NeuroDevNet

working together for healthy brains

Annual Report 2010 | 2011

NeuroDevNet, a Canada Network of Centres of Excellence (NCE), is dedicated to helping children and their families overcome neurodevelopmental disorders.

Vision

The vision of the network is to accelerate the pace of understanding disorders of brain development and to implement solutions that improve the lives of affected children and families.

Mission

Through our multidisciplinary collaborative network, NeuroDevNet supports transformative research; provides training opportunities to build the next generation of Canadian researchers; empowers communities with the right tools and information; and translates research findings into early diagnostic, preventative, and therapeutic strategies for children with neurological disorders to live healthier lives.

Objectives

Capacity Building

Train the next generation of experts in brain development disorders

Research

Support and conduct multidisciplinary research excellence

Knowledge Transfer

Raise awareness of brain development disorders and disseminate research findings to help with care delivery and policy decisions

Business Development

Translate research findings into diagnostic, preventative, and therapeutic applications

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

Support

NeuroDevNet is made possible by the Networks of Centres of Excellence, a program of the federal government to advance science and technology.

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

NCE RCE
Networks of Centres | Réseaux de centres
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UBC
a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA

CHILD & FAMILY RESEARCH INSTITUTE

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FROM HOPE TO DISCOVERY

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MESSAGE FROM THE Scientific Director

WITH OVER TWELVE RESEARCH PROJECTS launched to investigate children's neurodevelopmental disorders, NeuroDevNet is in the process of moving from hope to discovery. We have made early advances to identify genetic variations that may predict risk for autism. Our efforts have established a cerebral palsy registry in Quebec, Ontario, and Alberta, which will expand to encompass Canada. Using eye movement, brain imaging, and psychometric testing, we made rapid gains to establish a neurobehavioural profile for children with fetal alcohol spectrum disorder.

These early successes resulted from the launch of three large multidisciplinary research projects that focus on autism spectrum disorders, cerebral palsy, and fetal alcohol spectrum disorders. We also initiated three cores in neuroethics, neuroinformatics, and knowledge transfer exploitation and exchange, which support research and outreach throughout the network. We are excited about the passion and commitment of our researchers and staff, whose major accomplishments still lie ahead.

We are building a robust network that transcends discipline and geography to help children with neurodevelopmental disorders. NeuroDevNet held the first national brain development conference in June 2010, which brought together over one hundred Canadian delegates from various fields, including genetics, developmental biology, clinical practice, and imaging. New trans-disciplinary research has been supported through our Opportunities Initiative program, which awarded $900,000 over two years to nine innovative projects nation-wide.

Cultivating expertise begins with each new generation of Canadian researcher and clinician. This year, we provided research funding, training support, and networking opportunities for over fifty highly qualified personnel, which included ten post-doctoral fellows, four PhD candidates, and six Master's candidates. Our integrated training program has attracted partners to support innovative opportunities, such as the multidisciplinary Winter Institute held in collaboration with the Autism Research Training Program and the Sinneave Family Foundation. Effective partnering has also resulted in the award of over $200,000 in total over two years to five trainees through our training initiatives.

In the coming year, we will build on our initial accomplishments by leveraging early discoveries, broadening funding partnerships, facilitating trainee development, and establishing NeuroDevNet as a leading research institution in the quest to improve diagnostics and therapeutics for children with brain disorders in Canada and around the world.

In this report, we highlight NeuroDevNet's research achievements and the results of our current partnerships. Our progress would not have been possible without the generous support of our funders. We would also like to acknowledge the strong and insightful leadership of our Board of Directors, the contribution of our international Scientific Advisory Board, and our internal Research Management Committee to our research progress. Last but not least, we would like to thank our partners for their continued collaboration to advance research and training. We are pleased with the progress made by our core and demonstration projects, and have high hopes for our collaborative research, trainees, and partnerships in the years to come.

Daniel Goldowitz
Scientific Director, NeuroDevNet

MESSAGE FROM THE Chair, Board of Directors

AT NEURODEVNET, WE BELIEVE strong networks must be guided by sound governance. Fourteen dynamic individuals now serve on the Board of Directors, providing grounded network policy and practice. NeuroDevNet created five standing committees of the board to steer governance, finance, ethics, research, and administrative activities. One of the Board of Directors' initial efforts included the development of a strategic plan for NeuroDevNet. To date, we have completed twenty-five interviews with key experts from across the country, an overview of the "brain" environment, stakeholder meetings with potential partners, and outcome metrics for each research project.

By opening dialogues with stakeholders, partners, and researchers, NeuroDevNet has forged links to help find solutions to assist children with neurodevelopmental disorders. One of our most exciting projects emerged from a collaboration with GRAND NCE (Graphics, Animation, and New Media), which joins neuroscientists and computer scientists using game technology, social networking, and digital media to treat neurodevelopmental disorders.

Our next challenge is to extend our research networks beyond Canada to span the globe. Formative exchanges between Canada and Israel have been fostered by Dr. Daniel Goldowitz, NeuroDevNet's Scientific Director. As a member of an international brain research steering committee, Dr. Goldowitz led a team of Canadian experts in a bi-lateral round table on brain research cooperation as part of the 2011 Canada-Israel Innovation Summit. NeuroDevNet researchers have linked with counterparts in India, and have joined with colleagues in Australia to inaugurate a cerebral palsy conference that accelerates international collaboration and begins building a global

cerebral palsy registry. In the year ahead, we plan to extend our global reach even further with counterparts in other countries, notably Brazil and China.

Effective partnerships will allow NeuroDevNet to translate scientific findings into new therapies and diagnostic tools for clinicians, families, and children with neurodevelopmental disorders. We have initiated relationships with companies to develop biosensors and to eliminate maternal-fetal infections that can contribute to cerebral palsy. Through a rewarding collaboration with Mitacs, a national, not-for-profit research organization, we have joined interns with industry and other organizations, such as TELUS, Bionetics Inc., Neurochip Corporation, and the BC Autism Assessment Network. NeuroDevNet also leads a pilot program to generate non-industry health internships through the Mitacs partner consortium, with the goal of producing thirty non-industry internships by the end of 2012.

We know that partnerships are essential for success, and we have worked hard to establish meaningful relationships with our partners, collaborators, and stakeholders. I would like to thank the efforts of our esteemed Board of Directors for their guidance, and our Research Management Committee for overseeing NeuroDevNet's research program. Our team, experience, strategies, and networks will help us translate scientific discovery into tools and therapies that reduce the economic burden of disease, and ultimately benefit children with brain disorders and their families.

