



MICYRN Year-end Report 2010

Founded in 2006 MICYRN brings together the 17 Canadian academic child/child-maternal health centers and research institutes into a multi-disciplinary national initiative that is supported by the Children's Hospital Foundations of Canada. With administrative offices based at the Child & Family Research Institute in Vancouver since April 2009, MICYRN is led by Drs. Anne Junker (Director) and Aubrey Tingle (Associate Director)

VISION

The synergistic strength gained from formal collaborative networks of investigators and integrated infrastructure spurs tremendous advances unattainable by individual groups working in isolation

MISSION

To foster and enhance national and international collaborations by removing barriers and building capacity for the conduct of high quality health research

The following report summarizes MICYRN activities and plans developed over the past year.

Communication

MICYRN has developed a communication list with ~900 recipients to whom newsletters are sent quarterly. The e-list also serves to forward time-sensitive notices from networks and organizations that are affiliated with MICYRN. Reports, announcements, and notices of events are also viewable on the MICYRN website. This past year, MICYRN was able to pass along several unique announcements:

1. Funding opportunities from networks affiliated with MICYRN
 - a. NeuroDevNet Network Centres of Excellence – 9 proposals funded
 - b. Rare Diseases Foundation – 19 proposals funded
2. Webinar hosted by the National Infant Child Youth Mental Health Consortium and CIHR to discuss upcoming research opportunities in Mental Health Services for children & youth
3. A call for rare/unusual patient cohorts by the Canadian Pediatric Genetic Disorders Sequencing Consortium – 120 responses in 3 weeks
4. A call for nominations to the Young Investigator Award from the Canadian Pediatric Society

Consultation

MICYRN has gained prominence as a Canadian national 'voice' for maternal-child health research. This year MICYRN responded to a number of invitations and contributed to national and international

discussions on key issues, which could shape research strategies, commitment of resources, and lead to changes in policy. Meetings included:

1. Canadian Institutes for Health Research (CIHR)-Institute for Human Development Child & Youth Health invitational workshop: *“A Health Services Research Agenda: Building Capacity within the Maternal, Child & Youth Sector”* (Feb 2010)
2. American Academy of Pediatrics-sponsored invitational workshop: *“Pediatric Clinical Research Networks - optimizing effectiveness”* (Nov, 2010)
3. Pediatric Expert Advisory Committee-Health Canada-sponsored invitational roundtable to develop a Canadian Academy of Sciences application for review on *“Mind the Gap: Therapeutic Products for Children & Youth”* (Nov 2010)
4. CIHR-Canadian Child & Youth Health Coalition-Sick Kids Foundation-sponsored invitational workshop: *“Health Clinician Scientists in Academic Health Centers – protecting an endangered species”* (Nov 2010)
5. CIHR-sponsored invitational roundtable: *“CIHR-SPOR (Strategy for Patient Oriented Research) Support for National Research Networks”* (Jan 2011)
6. CIHR-Canadian Tumor Tissue Repository Network-sponsored invitational workshop: *“Models for National Biobank Certification and Education”* (Jan 2011)
7. European Medicines Agency-sponsored invitational workshop: *“Developing Collaborations between Inter/National Pediatric Research Networks”* (March 2011)
8. CIHR-Genome Canada-Social Sciences and Humanities Research Council-sponsored invitational roundtable: *“Essential Building Blocks of a Framework for Data Harmonization for Canada”* (March 2011)

Knowledge Generation

MICYRN conducted reviews and updates to document national maternal-child research activities.

MICYRN was also involved in a number of surveys conducted by other principal investigators (PI)

1. Comprehensive review of Canadian Pediatric Clinical Trials 2005-2009
2. Comprehensive review of Canadian Maternal Clinical Trials 2005-2009
3. Survey update on MICYRN inventory of Canadian Birth Cohorts
4. Survey update on MICYRN inventory of Canadian Pediatric & Perinatal Research Networks
5. Survey on *Genetics and Pediatric Health* for Knowledge Synthesis grant (PI Avard)
6. Survey for the Pediatric Chairs on their Academic Workforce (PI Schleyer)
7. Survey on Risk of Bias in clinical trials design (PI Hamm)
8. Survey on Consort© pediatric trials reporting guidelines (PI Offringa)
9. Survey on Perinatal Biobanking needs (PI Adamson)

Knowledge Exchange

MICYRN’s Mission ‘to foster and enhance national and international collaborations’ is arguably best achieved by creating opportunities for investigators and other stakeholders to meet. Several excellent meetings were hosted by MICYRN, and support has been committed to a number of other proposals.

