainees

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Taryn Bemister
Terry Bennett
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Corneliu Bolbocean*
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Zachary Boychuck
Merike Bruen
Zhang Chen
Isabelle Chouinard
Jennifer Corrigan
Colleen Curtis
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Krissy Doyle-Thomas
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Eric Duku
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Nicholas Foster
Jesse Frender
Stelios Georgiades
Justine Gersberg

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 Kasey Hemington
 Amy Hewitt
 Sandra Hodgetts
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 Jamil Jivrav
 Meaghan Jones
 Kyle Koss
 Andrea Kucyznski
 Katrina Kully-Martens
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 Vivian Lee
 Johnathan Leef
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 Anath Lionel*
 Graham Little
 Alexandre Lussier
 Jennifer Marshall
 Kaitlyn McLachlan*
 Mathew Milen
 Kara Murias
 Anne-Marie Nader*
 Antoinette Nguyen
 Kieran O'Donnell*
 Tia Ouimet
 Angelina Paolozza
 Anna Patten*
 Anne-Marie Przyslupskia
 Kathryn Rancourt*
 Lisa Anne Rasmussen
 Crystal Ruff
 Lori Sacrey
 Jennifer Salmon
 Jenny Saunders
 Keiko Shikako-Thomas*
 Katarzyna Anna Stepien*
 Sukhpreet Tamana
 Sarah Treit
 Ana Tryfon
 Katelyn Verstraten
 Emily Walker
 Susan Walker*
 Julia Jia Wei*
 Ryan Yeun
 Farah Zahir*
 Dongming Zhou
 Natalie Zizzo
 Jill Glennis Zwicker*

Founding Investigators

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 Lara Boyd
 Jessica Brian
 Jim Frederick Brien
 Richard E. Brown
 Susan Bryson
 Sterling Clarren
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 Max Cynader
 Marc Del Bigio
 Marie-Pierre Dubé
 Ruth Eckstein Grunau
 David Eisenstat
 Alan Evans
 Darcy Fehlings
 Michael Fehlings
 Eric Fombonne
 Jan Friedman
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 Richard Hawkes
 Michael Hayden
 Anthony Herdman
 Clyde Hertzman
 William Honer
 Grace Iarocci
 Judy Illes
 Sheila Innis
 K.S. Joseph
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 Bryan Kolb
 Ron Lafrenière

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 Suzanne Lewis
 Catherine Limperopoulos
 Bruce McNaughton
 Annette Majnemer
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 Ravi Menon
 Freda Miller
 Steven Miller
 Pat Mirenda
 Nazeem Muhajarine
 Tim F. Oberlander
 Timothy O'Connor
 Paul Pavlidis
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 Eric Racine
 Catharine Helen Rankin
 James Reynolds
 Urs Ribary
 Bryan S. Richardson
 Wendy Roberts
 Peter Rosenbaum
 Stephen Scherer
 Stuart Shanker
 Michael Shevell
 Isabel M. Smith
 Peter Szatmari
 Moshe Szyf
 Derek van der Kooy
 Wyeth W. Wasserman
 Daniel Weeks
 Joanne Weinberg
 Janet Werker
 Ian Q. Whishaw
 Jerome Yager
 Lonnie Zwaigenbaum

**NeuroDevNet Doctoral/Postdoctoral Fellows (2011-2014)*

CORPORATE

CORPORATE INFORMATION

Senior Staff

Scientific Director, Daniel Goldowitz
Associate Scientific Director, Michael Fehlings
Executive Director, Jim Brookes (starting March 2014)
Executive Director, Nicola Lewis