Henri Rothschild
Chair, Board of Directors, NeuroDevNet

MESSAGE FROM THE Executive Director

AT EVERY OPPORTUNITY, we have worked closely with our membership and key stakeholder communities to make sure we understand their needs and meet their expectations for improved tools and resources that help children with neurodevelopmental disorders and their families. This approach has allowed us to expand our network membership, and to engage a broader community of researchers, trainees, clinicians, individuals, and families. This year, our network has grown to include sixty-eight investigators in twenty-two academic institutions. We have also established a membership structure that boasts a membership of over one hundred investigators, trainees, and individuals.

We have reached out to members in our key stakeholder communities to raise awareness about NeuroDevNet and to find opportunities for collaboration. Starting in British Columbia, and extending across Alberta, Ontario, and Quebec, we met with provincial government and industry leaders, as well as not-for-profit groups in health, technology, and child development. International links were also made with government bodies and brain research institutes, such as the National Institute of Aging, and the International Brain Research Organization. This has led to several exciting possibilities for partnership that we hope to bring to fruition in the coming years.

NeuroDevNet is committed to obtaining diverse funding sources that will help sustain new and ongoing research ventures. To that end, we have worked to secure additional monies to extend existing research dollars. Our investigators have received over $200,000 in external support to study fetal alcohol spectrum disorder (FASD) and knowledge exchange outcomes, and to investigate how we report FASD diagnostic data. We also have a number of grant applications under review, and we plan to continue seeking external support to expand our projects and programs.

Determined efforts have been made to establish our administrative centre and to ensure that our practices and procedures will support our research endeavours. In addition to developing internal finance structures and controls, we continued to hire additional staff, and create a communications strategy to promote NeuroDevNet's research findings and events.

Thriving networks are only possible with the dedicated participation of the communities in which we are embedded. I would like extend my gratitude to our stakeholders and members who help make our efforts worthwhile, and help NeuroDevNet bring hope to children and families at the heart of all our intentions.

Nicola Lewis
Executive Director, NeuroDevNet

YEAR IN REVIEW

GETTING ESTABLISHED

DURING THE FIRST FULL YEAR OF OPERATION, NeuroDevNet moved into a dedicated office space at the BC Children's and Women's Health Centre, with support from the Child & Family Research Institute and the University of British Columbia.

To complement the existing administrative team, NeuroDevNet hired individuals with expertise in administration, communications, and finance. Two Work Study students from the University of British Columbia rounded out the complement of staff. Other activities included completing lease agreements for office infrastructure, and selecting an insurance policy for the Directors and Officers, as well as general office liability. After completing the first financial audit for fiscal year 2009-2010, we began developing financial procedures and processes.

Communications Achievements 2010-2011

- **Launched bilingual website**
- **Developed monthly e-bulletin, which was distributed to over 700 subscribers**
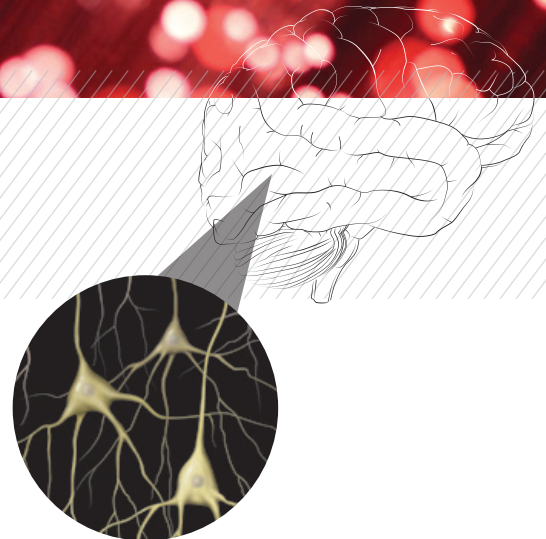
NeuroDevNet developed criteria for a skills-based Board of Directors, and continued to recruit outstanding individuals to the Board, which achieved full membership in September 2011. Five standing committees of the board were formed shortly afterwards, including the Executive, Governance and Nominations, Finance and Audit, Ethics and Conflict of Interest, and Research Management committees.

Management Operations Achievements 2010-2011

- **Engaged fifty key stakeholders in meetings, including those in industry, government, and not-for-profit sectors**
- **Established strong governance practices including the formation of standing committees for the Board of Directors and the development of terms of reference**

TRAINING AND EDUCATION

THIS YEAR, NEURODEVNET LAUNCHED an integrated training program that includes workshops, awards, internships, and fellowships. Eager trainee participation made the first Winter Institute an outstanding success. Co-hosted by NeuroDevNet, Autism Research Training, and the Sinneave Family Foundation, the institute engaged 44 trainees, 33 faculty, and 20 stakeholders in an interactive, multidisciplinary curricula. The workshop was held over four days in March 2011 at the Banff Centre in Alberta.

"Thank you for sponsoring me to attend the winter institute. I learned a great deal and it was a wonderful experience. More importantly, I am grateful to know that I am now part of the NeuroDevNet family and look forward to more opportunities to work with and learn from faculty and trainees within NeuroDevNet."

– Dr. Jill Zwicker, Post-doctoral Fellow, Department of Pediatrics, University of British Columbia

This year, five new trainees received awards through NeuroDevNet, which were co-funded by the Child & Family Research Institute and the Canadian Child Health Clinician Scientist Program. Awardees include three PhD students and two Master's candidates from Quebec, Ontario, and British Columbia, who were selected for their academic excellence and the quality of their research program.

Trainee Program Achievements 2010-2011

- **Co-funded five new trainees through partnerships with the Child & Family Research Institute and the Canadian Child Health Clinician Scientist Program**
- **Launched NeuroDevNet Fellowship Awards Competition**

TRAINING AND EDUCATION
continued

Following an intensive planning and development process, we launched the NeuroDevNet Fellowship Awards Competition in March 2011. The fellowship is intended to be an annual competition for doctoral, post-doctoral, and clinical research students.

Productive collaborations between NeuroDevNet and Mitacs have yielded internships in neurodevelopmental research. Through the Mitacs Accelerate program, we secured our first internship that linked the Sunny Hill Health Centre and a Simon Fraser University researcher in British Columbia. Dr. Tamon Stephen led the project, which evaluates impacts of a new online referral system for autism and FASD evaluations. More internships are currently under negotiation with industry and non-industry partners, which we eagerly anticipate in the coming year.

"Credit certainly goes to Timothy for making [the research project] work; He has a terrific combination of initiative and common sense. He was able to start working from the project outline and come up with something sensible without too much input from either myself or Karen. Thank you again for your help in arranging the internship!"

