

# MICYRN Network News

## Newsletter 7

maternal infant  
child & youth  
research network



## Winter 2009

réseau de recherche  
en santé des  
enfants et des mères

### MICYRN News

MICYRN Directors Dr. Anne Junker and Dr. Aubrey Tingle were very pleased to be able to participate in meetings associated with the CAPHC Conference in Halifax this past October. In it's first phase MICYRN has been a 'virtual' network. The new directors proposed a shift, which was unanimously endorsed by the Council for Canadian Child Health Research, and the Canadian Children's Hospital Foundation executives, to firmly associate MICYRN with the participating academic health centres across the country. A MICYRN presence at sites will help Foundations raise awareness of MICYRN's agenda with donors. The importance of secure funding for core staff, who provide support for clinical research activities and national networks, is recognized. In a 'hub-and-spoke' model, the directors propose to fund "MICYRN Correspondents" who will help in the relay of information from the MICYRN Coordinating Centre, and between sites.

### Congratulations!

Congratulations to NeuroDevNet led by Dr. Daniel Goldowitz (CMMT/CFRI, Vancouver) whose team has been awarded \$19.5 million in funding over five years from the Networks of Centres of Excellence of Canada. NeuroDevNet plans to begin with research projects focused on the genetic and environmental causes of cerebral palsy, autism spectrum disorders and fetal alcohol spectrum disorders. Better understanding of brain development in children, will lead to improved diagnosis, treatments, and interventions that will inform care delivery and policy decisions. MICYRN was happy to write a letter of support for NeuroDevNet, and will continue to volunteer support and guidance through the exciting years to come.

*MICYRN' s Vision: A cohesive national network that facilitates maternal-child*

## MICYRN hosts the Canadian Birth Cohorts Registry

Work begun by MICYRN has culminated in a national Birth Cohorts Registry which holds extensive detail regarding some 50 Canadian birth cohort studies involving around 40,000 pregnancies. The Canadian Institutes of Health Research (CIHR), in partnership with the Maternal, Infant, Child and Youth Research Network (MICYRN) and the Strategic Knowledge Cluster on Early Childhood Development (SKC-ECD), compiled an Inventory of Pregnancy and Birth Cohort studies in Canada. The inventory lists Canadian cohort studies that are completed, ongoing, or in development. It provides detailed information on the content and design of such studies, and compares features amongst studies to facilitate both national and international comparisons. This initial version provides information on over 45 studies.

**From the CIHR website:** "Pregnancy and birth cohort studies are fundamental research tools to monitor children's health and development and to link prenatal and early postnatal exposures to long-term outcomes. The longitudinal perspective of these

studies allows firmer causal inferences about the relationship between environmental and genetic factors to which children have been exposed and their subsequent outcomes."

Based in an Excel format, the inventory offers multiple spreadsheets of information covering content ranging from study title and investigator to much more complex information such as bio-genetic samples taken, social and physical environment, and descriptive categories of study design. Where available, birth, child, and maternal outcomes are also listed.

The link to the CIHR webpage that provides greater detail on the Inventory of Pregnancy and Birth Cohort Studies can be found here:

<http://www.cihr-irsc.gc.ca/e/40753.html>

The Inventory of Pregnancy and Birth Cohort Studies are posted on the MICYRN website:<http://www.micyrn.ca/cores/research-partnership-core.html>

### Data Management Core Update

The MICYRN Data Management Core is chaired by Dr. Lawrence Richer in Edmonton, Alberta, at the Women's and Children's Health Research Institute (WCHRI) at the University of Alberta/Stollery Children's Hospital. WCHRI and the BC Child and Family Research Institute (CFRI) have been testing different data management software systems. In November the WCHRI and CFRI data management groups met by videoconference to discuss their experiences with systems including the Montreal-

based Dacima; Open Clinica; and Vanderbilt-originated Redcap that have been trialed for use in clinical trials and research studies. The full report on the meeting is available on the MICYRN website: <http://www.micyrn.ca/cores/data-management-core.html>

You are invited to contact Lawrence for advice on your data management needs: [lawrencericher@albertahealthservices.ca](mailto:lawrencericher@albertahealthservices.ca)

### New Reports Published

MICYRN groups have been busy this past fall and as a result published reports on their activities are now available on the MICYRN website. The Training Core undertook an environmental scan with the assistance of Kathy O'Leary, RN, to provide a greater understanding of the current roles of research coordinators in the maternal and pediatric research fields and to discuss and investigate their unique training needs. <http://www.micyrn.ca/cores/training.html>

The newly formed Pediatric Anesthesia Investigators Network of Canada (PINC) has published a report following their successful meeting in November 2009. This meeting was funded by a competitive seed grant provided by MICYRN to support the initial meeting of a group in the creation of a new collaborative research network. Congratulations to the PINC team for all your hard work and success to date! <http://www.micyrn.ca/news.html>

## Moving ahead with MICYRN in 2010

The MICYRN Coordinating Centre has continued to work on the "value proposition" MICYRN brings to maternal-child researchers across Canada. In order to move forward on an expedited timeline, the MICYRN directorship were supported by the CCCHR to create an ad-hoc executive committee to clarify objectives and develop action plans. Nominees were sought at the annual CCCHR meeting in Halifax in October 2009, and led to naming of Brent Scott (Calgary), Alan Rosenberg (Saskatoon), David Malkin (Toronto), Martin Osmond (Ottawa), Bill Fraser (Montreal), and Pat McGrath (Halifax).

This group met in Ottawa in December 2009. Thanks to their hard work, the MICYRN Coordinating Centre was able to emerge with a clearer picture of what needs to be done in the next few months as well as over the coming years to position ourselves as a group that can be of service in the most effective ways possible to those on the front lines of research. Business planning is underway, in line for budget discussions with the Institutes and Foundations.

MICYRN's leadership proposes a reshaping of MICYRN's framework to 4 cores (Training & Professional

Development, Research Ethics & Regulatory Affairs, Data Management (wet and dry), and Relationships), with institution of 3 cross-cutting research activity themes (Cohorts, Trials, and Health Services Delivery). It was felt that work related to Research Methods and KT could develop in respect to the research activity themes. Renovations of the MICYRN website will include searchable databases of networks, researchers, and research resources available in Canada. We would also like to include a "toolbox" of templates and guidelines covering a variety of topics.

MICYRN's Coordinating Center has continued working to support new networks in their "start-up" periods, offering support with meeting scheduling, planning of tele/video-conferences, and the creation and execution of surveys for those groups who require an environmental scan to focus their efforts.

Jennifer Zander has been working with the Pediatric Inflammatory Bowel Disease (IBD) Group and the Urology Research Network Group, and looks forward to beginning work with the Pediatric Anesthesia Investigators Network of Canada (PINC) and the Pediatric Orthopaedics Research Group this January.

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☆☆ Anne and Aubrey are sorry to announce that Jennifer ☆  
☆☆ will be leaving MICYRN for a great opportunity with the ☆  
☆☆ Rick Hanson Foundation. We thank Jennifer for all her ☆  
☆☆ work to arrange MICYRN's transition from Edmonton to ☆  
☆☆ Vancouver. ☆  
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