1. Hosted and organized the international **StaR** Child Health Summit (**S**tandards for **R**esearch in **C**hildren) (Sept 2010; PI Klassen, Offringa)

2. Hosted and organized a global pediatric research workshop: *“Challenges in the Conduct of Pediatric Clinical Trials in Low & Middle Income Countries”* (Sept 2010; PI Macleod)
3. Hosted and organized a national workshop with research ethics boards on *“Harmonizing Reproductive and Child Health REB review: From Principles to Practice”* (Feb 2011; PI Junker)
4. Hosting and organizing a national workshop: *“Towards Development of a national Integrated Pediatric-Perinatal Clinical Trials Platform”* (May 2011; PI Macleod, Klassen, Junker)
5. Support for a Longitudinal Studies workshop with the Canadian Obesity Network Centers of Excellence *“Breaking the Obesity Cycle: Understanding the Origins in the Maternal-Infant Dyad”* (April 2011; PI Bellar, Atkinson)
6. Support for a First Nations-University Partnership workshop: *“Shining a Positive Light”* (June 2011; PI Young)
7. Support for a Methodology workshop with TROPIC (*Treatment & Research of Obesity in Pediatrics in Canada*) (tba; PI Ball, Chanoine)
8. Support for a Technology Development workshop with Connect2Care: *“Building a mobile-communications platform to improve maternal and child health”* (tba; PI Ansermino, Collet, Ho)
9. Support for a Knowledge Translation workshop with TREKK (*Translating Emergency Knowledge for Kids*) KT Network Centers of Excellence (tba; PI Klassen)
10. Support for a Methodology workshop with I-HOP (*Improving Health Outcomes in Pregnancy*) New Emerging Team (tba; PI Atkinson)
11. Support for focus group meetings: *“Direct to Consumer Genetic Testing”* (tba; PI Avar)

Knowledge Mobilization

MICYRN’s Vision of ‘synergistic strength gained from networks of investigators and integrated infrastructure spurs tremendous advances unattainable by individual groups working in isolation’ means that groups need to know about each other’s activities, and be able to share best practices. In addition to support of meetings, MICYRN is being used by groups to showcase their work.

1. MICYRN hosted and organized consultation focus group meetings on the *“Ethics Best Practices for Health Research in Children”* document (May 2010, Feb 2011, May 2011)
2. MICYRN shared Best Practices and Tools (posted @www.micyrn.ca):
 - a. Biobank Standard Operating Procedures for Collection of Perinatal Specimens for Research (source, Research Center for Women’s & Children’s Health, Mt. Sinai, Samuel Lunenfeld Research Institute)
 - b. Biobank Evaluation and Accreditation Guidelines (source, CTRnet)
 - c. Ethics Best Practices for Health Research in Children & Youth (source, NCEHR/CIHR/3PG)
 - d. Ethics Privacy Assessment tool (source, PI El Amam)
 - e. National Standard Operating Procedures for clinical studies (CanReg-approved)(source, CIHR-N2 Network of Networks)
 - f. International Standards for Conducting Clinical Trials in Children: recruitment and consent, adequate sample size, data monitoring boards (source, StaR Child Health)
 - g. Network Best Practice: Publication & Authorship (source, STOPP study PI Ward)
3. MICYRN shared reports from CIHR-sponsored Meeting-Planning-Dissemination and Knowledge Translation workshops (posted @www.micyrn.ca):

- a. *“Towards a harmonized approach to the conduct of research in childhood arthritis worldwide”* (PI Yeung)
- b. *“Harmonizing Reproductive and Child Health REB review”* (PI Junker)
- c. *“Towards a wireless pain diary decision support system for youth with JRA”* (PI Stinson)
- d. *“Improving the health of late Preterm Infants: developing a Canadian research agenda”* (PI Bassil)
- e. *“Shining a Positive light: First Nations-University partnerships to measure children’s well-being”* (PI Young)

MICYRN Data Core services

MICYRN’s Data Core is based in Edmonton, at the Women and Children’s Health Research Institute. Several data management systems and a range of services are offered, including advice on research data management platforms, and software and hardware purchases; web-based demonstrations of different system features; and assistance with study data management and hosting. The following groups took advantage of MICYRN Data services this year:

1. NeuroDev Network Centers of Excellence (PI Goldowitz)
2. Canadian Pediatric Genetic Disorders Sequencing Consortium (PI Boycott, Michaud)
3. Lunenfeld Research Centre for Women’s & Infant’s Health, Mt Sinai (PI Adamson)
4. Academic Pediatric Chairs of Canada (PI Schleyer)
5. Improving Health Outcomes in Pregnancy New Emerging Team (PI Atkinson)
6. Ste Justine Applied Clinical Research Unit (PI Ducharme)
7. Direct to Consumer Genetic Testing (PI Avard)

MICYRN Ethics Core services

MICYRN’s Ethics Core is based in the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, at McGill University, with Bartha Knoppers (Director), Denise Avard (Research Director), and Lee Black (Academic Associate). MICYRN’s 2010 research ethics priorities work plan included:

1. Broad consultation and on-going revisions to *“Ethics Best Practices for Health Research in Children”* document
2. Expert opinion and facilitation for workshop: *“Harmonizing Reproductive and Child Health REB review: From Principles to Practice”*
3. Analysis of pediatric consent forms used at locations across Canada for the Canadian Pediatric Genetic Disorders Sequencing Consortium; and development of a universal approach (e.g. points to consider/template consent) for pediatric consent forms for pediatric genetic studies in Canada (*Draft*)
4. Analysis of consent forms from REB-approved Birth Cohort/Longitudinal Studies used at locations across Canada; and development of a universal approach (e.g. points to consider/template consent) (*Draft*)
5. Review regarding ethical and legal guidance on newborn bloodspot storage and secondary use across Canada (*in progress*)

Training

MICYRN is committed to training and continuing professional development. We were pleased to be able to provide a number of opportunities for learners.

