

MICYRN - RRSEM

maternal infant
child & youth
research network



réseau de recherche
en santé des
enfants et des mères

Newsletter

FALL/WINTER 2011

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MICYRN GOVERNANCE

MICYRN incorporated as a federal not-for-profit society in January 2011. This process helped define the membership of MICYRN, and set official bylaws by which MICYRN is governed. The inaugural member “owners” of MICYRN are the research organizations which had founded MICYRN in 2006. These research organizations control resources, shape research directions, and hold relationships with their respective Foundations and Health Centers. MICYRN’s ability to achieve the vision of *“synergistic strength gained from formal collaborative networks of investigators and integrated infrastructure spurs tremendous advances unattainable by individual groups working in isolation”* depends upon the strong continued collaboration amongst these organizations. Each organization has named a voting representative, as follows: CFRI (Vancouver), Dr. Jan Friedman; WCRI (Calgary), Dr. Brent Scott; WCHRI (Edmonton), Dr. Sandy Davidge; Saskatchewan University, Dr. Alan Rosenberg; MICH (Winnipeg), Dr. Terry Klassen; LHSC (London), Dr. Victor Han; Laurentian University (Sudbury), Dr. Nancy Young; McMaster University (Hamilton), Dr. Stephanie Atkinson; Sick Kids (Toronto), Dr. Janet Rossant; Queen’s University (Kingston), Dr. Michael Flavin; CHEO (Ottawa), Dr. Martin Osmond; Université Laval, Dr. Isabelle Marc; CHU Sainte Justine (Montréal), Dr. Guy Rouleau; MUHC (Montréal), Dr. Robert Brouillette; Université Sherbrooke, Dr. Guillaume Sébire; IWK (Halifax), Dr. Patrick McGrath; Memorial University (St. John’s, NFLD), Dr. Roger Chafe. On October 13th, 2011, the inaugural Annual General Meeting of MICYRN was held and the member- voting representatives elected their first Board of Directors. Dr. Aubrey Tingle resigned from his position as Associate Director of MICYRN and was elected to Chair the Board. The Board of Directors are Dr. Stephanie Atkinson (Vice-Chair), Dr. Alan Bocking (Toronto, Mt Sinai), Dr. Roger Chaff, Dr. Victor Han, Dr. Terry Klassen, Dr. Guy Rouleau, and Dr. Brent Scott.

A brief Board meeting was held on October 13th to conduct required business. A planning retreat of the Board is being held February 19-20th, 2012. In preparation for the retreat, a survey is underway for the members to provide input into strategic directions for MICYRN. The next Annual General Meeting is scheduled for Spring 2012.

MICYRN STRATEGIC INITIATIVES: ETHICS

Excellent progress has been made towards reducing the need for full Ethics Board review at every site involved in a multi-center study at the MICYRN-affiliated organizations. A novel approach proposes a Canadian national federated (=joint) Research Ethics Board (REB) be comprised of the Chairs and other members from the MICYRN-affiliated REBs, such that all necessary local jurisdictional issues could be brought to bear in a ‘central’ deliberation. This model respects the legislation governing REB in Quebec, Alberta and Newfoundland, as the federated committee would not replace local REBs who will retain responsibility to release certificates of authority. If a site Chair has the authority to expedite applications they/their delegate had approved at the federated REB, repeat full board reviews could be reduced. The federated approach offers strong potential to improve the quality and harmonization of ethics review in Canada, particularly for rare and complex conditions where there is limited expertise at each center. A survey is underway to get an idea of the expected workload for the federated REB. To date, 20 research networks have responded on plans to conduct a total of 42 multi-center studies in 2012. Given the number of sites involved with each study, a total of 318 REB reviews would be conducted in the current system. Nine of the networks have indicated interest in working with MICYRN on testing and evaluation of the federated REB which will launch in Spring 2012. This work has been supported in part through 2 CIHR Meeting Planning & Dissemination grants. More information about the process is on the website (www.micyrn.ca) under Reports.