– Dr. Tamon Stephen, Assistant Professor, Department of Mathematics, Simon Fraser University

STAKEHOLDER ENGAGEMENT

STRONG CONNECTIONS are the backbone of our network. We have actively engaged institutions and individuals in the brain development community to raise awareness of NeuroDevNet, and to determine possibilities for collaboration. In the provincial sector, we met with senior administration in various ministries in British Columbia and Ontario, including the BC Ministries of Health, Child and Family Development, and Advanced Education, and the Ontario Ministries of Children and Youth Services, and Research and Innovation. We also made germane connections with national health organizations, such as the Canadian Association of Paediatric Health Centres, Neurological Health Charities Canada, and the Public Health Agency of Canada FASD Team. To further our plans to commercialize research findings and create products, therapies, and diagnostic tools, we met with representatives of the Ottawa biotechnology industry. We have also begun to realize relationships with industry partners, such as Bionetics, who will work on therapies for maternal-fetal infections as they relate to cerebral palsy, and NeuroChip Inc., a start-up company developing biosensors.
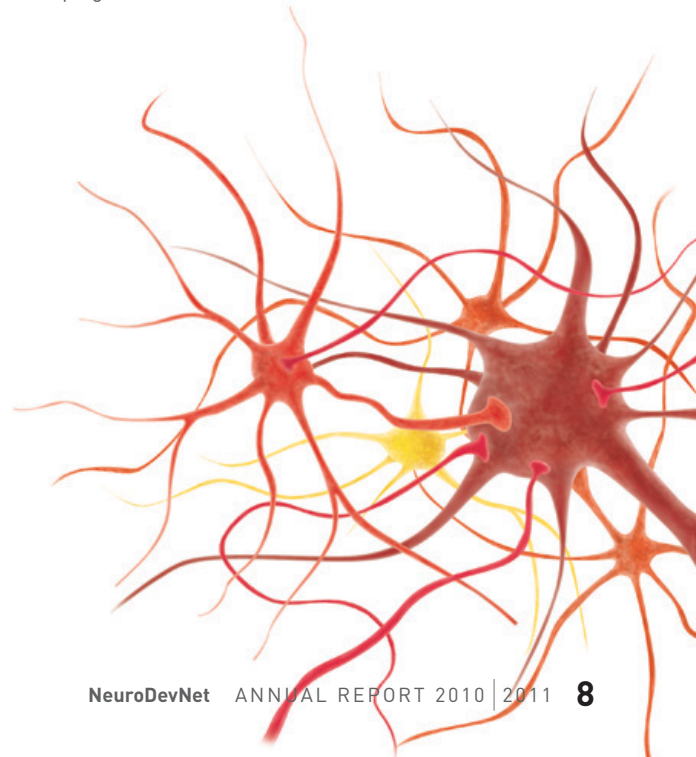
RESEARCH

NEURODEVNET PROUDLY INAUGURATED three large interdisciplinary, multi-site research programs in autism spectrum disorders, cerebral palsy, and fetal alcohol spectrum disorders. Three smaller core projects in knowledge translation, neuroethics, and neuroinformatics were also initiated to provide resources and support for these large projects. Each core and demonstration project resubmitted their research proposal to the international Scientific Advisory Board (SAB) in April 2010. Subsequently, the SAB evaluations were reviewed by the Research Management Committee, which provided further direction and an opportunity for the demonstration and core projects to strengthen their research programs.

Research Achievements 2010-2011

- Hosted two intensive research workshops: *When Virtual Meets Reality* (gaming and neurodevelopmental disorders), *NeuroDevNet Initiative on Imaging-Genetics Workshop*
- Funded eleven research projects through the Opportunities Initiatives Program—four of these were co-funded by GRAND NCE
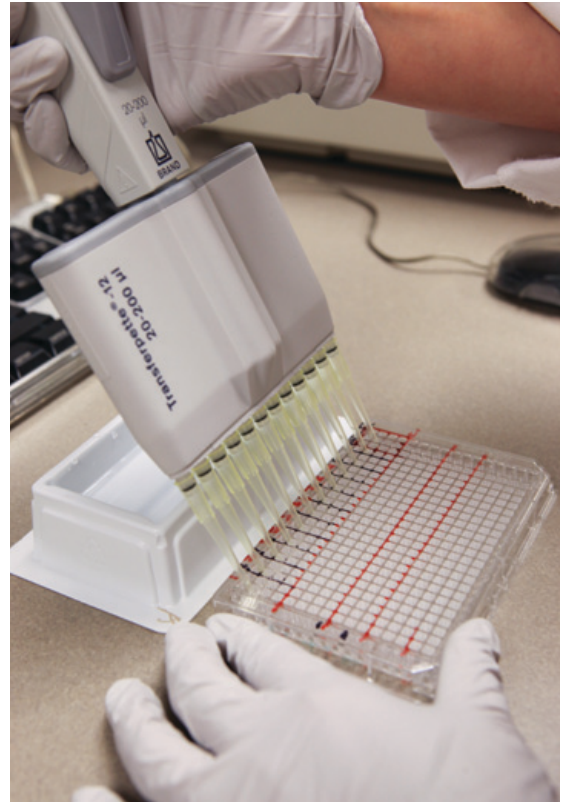
ANNUAL SCIENTIFIC CONFERENCE

OUR FIRST ANNUAL Brain Development Conference was planned and launched within four months of operation. Held in Montreal during June 2010, over one hundred delegates participated in the meeting, including 23 trainees. Our goals for the conference included launching the NeuroDevNet NCE, engaging the neurodevelopmental research community, and building the research network. We held a public forum in cerebral palsy, which was attended by 26 community members, and was one of the most noteworthy components of the conference program. Preparations for the 2011 conference began in fall 2010. We instituted a volunteer scientific program committee to develop the program, and we immediately began planning the budget and logistics for the conference. In addition, we embarked on a new sponsorship program to help support the conference and provide revenues to facilitate program expansion.