Board of Directors

Henri Rothschild, Chair NeuroDevNet Board of Directors, President and Chief Executive Officer,
Canada-Israel Industrial Research & Development Foundation
Margaret Clarke, Professor, Mount Royal University; Vice-President, Sinneave Family Foundation and the Ability Hub
Glenys Godlovitch, Associate Professor, University of Calgary, (retired)
Daniel Goldowitz, Scientific Director, (Ex-Officio)
Judy Illes (Principal Investigator Representative) Professor, University of British Columbia
Patrick Lafferty, Partner of PricewaterhouseCoopers LLP (retired)
Sheila Laredo, Assistant Professor, University of Toronto; Chief of Staff, Women's College Hospital
Angus Livingstone, Managing Director, University-Industry Liaison Office, University of British Columbia
John O'Neil, Professor and Dean of the Faculty of Health Sciences, Simon Fraser University
Peter Morand, President, Peter Morand & Associates Inc.
David Phipps, Director, Research Services & Knowledge Exchange, York University
Carol Richards, Professor, Université Laval
Kathleen Thurber, Director, Corporate Communications, Alberta Innovates – Health Solutions
Gary Wechsler, FCPA CA, Optimal Group

Scientific Advisory Committee

Samuel Weiss, Chair NeuroDevNet Scientific Advisory Committee, Professor, University of Calgary
Bernie Devlin, Professor, University of Pittsburgh
Joseph Fins, Director of Medical Ethics and Attending Physician, Weill Cornell Medical College (USA)
Jay Giedd, Principal Investigator, National Institute of Mental Health (USA)
Neal Halfon, Professor, University of California
Mark Hoffman, Director, Centre for Health Insights, University of Missouri
Michael Johnston, Senior Vice President and Chief Medical Officer, Kennedy Krieger Institute (USA)
Ivica Kostovic, Professor, University of Zagreb
Pat Levitt, Professor, University of Southern California
Edward Riley, Professor, San Diego State University

Valorization Committee

Angus Livingstone, Chair Valorization Committee, Managing Director, University-Industry Liaison Office, University of British Columbia
 Jim Brookes, Executive Director, NeuroDevNet
 Tom Collins, President, Sinneave Family Foundation
 Ryan D’Arcy, Professor, Simon Fraser University
 Michael Fehlings, Medical Director, Krembil Neuroscience Centre, University Health Network
 Chris Fibiger, Chief Scientific Officer, MedGenesis
 Anne Fuller, Provincial FASD Consultant, BC Ministry of Children and Family Development
 David Phipps, Director, Research Services & Knowledge Exchange, York University
 Anneliese Poetz, Manager Knowledge Translation Core, York University

Research Management Committee

Daniel Goldowitz, Chair Research Management Committee, Scientific Director, NeuroDevNet
 Evdokia Anagnostou, Associate Professor, University of Toronto
 Daniel Ansari, Associate Professor, Western University
 Mark Bieda, Assistant Professor, University of Calgary
 Kym Boycott, Associate Professor, University of Ottawa
 James Brien, Professor, Queen’s University
 Jim Brookes, Executive Director, NeuroDevNet (Ex-Officio)
 Ryan D’Arcy, Head, Health Sciences & Innovation, Simon Fraser University
 Richard Hawkes, Senior Associate Dean, University of Calgary
 Jan Friedman, Professor, University of British Columbia
 Mary Johnston, Acting Associate Director (Retired), FASD Initiative, Public Health Agency of Canada
 Bryan Kolb, Canadian Centre for Behavioural Neuroscience, University of Lethbridge
 Lucy Lach, Associate Professor, McGill University

CORPORATE INFORMATION

continued

Research and Training Committee

David Eisenstat, Chair Research and Training Committee, Professor, University of Alberta
Christian Beaulieu, Professor, University of Alberta
Richard E. Brown, University Research Professor, Dalhousie University
Lucy Osborne, Associate Professor, University of Toronto
Ellen Wood, Associate Professor, Dalhousie University

Staff

Bethany Becker, Communications Manager
Jim Brookes, Chief Development Officer
Kirsten Lawrie, Senior Administrator
Anthony Santelices, Project Coordinator
Anita Sham, Assistant to Scientific Director
Shum Sidhu, Finance Administrator
Denise Wong, Communications Assistant

Auditors

Hay & Watson, Chartered Accountants

Legal Counsel

Borden Ladner Gervais LLP, Vancouver, BC

FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2014 and 2013



900 – 1450 Creekside Drive, Vancouver BC V6J 5B3
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INDEPENDENT AUDITOR'S REPORT

To the Directors of NeuroDevelopment Network, Inc.