MICYRN STRATEGIC INITIATIVES: DATA MANAGEMENT

To meet the strongly expressed need for support of research data management (DM), MICYRN is coordinating the installation and support for REDCap (Research Electronic Data Capture) software across MICYRN organizations. REDCap was designed for 'small and medium-sized' studies, and is a validated, user-friendly program that allows investigators to meet standards for electronic research data capture. The REDCap program continues to undergo improvement by the developer Bioinformatics group at the University of Vanderbilt, and a now-international Consortium of users. Research study forms can be stored in a REDCap Library, reducing design and programming time, and offering great potential for standardization. Not all research needs are met by REDCap and priorities for the next 'plank' in the platform will be developed by MICYRN's Data Management Core which is led by Dr. Lawrence Richer based at WCHRI (Edmonton). A working group now includes people from CFRI/Vancouver (Victor Espinosa, Ricardo Gamero, Ashley McKerrow), WCHRI/Edmonton (Rick Watts, Pam Marples), MICH/Winnipeg (Steve Nesbitt), McMaster (Lehana Thaban), CHEO/Ottawa (Liza Bialy), Sick Kids/Toronto (Rulan Parekh, Chris Battiston, Wayne Arnold), Ste Justine/Montréal (Benoit Masse, Jacques Lacroix) and IWK/Halifax (Marjorie Sullivan) This group will next meet June 1st, 2012 in Calgary, in conjunction with the MICYRN, CCHCSP and CCCHR meetings.

MICYRN STRATEGIC INITIATIVES: QUALITY MANAGEMENT SYSTEMS

Quality Management Systems (QMS) direct and control an organization with regard to quality, and cover the required organizational structure, procedures, processes, responsibilities and resources. With heightened attention to patient safety there has been much attention to implementation of QMS in health care organizations, but little if no support for this in research organizations which also have a responsibility to ensure the integrity of data generated from research studies. Quality assurance and quality control systems with written policies and procedures (SOPs) need to be developed and maintained. MICYRN proposes a quality initiative with three steps: Institutional assessment (elective); provision of written Quality Management System templates with accompanying SOPs, forms and basic QMS training modules; and collaboration on a Quality Systems Development Plan. CFRI in Vancouver commissioned a Quality Audit in Spring 2011, and is now developing QMS templates which will be made available to the other MICYRN organizations. A questionnaire under development will help guide discussion at each organization as to gap between systems that are in place versus required.

MICYRN's Executive Director



We are pleased to announce that Stephen Barbazuk has joined MICYRN as Executive Director, effective January 3rd, 2012. Stephen will be responsible for the strategic planning process and the subsequent development, implementation and evaluation of all projects and activities. In addition, he will have management responsibility for the coordination and oversight of all communication and administrative functions in the central office of the Network.

Prior to joining MICYRN, Stephen served as Corporate Director, Strategic Planning and Transformation Support at the BC Provincial Health Services Authority where his most recent accomplishment was in leading the strategic plan implementation across all of PHSA's Agencies and Services. Stephen also has experience in the Life Sciences Industry having held a variety of project management roles in both private biotechnology and public research organizations, most notably with the BC Cancer Agency's Michael Smith Genome Sciences Centre where he managed the Bioinformatics Platform, a research-enabling service providing computational research expertise for large-scale genetic sequencing projects of combined budgets totaling more than \$10M.

Stephen has a background in Life Sciences, having graduated from the University of British Columbia in Cell and Developmental Biology with subsequent work in Immunology research projects for the Department of Microbiology & Immunology and has since amassed expertise in strategic planning and project management in biotechnology, research and healthcare over the past 15 years. He is a certified Project Management Professional (PMP) with the Project Management Institute, holds a 6-Sigma Green Belt process improvement certificate and is currently pursuing his International Coaching Certification in order to apply additional skills to support organizations in realizing their vision.

Stephen brings experience and a proven track record of success in strengthening the link between strategy and project implementation by improving the way the organization selects, prioritizes, initiates and manages projects across the organization, which will be invaluable in enabling the goals and objectives of MICYRN. We are confident that Stephen is an excellent match for this role and will be a strong asset to MICYRN and as a member of the Executive team.

Congratulations go to a number of teams and networks led by investigators from MICYRN organizations that were successful in receiving funding in the past 6 months. These teams draw attention to the amount of research collaboration across Canada.