RESEARCH
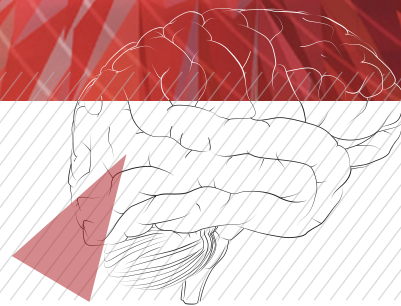
NEURODEVNET'S INITIAL DEMONSTRATION PROJECTS
focus on three developmental disorders: autism
spectrum disorders, cerebral palsy, and fetal alcohol
spectrum disorders. Three core projects in neuroethics,
neuroinformatics, and knowledge transfer exploitation
and exchange, support research and outreach
throughout the network. Our research aims to accelerate
our understanding of brain development disorders and to
find solutions for affected children and their families.
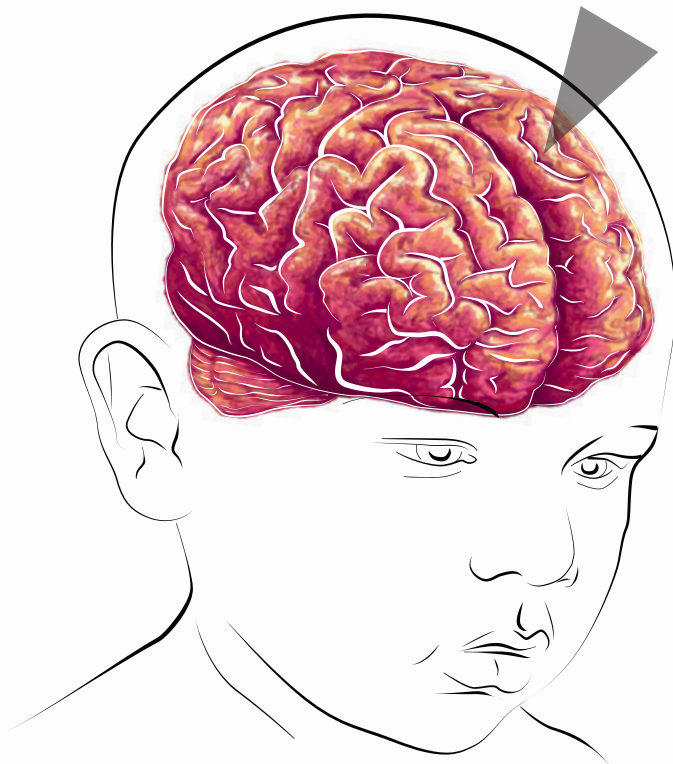
AUTISM SPECTRUM DISORDERS (ASD):

ABOUT ONE IN 110 CHILDREN are born with autism spectrum disorders (ASD) and experience lifelong social and communication challenges as a result of this neurological condition. ASD not only affects children's development and life experiences, but also exerts immense emotional and financial pressures on families and other caregivers.

Our project will characterize the genetic basis of neurobiological vulnerability to ASD, and will improve how we understand variation in brain and behavioural development in affected individuals. This project has four research aims. First, we will use state-of-the-art sequencing approaches to identify rare genetic variants associated with ASD. Second, we will use neuroimaging studies of children with ASD to assess the effect of these variants on brain development and connectivity. Third, we will examine the clinical utility of these variants to predict ASD diagnosis, developmental course, and long-term outcomes in persons with ASD. Finally, we are committed to working with key stakeholders, including persons with ASD, parents, clinicians, health and policy decision-makers, and industry partners, to ensure that these discoveries are meaningful to families and society as a whole, so that we can optimally capitalize on new genomic advances and deliver them to the broader community in the most effective way.

This year, we initiated a whole exome, next generation sequencing (NGS), on ASD affected individuals to identify novel genes associated with ASD. Using samples from previous studies, we completed exome libraries of 192 subjects. From these libraries, we carried out NGS on 64 individuals with 30 more that are ready for sequencing and analysis. To date, we have identified, validated, and confirmed the inheritance of four unique variants in the DNA sequence. Further follow-up is needed to determine if these variants contribute to the ASD phenotype, or if they are newly identified single nucleotide polymorphisms.

As part of our knowledge translation efforts, Dr. Scherer, in collaboration with Autism Speaks, hosted a successful workshop in Toronto in September 2010 that included stakeholders from the ASD advocacy and clinical communities, researchers, and the biotechnology industry. This workshop identified priorities for public education, for engagement with policy makers, and for further dialogue that facilitates optimal approaches to translation of genomic discoveries into clinical practice.

One goal for the upcoming year includes updating our analysis pipeline in order to reduce the number of false positive variants identified. This will enable us to attain our goal of identifying new ASD susceptibility genes. We will continue to work on knowledge translation activities, which include a discussion paper on ethical and clinical issues related to the use of new microarray technologies in Canadian clinical diagnostic testing, as well as a follow-up stakeholder workshop on these issues.

ASD Project Achievements 2010-2011

- **Identified four single nucleotide polymorphisms associated with autism risk**
- **Hosted annual ASD Research Parent Conference with 350 attendees**

Team Leads

Lonnie Zwaigenbaum, University of Alberta
Stephen Scherer, University of Toronto

CEREBRAL PALSY (CP):

CEREBRAL PALSY (CP) IS THE MOST COMMON CAUSE of physical impairment encountered in pediatrics. It is a "symptom complex" that is heterogeneous in all its manifestations. Cerebral palsy is a neuromotor impairment that results from either a developmental or an acquired injury to the not-yet-mature brain. Although all individuals with CP have a neuromotor impairment, co-morbidities, such as epilepsy, cognitive limitations, primary sensory impairments, language difficulties, behavioural challenges, and orthopedic deformities are frequently experienced and may constitute the major burdens of care. CP is a lifelong disorder that has considerable additional costs at individual, familial, and societal levels.

The CP demonstration project has three primary objectives. First, we will establish a multi-regional Canadian CP registry that will serve as a platform for describing the profile of CP in the Canadian population as well as identifying its risk factors. Second, we will provide a subject base for advanced imaging and genetic studies. Third, we will inform and modify existing animal models and regenerative research to address specific issues in causation and novel treatment approaches. The CP demonstration project has a mission to increase the understanding of how brains develop, and how abnormal development or acquired injury result in activity limitations for some Canadian children. Through this collective effort, we anticipate that the burdens of this disorder in the Canadian population will be lessened at different levels.

The Canadian cerebral palsy registry is now operational in the province of Quebec, Edmonton, and the greater Toronto area. Biological material will be collected from parents and children participating in the registry and will be sent to Toronto for genetic analysis by the fall of 2011. We have enrolled children in our imaging study in British Columbia and will soon begin enrollment in Montreal. Our animal model and stem cells projects are on track with preliminary results already yielding promising regenerative results.
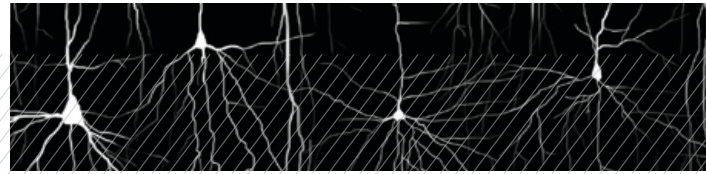
As part of our outreach efforts, members of NeuroDevNet's cerebral palsy project and the knowledge translation core collaborated to write a guide and fact sheet on stem cell research and CP in Canada to inform patients, families and service providers. This guide was accompanied by a fact sheet on CP for patients and families. As well, the CP demonstration project helped organize a symposium, *Advances in cerebral palsy – from cell to person,* held in Toronto in May 2011.