We have audited the financial statements of NeuroDevelopment Network, Inc. (the "Network"), which comprise the statements of financial position as at March 31, 2014 and 2013, and statements of operations and financial position and of cash flows for the years then ended, and a summary of significant accounting policies and other explanatory information.

Management's Responsibility for the Financial Statements

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

Auditor's Responsibility

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

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

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

Opinion

In our opinion, the financial statements present fairly, in all material respects, the financial position of the Network as at March 31, 2014 and 2013, and its financial performance and its cash flows for the years then ended in accordance with Canadian Accounting Standards for Not-for-Profit Organizations.

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

Chartered Accountants
 Vancouver, British Columbia
 June 26, 2014

FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2014 and 2013

Statements of Financial Position As at March 31, 2014 and 2013

	Mar 31, 2014 \$	Mar 31, 2013 \$
Assets		
Current assets		
Cash – held in trust by University of British Columbia	1,789,247	836,382
Cash – held at bank	121,691	109,286
Accounts receivable	8,500	–
Unspent research grants paid to participating institutions (note 6)	629,464	801,435
Prepaid expenses	33,914	6,478
	2,582,816	1,753,581
Furniture and equipment (note 4)	967	–
	2,583,783	1,753,581
Liabilities		
Current liabilities		
Accounts payable and accrued liabilities	149,928	200,713
Deferred contributions (note 5)	2,311,197	1,442,083
Deferred capital contributions (note 5)	967	–
	2,462,092	1,642,796
Net assets	121,691	110,785
	2,583,783	1,753,581

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

APPROVED BY THE BOARD OF DIRECTORS



Henri Rothschild, Chair, Board of Directors Committee



Gary Wechsler, Chair, Finance and Audit

FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2014 and 2013

Statements of Operations and Changes in Net Assets Years Ended March 31, 2014 and 2013

	2014 \$	2013 \$
Receipts		
Grant from Networks of Centres of Excellence (note 5)	2,902,362	5,349,421
Grants from other agencies and organizations (note 5)	385,738	142,500
Conference registration fees and support	100,776	80,954
Amortization of deferred capital contributions (note 5)	219	4,497
	3,389,095	5,577,372
Expenditures		
Communications	38,260	80,192
Amortization	219	4,497
Insurance	7,440	7,382
Professional and consulting fees	40,940	82,100
Research and training (note 6)	2,401,278	4,343,773
Salaries and benefits	577,872	606,152
Supplies and office costs	27,402	25,614
Travel, meetings & networking	284,778	370,219
	3,378,189	5,519,929
Excess of receipts over expenditures	10,906	57,443
Net assets, beginning of year	110,785	53,342
Net assets, end of year	121,691	110,785

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

FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

For the Years Ended March 31, 2014 and 2013

Statement of Cash Flows

Years Ended March 31, 2014 and 2013

	2014 \$	2013 \$
Cash flows from (used in) operating activities		
Excess of receipts over expenditures	10,906	57,443
Non-cash items		
Amortization	219	4,497
Changes in non-cash working capital items		
Accounts receivable	(8,500)	-
Unspent research grants	171,971	14,467
Prepaid expenses	(27,436)	11,525
Accounts payable and accrued liabilities	(50,785)	3,877
Deferred contributions	870,081	(1,436,418)
	966,456	(1,344,609)
Cash flows from (used in) investing activities		
Purchase of furniture & equipment	(1,186)	-
Increase (decrease) in cash	965,270	(1,344,609)
Cash, beginning of year	945,668	2,290,277
Cash, end of year	1,910,238	945,668
Cash composed of:		
Cash – restricted	1,789,247	836,382
Cash – unrestricted	121,691	109,286
	1,910,938	945,668

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

1. OPERATIONS

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

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

The Network has been approved for \$19,572,000 in funding from the NCE from 2009-2015 (Note 7). On June 11, 2014, NeuroDevNet submitted a renewal application for a second cycle of funding from the NCE for \$30,000,000 over a 5 year period. Results of this application will be released in the fall of 2014.