A **CIHR Catalyst Grant for Maternal Health: From Pre-Conception to the Empty Nest** to Dr. Peter von Dadelszen (CFRI/Vancouver) and co-investigators Mark Ansermino, Geoff Cundiff, Myrtle Douglas, Stephen Lapinsky, Shoo Lee, Laura Magee, Steven Reynolds, James Russell, Percival Seaward, Keith Walley, and Paul Yong. This team plans to validate clinical prediction models that aim for early identification of pregnant/postpartum women at risk for becoming critically unwell.

A **CIHR Emerging Team Grant in Maternal Health: From Pre-conception to the Empty Nest** to Principal Investigator(s): KS Joseph, Rob Liston, and Laura Magee (CFRI/Vancouver) and Co-Investigators Victoria Allen, Mark Ansermino, Francois Audibert, Jon Barrett, Rollin Brant, Emmanuel Bujold, George Carson, Eliana Castillo, Joan Crane, Nestor Demianczuk, Myrtle Douglas, Robert Gagnon, Robert Gratton, Jennifer Hutcheon, Sarah McDonald, Olufemi Olatunbosun, Evelyne Rey, Graeme Smith, Peter Von Dadelszen, Mark Walker, Wendy Whittle, and Steve Wood on **Preventing Severe Maternal Morbidity** proposes to carry out detailed clinical and epidemiologic investigations of severe maternal illnesses in order to improve maternal health and build a stimulating research training environment for students. Knowledge translation activities will be carried out along with external partners such as the Public Health Agency of Canada and the Society of Obstetricians and Gynecologists of Canada.

Two awards came from the **Canadian Networks of Centres of Excellence Knowledge Mobilization (NCE-KM)** initiative which supports networking and collaboration among well-established research teams and receptor communities to further the application and mobilization of knowledge. The NCE-KM initiative is intended to support national multidisciplinary, multi-sectoral networks in applying and mobilizing the results of world-class research. The impacts of the network must be of social, health-related and/or economic benefit to Canadians. Led by Dr. Michael Ungar (Dalhousie University, Halifax) the **Children and Youth in Challenging Contexts** plans to inform the design and implementation of diverse health and social services, and the broader changes in social policy and institutions necessary to nurture the well-being of children and youth who are trapped in challenging circumstances. Led by Dr. Terry Klassen (Manitoba University, Winnipeg) the **Translating Emergency Knowledge for Kids (TREKK)** focuses on ensuring that the latest research in pediatric emergency medicine is applied within general emergency departments.

Four new **Team Grants** were awarded by the CIHR Institute of Cancer Research in collaboration with the Cancer Research Society, C17, and the Canadian Partnerships for Tomorrow Project to study the late effects of treatment in Childhood Cancer with the overall objective to modify, prevent or mitigate biologic late effects.

From Sick Kids/Toronto Principal Investigator(s) Shinya Ito, Sharon Guger, Johann Hitzler, Deborah O'Connor, Russell Schachar, Brenda Spiegler, and Rosanna Weksberg, with Co-Investigator Bruce Carleton (CFRI/Vancouver) will study **Neurocognitive-Phenome, Genome, Epigenome and Nutriome In Childhood leukemia Survivors: N-PhenoGENICS**.

From Sick Kids/Toronto Principal Investigator(s) Paul Nathan, Paul Kantor, Peter Liu, Luc Mertens, and Seema Mital, with Co-Investigators from Vancouver, McMaster, London, Ottawa and Montreal Ron Barr, Rejane Dillenburg, Marie-Pierre Dubé, Mark Greenberg, David Hodgson, Jane Loughheed, Karen Mandel, Cedric Manlhiot, Bruce McManus, Michael Phillips, Herschel Rosenberg, George Sandor, Stephen Scherer, and Shayna Zelcer will study **Novel approaches to the prediction, diagnosis and treatment of cardiac late effects in survivors of childhood cancer**.

From CFRI/Vancouver, Sick Kids/Toronto and MUHC/Montréal Principal Investigator(s): Kirk Schultz, Sylvain Baruchel, Mary McBride, Lesley Mitchell, Rod Rassekh, Ross Tsuyuki, and Michele Zappitelli, with Co-Investigators Tom Blydt-Hansen, Leonardo Brandao, Raewyn Broady, Bruce Carleton, Geoff Cuvelier, Michael Hayden, Agnes Lee, Maury Pinsk, Colin Ross, and Maria Spavor will be **Applying Biomarkers to Long-term Effects in Child and Adolescent Cancer Treatment (ABLE Team)**.