The CP demonstration project's plans for next year will build on this year's achievements. Specifically, we will increase enrollment in the Canadian CP registry, and we will expand the registry to include other provinces, namely Newfoundland, Nova Scotia, and British Columbia. We will conduct preliminary genetics analysis of biological samples collected through the registry, and we will also examine the effectiveness of neural stem cells in animal models of CP using models of placental insufficiency and perinatal stroke.

CP Project Achievements 2010-2011

- **Expansion of CP registry approved to include locations across Canada**
- **Published guide and fact sheet for patients and clinicians on stem cell research in CP**

Team Leads
Michael Shevell, McGill University
Jerome Yager, University of Alberta

FETAL ALCOHOL SPECTRUM DISORDER (FASD):

PRENATAL ALCOHOL EXPOSURE is a major, preventable cause of behavioural and cognitive deficits in children. Despite extensive research, a unique neurobehavioural profile for children affected by prenatal alcohol exposure remains elusive.

In the project that is underway, we will examine how genetic and environmental factors interact with gestational alcohol exposure to produce neurobehavioural and neurobiological deficits in children. The fetal alcohol spectrum disorders (FASD) project will address two primary objectives. First, we will identify genetic and epigenetic modifications induced by gestational alcohol exposure that may predict neurobehavioural and neurobiological dysfunctions in offspring. Second, we will determine the relationship between structural alterations in the brain induced by gestational alcohol exposure and functional outcomes in offspring.

Each child enrolled in the study will undergo a series of psychometric and eye movement tests, genetic and epigenetic screening, and structural and functional brain imaging. Established animal models will be used not only to confirm the role of candidate genes and epigenetic markers suggested by the human studies, but also to correlate these with neurobehavioural and imaging outcomes. By identifying genetic and epigenetic markers that are associated with neurobehavioural outcomes or structural brain injury, we will be positioned to develop biomarkers that predict how severely gestational alcohol exposure affects behavioural and cognitive deficits in children. This will profoundly impact our ability to identify children at risk.

During the fiscal year 2010–2011, we reached our goals in both the clinical and animal model studies. In the clinical study, we established standardized protocols for multi-site collection of eye movement and psychometric data, as well as biological materials for genetic and epigenetic analyses, and structural and functional brain imaging. We also identified six FASD diagnostic clinics in Ontario, Manitoba, Alberta, and British Columbia to participate in the study, and received approvals from the Research Ethics Boards for all test sites. Finally, we recruited 72 children to the study between the ages of 5 and 17 years old, and began collecting data for use in the study. In the animal models component of the study, we established mouse breeding colonies, which will be examined along different time points. We also completed behavioural and cognitive testing with the first rat cohort, with a subset tested for immunohistochemistry and epigenetics.

In the next year, we aim to build on these accomplishments. We plan to conclude primary data collection on the full cohort of children in the clinical study before the end of year two, which allows a full year for analysis and interpretation of the data. In addition, we expect to expand recruitment of children to the project, especially at our clinical sites in Alberta and British Columbia. From our animal model research, we will glean insights into the genetics of FASD susceptibility and will begin preliminary epigenetic analysis by the end of 2012. We are also excited to be part of a major new research collaboration between NeuroDevNet and GRAND Networks of Centres of Excellence, co-led by FASD investigator Dr. James Reynolds, which will investigate computer-based interventions for children with neurodevelopmental disorders.

FASD Project Achievements 2010-2011

- **Established standard protocols and procedures for multi-site data acquisition**
- **Led NeuroDevNet-GRAND research collaboration on computer-based interventions for children with neurodevelopmental disorders**

Team Leads
James Reynolds, Queen's University
Joanne Weinberg, University of British Columbia
Sterling Clarren, University of British Columbia

KNOWLEDGE TRANSLATION:

KNOWLEDGE TRANSLATION (KT) at NeuroDevNet focuses on the interface between knowledge creation and the application of the resulting innovations for the common good of the child. The objective of the KT core is to work together with investigators from across NeuroDevNet to share established and new knowledge about identification, treatment, and prevention of cerebral palsy, autism spectrum disorders, fetal alcohol spectrum disorders, and other neurological disorders, so that this knowledge can move into policy and practice, thus improving the lives of children and families across Canada.

The KT core's mission is to provide a knowledge translation service by meeting the KT needs of the projects and cores, and by assisting the development of KT capacity within network members. There are three primary strategies for achieving this mission. First, the KT core will take the lead in developing strategies that connect the network and its research to our external stakeholders through partnerships and communications platforms and materials. Second, we will work with NeuroDevNet's demonstration projects to develop products that translate complex scientific ideas to clinicians, the public, patients, and their families. Third, we will increase KT capacity throughout the network by facilitating training opportunities.

In the first year, one of the main objectives of the KT core was to conduct an environmental scan of members to determine their baseline KT activities and knowledge, to identify where capacity building should be focused,

and to establish priority activities for the KT core that best meet NeuroDevNet's needs. We conducted fourteen interviews with members from across Canada by October 2010, and completed coding and analysis of these discussions by March 2011.

Significant contributions have been made by the KT core to NeuroDevNet's 2010 and 2011 Brain Development Conferences. In 2010, the KT core helped develop and evaluate the cerebral palsy public forum. In preparation for the 2011 conference, The KT Manager chaired the scientific program committee, and helped develop an innovative and compelling program for the conference.

We have undertaken other knowledge translation activities, including participation in the FrameWorks Institute Workshops through the Norlien Foundation, and collaboration with FASD project researchers to develop a briefing note on light drinking in pregnancy. We also developed KT content for the NeuroDevNet website to build KT capacity throughout the network, and contributed to educational fact sheets for clinicians, patients, and families on stem cell research in cerebral palsy.

Moving forward, the KT core will continue to provide services to NeuroDevNet's demonstration projects. Planned activities include identifying, synthesizing, and sharing current and new knowledge, and best practices amongst projects and stakeholders.

KT Project Achievements 2010-2011

- **Conducted environmental scan of NeuroDevNet members to measure KT capacity**

Team Lead
Nazeem Muhajarine, University of Saskatchewan

RESEARCH

NEUROETHICS:

THE OVERARCHING GOAL of the Neuroethics core is to advance the understanding of ethical, social, legal, and policy challenges for children and families affected by autism spectrum disorders (ASD), cerebral palsy (CP), and fetal alcohol spectrum disorders (FASD), and to deliver responses and solutions to ethics challenges that arise in research designed to benefit these related communities.