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 Canadian 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 were applied retrospectively at the transition date. There were no adjustments to the Network’s assets, liabilities and net assets as a result of the adoption of ASNPO and none of the exemptions which could be applied on the transition to ASNPO were applicable to the Network.

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

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

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 furniture & equipment and the recoverability of accounts receivable.

Cash - Restricted and Unrestricted

Based on the funding agreement between NeuroDevNet and the NCE, grant funds from the NCE are considered restricted and are to be held in trust and administered by the University of British Columbia ("UBC"), the Network's host institution. Other funds are administered by the Network and are considered unrestricted cash. Unrestricted cash is held in a separate bank account.

Financial Assets and Liabilities

Financial assets and financial liabilities are initially measured at fair value adjusted by, in the case of a financial instrument that will not be measured subsequently at fair value, the amount of transaction costs directly attributable to the instrument. The Network subsequently measures its financial assets and financial liabilities at amortized cost. As at March 31, 2014, the recorded amounts of financial assets and financial liabilities approximate fair values.

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

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

3. SIGNIFICANT ACCOUNTING POLICIES *continued*

Unspent Research Grants Paid to 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.

Furniture and equipment

Furniture and equipment are recorded at cost and amortized on a straight-line basis over their respective estimated useful lives at the following annual rates:

Furniture	20%
Computers	30%

Recognition of Receipts

The Network follows the deferral method of accounting for contributions, which include government grants. Funds are received from the Canadian federal government, the host institution, and other private and public sector partners.

Contributions which have external restrictions governing the types of activities they can be used to fund are deferred and recognized when the eligible expenditures are incurred. Contributions approved but not yet received at the end of the reporting period are accrued.

Under the terms of the NCE agreement, 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, including conference registration fees and sponsorships, are recognized as receipts in the current period if the amount to be received can be reasonably estimated and collection is reasonably assured.

In-Kind Contributions

In-kind contributions from UBC (note 4) and other organizations are not included in these financial statements.

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

3. SIGNIFICANT ACCOUNTING POLICIES *continued*

Employee Future Benefits

NeuroDevNet's staff are eligible to join the UBC staff pension plan. The UBC staff pension plan provides benefits based on 2% of the average best three years' basic salary multiplied by the number of years of contributory service, less an adjustment to Canada Pension Plan contributory earnings. NeuroDevNet's contribution for staff is approximately 9% of salary. In the event of funding deficiencies, NeuroDevNet's contributions remain fixed and benefits for members may be reduced. Accordingly, NeuroDevNet records contributions to this plan as expenditures in the year the contributions are made. 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 \$28,764 (2013 - \$29,813).

Income Taxes

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

4. FURNITURE AND EQUIPMENT

Computers, at cost

Balance, March 31, 2012	\$	13,495
Additions		-
<hr/>		
Balance, March 31, 2013		13,495
Additions		1,186
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Balance, March 31, 2014	\$	14,681
<hr/>		
Accumulated amortization		
Balance, March 31, 2012	\$	8,998
Amortization		4,497
<hr/>		
Balance, March 31, 2013		13,495
Amortization		219
<hr/>		
Balance, March 31, 2014	\$	13,714
<hr/>		
Carrying amount		
Balance, March 31, 2013	\$	-
<hr/> <hr/>		
Balance, March 31, 2014	\$	967
<hr/> <hr/>		