1. Access to web-based Good Clinical Practice training modules (source, CITI/N2)
2. Support for a summer student project *“Updating the Birth Cohort Inventory”* (Johnson)
3. Support for a student project *“Updating the Network Inventory”* (Sarmiento)
4. Support for trainee attendance at StaR Child Health Summit (Zwicker, Zhou, Zhang, Song, Jing)
5. Support for trainee attendance at the REB Harmonization workshop (Duan)
6. Support for trainee attendance at the CON Maternal Child Obesity Dyad workshop (*tba*)
7. Support for trainee attendance at the Integrated Trials Platform workshop (*tba*)

Clinical Trials platform development

Canada is second only to the USA in the number of pediatric and maternal clinical trials being conducted world-wide: 580 pediatric clinical trials are actively recruiting in Canada at this time. There is unanimous commitment of the MICYRN membership to develop an integrated, national trials platform. This year, efforts towards this included:

1. Review of the current state of activity through reports on *“Canadian Pediatric Clinical Trials 2005-2009”*; and, *“Canadian Maternal Clinical Trials 2005-2009”*
2. Addressing issues with respect to Ethics by:
 - a. Review of international guidelines through report on *“Ethics Best Practices for Health Research in Children”*
 - b. Hosting a workshop to build consensus on Canadian Research Ethics Boards review of clinical trials protocols and consent forms (Feb 2011)
 - c. Developing inter-institutional agreements on multi-jurisdictional ethics review (*in progress*)
 - d. Developing a pilot project on national centralized ethics review, for C17 (Canadian Pediatric Cancer Centers) Phase 2 clinical trials (*in progress*)
3. Providing input into the Health Canada/Pediatric Expert Advisory Committee application to the Canadian Academy of Sciences for review on *“Mind the Gap: Therapeutic Products for Children & Youth”*, with the overarching question: What does Canada need to do to enhance science and innovation that enables safe and effective use of therapeutic products for the child?
4. Promoting Standards:
 - a. Assisting in the development and mobilization of international standards for clinical trial design and reporting (ie. recruitment and consent, adequate sample size, data monitoring boards, CONSORT© statement for trials reports) (with StaR Child Health)
 - b. Assisting in development and availability of national Standard Operating Procedures (SOPs) for clinical studies (CanReg-approved)(with CIHR-N2 Network of Networks)
5. Developing training plans for Methodology, KT and Technology “bootcamp” workshops
6. Strategic planning meetings
 - a. With StaR Child Health (October 2009, Sept 2010)
 - b. With WHO (July 2010)
 - c. With MICYRN membership (Sept 2010, May 2011, October 2011)

- d. With CIHR (Jan 2011, March 2011)
 - e. With EMA (Jan 2011, March 2011)
7. Developing International relationships
- a. Qualification as a network for pediatric research (npr) that meets standards set by the European Medicines Agency (EMA); and with 6 other national networks to form the Enpr-EMA Collaborating Group
 - b. Collaboration with D. Benjamin, PI, USA-NIH Pediatric Trials Network
 - c. Workshops with international participants to discuss challenges in the conduct of trials in low and middle income countries (July 2010, September 2010)

Longitudinal Studies platform development

With 50 birth cohort studies underway in Canada, and national research groups collaborating for the study of a multitude of chronic pediatric conditions, there is tremendous need to build capacity and reduce barriers to the conduct of longitudinal studies. This year, efforts included:

1. Addressing issues with respect to Ethics by:
 - a. Review of international guidelines through report on *"Ethics Best Practices for Health Research in Children"*
 - b. Hosting a workshop to build consensus by Canadian Research Ethics Board on issues pertinent to Longitudinal studies (ie. recontact, oversight of studies, secondary use of data, and broad consent) (Feb 2011)
2. Addressing issues with respect to Biobanking by:
 - a. Contributing to CIHR-Canadian Tumor Tissue Repository Network-sponsored invitational workshop: *"Models for National Biobank Certification and Education"* (Jan 2011)
 - b. Plan to hold Public engagement Deliberative Democracy workshop: *"Use of Newborn Screening Cards"* (tba; PI Burgess, O'Doherty, Vallence, Junker)
 - c. Plan to hold Public engagement Deliberative Democracy workshop: *"Youth Coming of Age and Consent for specimens past and future"* (tba; PI Burgess, O'Doherty, Knoppers, Junker)
3. Addressing issues with respect to Data Management
 - a. Contributing to CIHR-Genome Canada-Social Sciences and Humanities Research Council-sponsored invitational roundtable: *"Essential Building Blocks of a Framework for Data Harmonization for Canada"* (March 2011)
 - b. Development of data access & viewing Portal with the Canadian Perinatal Network
4. Strategic planning meetings
 - a. With Canadian Birth Cohort PIs (April 2009)
 - b. With Obesity Cohort PIs (April 2011)