Five strategic aims guide the Neuroethics core:
1. Ethics partnerships for NeuroDevNet researchers through research collaboration, training, and outreach
2. Encourage the early incorporation of ethics in all new NeuroDevNet project proposals, guidance and participation in research
3. Use of primary ethics research to create recommendations and guidelines for best practices, both locally for NeuroDevNet projects, and globally for research and translation in the three target neurodevelopmental areas
4. Work with NeuroDevNet communications staff and the Knowledge Translation core to develop appropriate health messages about neurodevelopmental disorders and NeuroDevNet research findings for the public
5. Facilitate partnerships between NeuroDevNet and media organizations to create opportunities for internships in science communication

In the past year, we have made significant progress in all key areas of our work: service, empirical research, grant submissions, publications, and outreach. We examined the extent to which advocacy websites for CP, FASD, and ASD inform stakeholders about treatment options, and identified the ethical challenges inherent in providing such information online. Based on our findings and

recommendations, we are developing guidelines on best practices for disseminating effective and high quality treatment information over the Internet to stakeholders. We completed our work examining the perspectives of adolescents and young adults with CP about the challenges that they face in accessing health care services, and look forward to publication of our findings shortly. We launched a study to examine media coverage of the Fragile X Syndrome, closely associated with ASD, within the treatment-enhancement debate.

We also actively participated in the annual scientific meeting this year by organizing and hosting symposia on ethics and genetics, on engaging with the press, and a special interactive event on science communication. In the coming year, we will also work with NeuroDevNet researchers to develop guidelines for best practices involving incidental findings, explore initiatives to work with Aboriginal communities, and will continue to publish articles on ethical issues related to health care for adolescents with CP, ethics in neonatal and antenatal decision-making, and pragmatic approaches to evaluating and studying ethics challenges in research on neurodevelopmental disorders.

Along every aspect of the NeuroDevNet-Neuroethics continuum, we enjoy collaboration and innovation with NeuroDevNet members, and pursue creative ways to disseminate results for the greatest impact and benefit of children with neurodevelopmental disorders and their families.

Neuroethics Project Achievements 2010-2011

- **Published three peer-review research articles (accepted and in-press)**

Team Leads
Judy Illes, University of British Columbia
Eric Racine, Université de Montréal

NEUROINFORMATICS:

THE NEUROINFORMATICS CORE helps researchers across the network to manage, standardize, and share their data, and helps implement innovative solutions that facilitate research.

Our mission is to serve the informatics needs of NeuroDevNet demonstration and core projects, and to perform informatics-based research that identifies relationships among neurodevelopmental disorders. To meet these goals, we are implementing informatics systems and software that allow researchers to manage data and information across sites. We provide resources in terms of personnel and infrastructure, work with project-specific informaticians in technology evaluation and software development practices, and coordinate efforts across sites. Our own research will include developing and applying informatics resources to analyze research data. One of our primary aims is to build on existing and new knowledge emerging from the network, and to increase our understanding of neurodevelopmental disorders and the relationships among them at the genetic and phenotypic level.

Over the last year, one of our major objectives was to fully assess the informatics needs and requirements across the NeuroDevNet network. We distributed a survey in June 2010, which identified better data management systems, more technical support, and more information on bioinformatics resources as immediate needs. Subsequently, we established working groups of about seven people for each project to ensure these requirements were met.
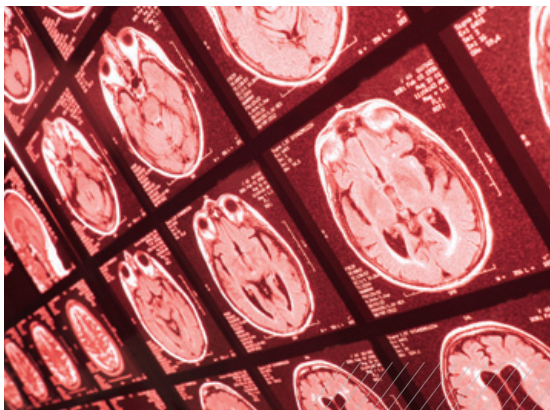
To improve data management across the network, we identified, customized, and implemented appropriate software to support NeuroDevNet's research efforts. Following an analysis of existing electronic systems, we selected and implemented the REDCap software to implement the CP registry, in partnership with WCHRI Clinical Research Informatics Centre. We also recognized the need for a network-wide file repository that would allow NeuroDevNet members to share large files in a secure system, and we selected and heavily customized the OWL intranet engine software for this purpose. In collaboration with the demonstration projects, we have begun populating our file repository with consent and information forms, ethics applications and policies, protocols and questionnaires. Other projects we have initiated include installing a confluence wiki system, and assisting in the development of NeuroDevNet's public website.

In year two, our predominant task will be to maintain and support all the NeuroDevNet resources that we have implemented. We will also customize the LORIS software for neuroimaging data management, in order to facilitate data sharing between research sites. We plan to complete installation of LORIS for each of the three demonstration projects by the end of 2011. In addition, we will launch a new informatics resource that integrates information on genes for the analysis and interpretation of neurodevelopmental data. We refer to this as the "candidate gene manager" (CGM) concept, which will enable the integration of information on genes with phenotypes, by using existing data and external resources, with a highly interactive component that leverages and enhances the research done in the network.

Neuroinformatics Project Achievements 2010-2011

- **Established informatics platforms to coordinate medical data collection and analysis across sites**

Team Leads
Paul Pavlidis, University of British Columbia
Alan Evans, McGill University

FINANCIAL STATEMENTS

NEURODEVELOPMENT NETWORK, INC.

Auditors' Report

**To the Directors of
Neurodevelopment Network, Inc.**

We have audited the accompanying financial statements of Neurodevelopment Network, Inc. (the "Network"), which comprise the statement of financial position as at March 31, 2011 and the statements of operations and fund balances and cash flows for the year then ended, and the related notes including a summary of significant accounting policies.

Management's responsibility for the financial statements
Management is responsible for the preparation and fair presentation of these financial statements in accordance with Canadian generally accepted accounting principles and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

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

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

Opinion
In our opinion, the financial statements present fairly, in all material respects, the financial position of the Network as at March 31, 2011 and the results of its operations and its cash flows for the year then ended in accordance with Canadian generally accepted accounting principles.

PricewaterhouseCoopers LLP

PricewaterhouseCoopers LLP
Chartered Accountants
Vancouver, British Columbia
June 22, 2011

NEURODEVELOPMENT NETWORK, INC.