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

5. DEFERRED CONTRIBUTIONS

Deferred Contributions Relating to Expenditures of Future Periods

	March 31, 2014 \$	March 31, 2013 \$
NCE Funds		
Balance – Beginning of year	1,308,745	2,698,166
Grants from the NCE received during the year	3,826,000	3,940,000
Grants from Host Institution	80,000	20,000
Amounts recognized as receipts during the year	(2,902,362)	(5,349,421)
Amounts applied toward furniture and equipment purchased during the year	(1,186)	-
	2,311,197	1,308,745
Other restricted funds		
Balance – Beginning of year	133,338	175,838
Grants received during the year	252,400	100,000
Amounts recognized as receipts during the year	(385,738)	(142,500)
	-	133,338
	2,311,197	1,442,083

Deferred Capital Contributions Relating to Furniture and Equipment

	March 31, 2014 \$	March 31, 2013 \$
Balance – Beginning of year	-	4,497
Allocation of deferred contributions	1,186	-
Amounts amortized to revenue	(219)	(4,497)
	967	-

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

6. RESEARCH AND TRAINING EXPENDITURES

NeuroDevNet disburses research grant funds to the host institution of the principal investigators of a research project following the approval of the project. Funds are held in trust by the host institutions and are recorded as unspent research grants by NeuroDevNet until eligible research expenses are incurred by the principal investigators.

	Balance – March 31, 2013 \$	Funds returned \$	Current year grant \$	Current year expenditures \$	Balance – March 31, 2014 \$
Institution – Master grants					
Holland Bloorview	16,030	–	184,218	(152,329)	47,919
Hospital for Sick Children	84,103	–	88,000	(42,013)	130,090
IWK Health Centre	54,105	–	69,490	(66,659)	56,936
McGill University	407,467	(185,866)	244,236	(347,111)	118,726
McMaster University	–	–	18,600	(18,600)	–
Montreal Heart Institute	(50,000)	–	50,000	–	–
Queen’s University	6,649	–	152,125	(152,980)	5,794
University Health Network	–	–	93,500	(93,500)	–
University of Alberta	131,412	–	338,810	(397,573)	72,649
University of British Columbia	96,002	(33,609)	630,895	(550,491)	142,797
University of Calgary	(2,300)	–	–	2,300	–
University of Manitoba	4,212	–	20,000	–	24,212
University of Montreal	–	–	50,747	(50,747)	–
University of Saskatchewan	44,287	–	–	(44,287)	–
University of the Fraser Valley	–	–	10,000	–	10,000
University of Victoria	48,487	(15,614)	–	(27,162)	5,711
York University	–	–	162,800	(148,170)	14,630
Other	(39,019)	–	–	39,019	–
	801,435	(235,089)	2,113,421	(2,050,303)	629,464
Other research and training				(350,975)	
Total research and training				(2,401,278)	

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

7. RELATED PARTY TRANSACTIONS AND ECONOMIC DEPENDENCE

Grants from the NCE

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	<i>received</i>
2010 – 2011	302,500	400,000	3,453,500	4,156,000	<i>received</i>
2011 – 2012	527,000	1,000,000	2,292,000	3,819,000	<i>received</i>
2012 – 2013	576,000	1,000,000	2,364,000	3,940,000	<i>received</i>
2013 – 2014	530,000	1,000,000	2,296,000	3,826,000	<i>received</i>
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 \$3,826,000 has been received for 2013/14 (\$3,940,000 in 2012/13) and has been included 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, management of intellectual property, information technology support and web hosting services.

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

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. The Network is exposed to credit risk from its cash and accounts receivable. The Network considers this risk to be minimal as cash is on deposit at insured financial institutions and accounts receivable are due from major universities and corporate sponsors.

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 is not exposed to significant interest rate risk.

Liquidity Risk

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

NOTES TO THE FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Years Ended March 31, 2014 and 2013

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.

WORKING TOGETHER TO HELP



CHILDREN AND FAMILIES



2013/14 ANNUAL REPORT PARTNERSHIP

WORKING TOGETHER TO HELP CHILDREN AND FAMILIES



A CANADIAN NETWORK OF CENTRES OF EXCELLENCE

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