From Hôpital Sainte-Justine/Montreal Principal Investigator(s) Daniel Sinnett, Nathalie Alos, Gregor Andelfinger, Maja Krajinovic, Caroline Laverdière, Emile Levy and Philippe Robaey, with Co-Investigators Guillaume Bourque, Daniel Curnier, Alan Evans, Matthias Friedrich, Jean-Marc Lina, Sarah Lippé, Valerie Marcil, Sophie Marcoux, Benoit Masse, Frank Rauch, and Chantal Seguin will study **Genomic Determinants of Common Long-Term Treatment Effects in Childhood Acute Lymphoblastic Leukemia Survivors**.

A **Meeting Planning and Dissemination Grant** to Dr. Geoff Ball (WCHRI/Edmonton) and co-investigators Kathryn Ambler, Jean Pierre Chanoine, Katherine Morrison, Ximena Ramos Salas, and Arya Sharma of the **Canadian Obesity Network**, to hold a "Pediatric Weight Management in Focus" workshop designed to provide a hands-on approach to assessing and managing obesity in children, youth and families for up to 70 Canadian primary care practitioners.

EVENTS



The Early Years Conference 2012. The Development of Children's Mental Health: How Do We Become Who We Are? **February 3-4th** 2012. Hyatt Regency, Vancouver
http://www.interprofessional.ubc.ca/Brochures/Brochure_EarlyYears2012.pdf



Fifth National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder: It's a Matter of Justice **April 18-21st**, 2012 Hyatt Regency Hotel, Vancouver
http://www.interprofessional.ubc.ca/AdultsWithFASD/AdultswFASD2012_Brochure.pdf



Child and Youth Mental Health Matters - Three Conferences in One: First National Family Mental Health Conference, First International Young Carers Congress, and Third International World Congress on Children of Parents with Mental Illness **May 6-8th**, 2012. The Coast Plaza Hotel and Suites, Vancouver
<http://www.interprofessional.ubc.ca/CYMHM/brochure.pdf>



International StaR SUMMIT 2012 *Bridge to Better Therapies* (**May 7-8th**) followed by the Cochrane Canada Symposium 2012 *Health Evidence for ALL* (**May 9-10th**). StaR Child Health (Standards for Research in Child Health) is a group of methodologists, clinicians and policy makers who seek to enhance the quality, ethics and reliability of pediatric clinical research by promoting the use of evidence-based standards or guidance for clinical studies with children. Fairmont, Winnipeg <http://star.proreg.ca/index.php>



89th Canadian Paediatric Society Annual Conference. **June 6-9th**, 2012. London, Ontario <http://www.cps.ca/English/annualconference/2012/Highlights.asp>

News about MICYRN Partners

Dr. Anne Junker, Scientific Director of MICYRN, has been elected co-Chair of the Canadian Child & Youth Health Coalition (CCYHC) (effective October 16, 2011). She joins continuing co-Chair Dr. Sarah Jones, Head, Department of Pediatrics, Queen's University and Program Medical Director, Pediatrics, Kingston General Hospital and Hôtel Dieu Hospital. In July 2011, the CCYHC Steering Committee held a productive retreat in Toronto to revisit the mandate and goals of the Coalition and to identify specific and feasible strategic directions for implementation going forward. Each of the 11 member organizations of the Coalition holds distinct mandates, but share many common goals and objectives. A collective goal of the CCYHC is to advocate on behalf of national child and youth health and healthcare, and to this end, a special Health Accord working group has formed, co-chaired by Dr. Junker and Dr. Jonathan Kronick. To read more on the Coalition members and initiatives, see www.ccyhc.org

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*Building capacity for high quality clinical
 research in Canada and beyond*

The Maternal Infant Child Youth Research Network (MICYRN) was formed in 2006 to build capacity for high quality clinical research in Canada and beyond. MICYRN links 17 participating academic health centers, and hundreds of investigation teams across the country.

MICYRN is committed to enhancing the productivity of the Canadian child-maternal research community, through sustaining and augmenting existing activities, and reducing impediments to multicentre research activity.

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