Statement of Financial Position
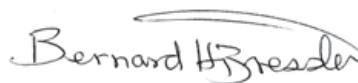
as at March 31, 2011	2011 $	2010 $
Assets		
Current Assets		
Cash held in trust by host institution	2,079,394	1,868,873
Cash held at bank	7,065	-
Accounts receivable	71,262	-
Unspent research grants paid to participating institutions	1,269,349	-
Prepaid expenses	10,714	-
	3,437,784	1,868,873
Equipment (note 3)	8,996	7,009
	3,446,780	1,875,882
Liabilities		
Current liabilities		
Accounts payable and accrued liabilities	228,419	113,644
Deferred contributions (note 4(a))	3,200,800	1,755,229
Deferred capital contributions (note 4(b))	8,996	7,009
	3,438,215	1,875,882
Unrestricted funds	8,565	-
	3,446,780	1,875,882

APPROVED BY THE BOARD OF DIRECTORS

_____
Henri Rothschild, Chair, Board of Directors

_____
Bernard Bressler, Member, Board of Directors

NEURODEVELOPMENT NETWORK, INC.

Statement of Operations and Fund Balances

	Year ended March 31, 2011	Dec. 9, 2009 to March 31, 2010
Revenue		
Grant from NCE (note 4(a))	2,766,443	191,627
Grant from other institutions (note 4(a))	7,500	-
Other sources of funds	12,426	-
Amortization of deferred capital contributions (note 4(b))	4,499	-
	2,790,868	191,627
Expenses		
Communications	30,922	1,667
Amortization	4,499	-
Insurance	3,312	-
Miscellaneous	740	-
Networking	81,615	35,647
Platform startup	2,954	26,969
Professional and consulting fees	144,544	12,547
Research and training (note 6)	1,910,017	-
Salaries and benefits	434,731	96,092
Supplies and office costs	44,651	2,691
Technology transfer	-	10,089
Travel and meetings	124,318	5,925
	2,782,303	191,627
Excess of revenue over expenses for the year	8,565	-
Unrestricted funds - Balance brought forward	-	-
Unrestricted funds - Balance carried forward	8,565	-

NEURODEVELOPMENT NETWORK, INC.

FINANCIAL

NEURODEVELOPMENT NETWORK, INC.

Statement of Cash Flows

	Year ended March 31, 2011	Dec. 9, 2009 to March 31, 2010
Cash flows from operating activities		
Excess of revenue over expenses for the year	8,565	-
Add: Non-cash items		
Amortization	4,499	-
Recognition of grant revenues	(2,773,943)	(191,627)
Amortization of deferred capital contributions	(4,499)	-
	(2,765,378)	(191,627)
Changes in non-cash working capital items		
Accounts receivable	(71,262)	-
Unspent research grants paid to participating institutions	(1,269,349)	-
Prepaid expenses	(10,714)	-
Accounts payable and accrued liabilities	114,775	113,644
Deferred contributions received	4,226,000	1,953,865
	2,989,450	2,067,509
	224,072	1,875,882
Cash flows from investing activities		
Equipment acquired	(6,486)	(7,009)
Increase in cash	217,586	1,868,873
Cash - Beginning of year	1,868,873	-
Cash - End of year	2,086,459	1,868,873

1. NATURE OF OPERATIONS

Neurodevelopment Network, Inc. ("NeuroDevNet" or the "Network") is a not-for-profit program under the Networks of Centres of Excellence ("NCE") that began operations on December 9, 2009. NeuroDevNet was formally incorporated under Part II of the Canada Corporations Act. NeuroDevNet 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.

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.

Grants from the NCE Network

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

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

The annual contributions will be released subject to:

Parliamentary appropriation of the funds in each fiscal period

Satisfactory progress, as determined by the NCE Secretariat, towards predetermined milestones for the NCE Network

Continuing eligibility of the NCE Network Host and the NCE Network, and

Compliance with the terms of the funding agreement.

Funding of $4,156,000 has been received for fiscal year 2010–2011. This amount has been reflected in these financial statements.

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.

1. NATURE OF OPERATIONS continued

Grant from Host Institution

In December 2009, the Host Institution Agreement was signed between NeuroDevNet and UBC. The agreement provides a cash grant as well as in-kind support. Gifts in kind are not recorded in the financial statements and include legal service coordination; payroll, purchasing, and grant management; and management of intellectual property, IT support and web hosting services.

2. SIGNIFICANT ACCOUNTING POLICIES

These financial statements have been prepared on the basis of Canadian generally accepted accounting principles ("GAAP") for non-profit organizations. NeuroDevNet follows the deferral method of accounting for contributions. Significant policies include the following:

Cash - Held in trust by the host institution

Based on the funding agreement between NeuroDevNet and the NCE, the grant funds are to be administered by the host institution, UBC. In addition, NeuroDevNet has a bank account to hold any unrestricted funds.

Unspent research grants paid to participating institutions

Research grants paid to the participating institutions are deferred on the statement of financial position and when the participating institution incurs costs, they are recognized as an expense. These amounts reflect the unspent portion of grants paid.

Revenue Recognition

Under the terms of the NCE agreement, the funding received will be directed to the granting of awards to the Network's participating institutions and the payment of NeuroDevNet's operating and capital expenditures. When received, the restricted contribution is deferred and recognized as revenue in the period in which the related expenses are incurred by NeuroDevNet or the participating institution. Restricted contributions applied toward the purchase of furniture and equipment are deferred and amortized to revenue on a straight-line basis at a rate corresponding with the amortization rate of the related furniture and equipment. Unrestricted contributions are recognized as revenue in the current period if the amount to be received can be reasonably estimated and collection is reasonably assured.

Financial Instruments

The Network has adopted the provisions of Section 3855, *Financial Instruments – Recognition and Measurement,* and Section 3861, *Financial Instruments – Disclosure and Presentation,* of the Canadian Institute of Chartered Accountants ("CICA") Handbook, as they apply to not-for-profit organizations.

The standards require that all financial assets and liabilities be measured at fair value with the exception of investments held to maturity, loans and receivables, and other liabilities that are measured at amortized cost using the effective interest rate method. Cash, accounts receivable and accounts payable and accrued liabilities are measured at amortized cost. As at March 31, 2011, the recorded amounts approximate fair values.

2. SIGNIFICANT ACCOUNTING POLICIES continued

Equipment

Equipment is recorded at cost and amortized on a straight-line basis over its estimated useful life as follows:

Computers   3 years

Use of Estimates

The preparation of financial statements requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those reported. Items requiring the use of management estimates include useful lives of equipment.

Employee future benefits

NeuroDevNet staff is 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 expenses contributions to this plan 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 made during the year were $25,547 (2010 - Nil).

3. EQUIPMENT

	Cost $	Accumulated amortization $	2011 Net book value $	2010 Net book value $
Computers	13,495	4,499	8,996	7,009

4. DEFERRED CONTRIBUTIONS

Deferred contributions represent unspent grants for operating expenses and capital purposes.

a) Deferred contributions relating to expenses of future periods

	2011 $	2010 $
Balance - Beginning of year	1,755,229	-
Contributions received during the year		
Grant from CIHR	3,453,500	28,500
Grant from NSERC	302,500	733,865
Grant from SSHRC	400,000	1,151,500
Grant from Host Institution	20,000	40,000
Grant from Others	50,000	-
	5,981,229	1,953,865
Amounts recognized as revenue during the year	(2,773,943)	(191,627)
Amounts applied toward furniture and equipment purchased during the year	(6,486)	(7,009)
Balance - End of year	3,200,800	1,755,229

b) Deferred capital contributions relating to equipment

	2011 $	2010 $
Balance - Beginning of year	7,009	-
Allocation of deferred contributions (note 4(a))	6,486	7,009
Amounts amortized to revenue	(4,499)	-
Balance - End of year	8,996	7,009

5. RELATED PARTY TRANSACTIONS AND ECONOMIC DEPENDENCE

Effective December 9, 2009, NeuroDevNet was awarded a grant of $19,572,000 under the NCE program funded by NSERC, SSHRC and CIHR in accordance with the terms and conditions of the funding agreement. The amounts received from these granting agencies represent a significant portion of funds received by NeuroDevNet and have been disclosed in note 4.

6. EXPENSES

NeuroDevNet advances funds to researchers at their host institutions. Funds are held in trust by the institutions and as expenses are incurred they are expensed by NeuroDevNet. During 2011, the expenses for research and training totalled $1,910,017 including $1,716,189 of expenses incurred from funds transferred to institutions for research. An additional $193,828 of expenses was incurred and expensed by the administrative centre for miscellaneous research and training programs.

	Balance April 1, 2010 $	Current Year Grant $	Current Year Expenditure $	Balance March 31, 2011 $
Institution – Master grants				
Holland Bloorview	-	111,750	17,794	93,956
Hospital for Sick Children	-	694,250	609,000	85,250
IWK Health Centre	-	31,000	11,466	19,534
McGill University	-	476,000	107,317	368,683
McMaster University	-	26,500	15,500	11,000
Montreal Heart Institute	-	50,000	50,000	-
Queen's University	-	182,000	137,402	44,598
University Health Network	-	106,000	65,785	40,215
University of Alberta	-	293,334	110,285	183,049
University of British Columbia	-	680,328	439,577	240,751
University of Calgary	-	37,500	4,343	33,157
University of Montreal	-	63,626	47,623	16,003
University of Saskatchewan	-	166,000	76,597	89,403
University of the Fraser Valley	-	18,750	-	18,750
University of Victoria	-	25,000	-	25,000
	0	2,962,038	1,692,689	1,269,349
Other research and training			217,328	
Total research and training			1,910,017	

7. 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 4. 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.

8. FINANCIAL RISK

NeuroDevNet is not exposed to significant credit, interest rate or currency risk.

PARTNERS

Our partnerships with industry, government, and not-for-profit organizations will help us translate research to inform basic science and affect clinical outcomes.

Network Members

Dalhousie University
Holland Bloorview Kids Rehabilitation Hospital
Institut de recherches cliniques de Montréal
IWK Health Centre Foundation
McMaster University
Montreal Heart Institute
Queen's University
Simon Fraser University
The Hospital for Sick Children
University Health Network (Ontario)
University of Alberta
University of British Columbia
University of Calgary
University of the Fraser Valley
University of Lethbridge
University of Manitoba
University of Montreal
University of Saskatchewan
University of Toronto
University of Victoria
University of Western Ontario
York University

Network Affiliates

Norlien Foundation

Universities

Canadian Centre for Behavioural Neuroscience
CANChild
Croatian Institute for Brain Research
Laval University
Manitoba Institute of Child Health
McGill University
Memorial University
San Diego State University
Sherbrooke University
SickKids Research Institute
The Hotchkiss Brain Institute
University of California
University of Ottawa
University of Pittsburgh
University of Zagreb
Vancouver Coastal Health Research Institute
Vanderbilt University
Sainte Justine University Hospital Centre
Zilka Neurogenetic Institute

Industry

Avid Radiopharmaceuticals Inc.
Bennet Jones, LLP
Cerner Corporation
Global Health Systems
Mercer Investments Ltd.
Peter Morand & Associates
Sangamo BioScience Inc.
The Vancouver Sun
WowWee Holdings Inc.

Government Agencies

Alberta Health Services
Alberta Innovates - Health Solutions
Canadian Institutes of Health Research (CIHR)
Michael Smith Foundation for Health Research
Networks of Centres of Excellence
National Institute of Mental Health (US)
National Research Council - Institute for
    Biodiagnostics (Atlantic)
National Sciences Engineering Research Council of
    Canada-Collaborative Research and Training
    Experience Program (NSERC-CREATE)

Not-for-profit organizations

BC Women's and Children's Hospital
Autism Community Training
Canadian Bioinformatics Workshop Series
Canadian Child Health Clinician Scientist Program
CanAssist
Graphics, Animation and New Media (GRAND) NCE
International Science and Technology Partnerships
    Canada (ISTP Canada)
Kennedy Krieger Institute
Maternal Infant Child and Youth Research Network
Mitacs
Montreal Children's Hospital
PrioNet NCE
SAMHSA FASD Centre for Excellence
Warneford Hospital

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Tim Oberlander
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Moshe Szyf
Derek van der Kooy
Daniel Weeks
Janet Werker
Ian Wishaw

Scientific Director, Daniel Goldowitz

Associate Scientific Director, Michael Fehlings

Executive Director, Nicola Lewis

Board of Directors

Henri Rothschild, Chair, NeuroDevNet Board of Directors, President and Chief Executive Officer, International Science and Technology Partnerships Canada

Peter Allen, Vice-Chair, NeuroDevNet Board of Directors, President, Mercator Investments Ltd.

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Gary Wechsler, Chief Financial Officer, WowWee Holdings Inc.

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Samuel Weiss, Chair, NeuroDevNet Scientific Advisory Board, Professor, University of Calgary

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Bernie Devlin, Professor, University of Pittsburgh

Jay Giedd, Principal Investigator National Institute of Mental Health

Neal Halfon, Professor, University of California

Mark Hoffman, Vice President Life Sciences, Cerner Corporation

Michael Johnston, Senior Vice President and Chief Medical Officer, Kennedy Krieger Institute

Ivica Kostovic, Professor, University of Zagreb

Pat Levitt, Professor, University of Southern California

Edward P. Riley, Professor, San Diego State University

Research Management Committee

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Evdokia Anagnostou, Assistant Professor, University of Toronto

Mark Bieda, Assistant Professor, University of Calgary

James Brien, Professor, Queen's University

Ryan D'Arcy, Group Leader, NRC-Institute for Biodiagnostics (Atlantic)

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FROM HOPE TO DISCOVERY

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