

maternal infant
child & youth
research network



réseau de recherche
en santé des
enfants et des mères

Annual Report



13

Connecting
Facilitating
Catalyzing
Informing

MICYRN was founded in 2006 to benefit maternal and child health and well-being by building capacity for applied health research and advancing knowledge through collaborative research. It is federally incorporated as a non-profit society, and joins together 20 maternal-child research organizations in Canada. The MICYRN member organizations are committed to harmonizing research processes, implementing best practices, and supporting collaborations both nationally and beyond, in order to improve the quality, effectiveness, and uptake of research.

MISSION

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

VISION

Formal collaborative networks of investigators and integrated infrastructure spur tremendous advances in research that are unattainable by individual groups working in isolation.



2013 annual report

Table of Contents

Message from the Scientific Director and Chair	1
2013 Highlights	2
Connecting	3-5
Connecting Networks	4
Connecting Birth Cohorts	4
Connections Made	5
Facilitating	6-8
Clinical Research Informatics	7
Public Population Project in Genomics (P ³ G)	7
Ethics	8
Towards Safe and Effective Treatment for Canadian Children	8
Catalyzing	9-11
Engaging Young Persons as Advisors for Research	10-11
Council of Canadian Child Health Research Support	11
Rare Diseases Catalyst Network	11
Informing	12-14
MICYRN Communications.....	13
Workshops, Presentations and Conferences	13-14
Looking Forward	15-16
Financial Report	17
MICYRN Board of Directors and Member Institutes	18



Message from the Scientific Director and Chair

As we look back on MICYRN's achievements and growth in 2013, due in no small part to the collaboration and engagement of our members, we are reminded that it is the only network of its kind in the world. There is no other country where all of the child health institutes have joined forces to enhance the investment in research. With precious resources, it is essential to work together; this collaboration is improving efficiency, use of funding, and ultimately addressing infant, child, youth and maternal health issues across the country.


Thanks to the tireless commitment of our institute representatives and their colleagues involved in developing a national strategy, MICYRN is poised to make significant contributions to the direction of maternal and child health in Canada. We are pleased to detail in this annual report the accomplishments made in these areas. It was a pivotal year, and the momentum gained will take us well into the next year with some exciting developments on the horizon.

We would like to take this opportunity to thank our members and partners for their contributions and our volunteers who have generously contributed their time and energy.

Sincerely,



Anne Junker, MD
Scientific Director



Aubrey Tingle, MD, PhD
Chair of the Board



2013 Highlights

MICYRN's dedicated board of directors, committed executive team, and engaged members are a few of the reasons why the Network saw a significant period of growth and advancement in 2013. Several important initiatives were completed, members contributed to a number of national meetings and conferences helping guide Canada's future maternal and child healthcare strategic plans, and initiatives currently in progress were moved forward. The Network also achieved charitable status, and four new directors were appointed to the board:

- Dr. Sandra Davidge (Director of the Women and Children's Health Research Institute (WCHRI) and Professor in the Departments of Obstetrics & Gynecology and Physiology at the University of Alberta, Edmonton)
- Katie Lafferty (Executive Director, Canadian Partnership for Stroke Recovery, Ottawa)
- Dr. Alain Moreau, (Director of Research, Sainte-Justine University Hospital, Full Professor Faculty of Dentistry – Stomatology Department, and Faculty of Medicine – Biochemistry Department, Université de Montréal, Montréal)
- Dr. Martin Osmond (CEO and Scientific Director of the Children's Hospital of Eastern Ontario Research Institute (CHEO RI) and Vice-President of Research at CHEO, Ottawa).
- MICYRN was also happy to welcome the Women's Health Research Institute in Vancouver as its newest member, with Dr Deborah Money (VP Research, BC Women's Hospital and Health Centre) as its representative.

Looking forward, MICYRN is participating in the development of a collaborative and patient-centered Canadian alliance that will harmonize and improve the diagnosis and care of patients with rare diseases. Joining forces with patient organizations, internationally renowned rare disease gene identification consortiums, and model organism scientists, the initiative brings together people across Canada. MICYRN is also working with its partners to galvanize the community around the creation of a national network to improve the evidence upon which to provide safe and effective treatments for children.

This year's annual report highlights the four ways by which MICYRN is working to make a difference: connecting, facilitating, catalyzing, and informing.

CONNECTING



Connecting Networks

Networking is absolutely essential to advance maternal and child health because each individual province has too few patients with any given condition or adverse outcome to conduct adequately powered clinical studies over reasonable time periods. Canada enjoys a wealth of networks that connect people at sites across the country to do research and learn how variations in clinical practices affect maternal and child health outcomes. Self-described as “coalitions of the willing” because there is very limited support for networks in Canada, the clinicians and researchers participating in these networks do so on the basis of collective need to collaborate in order to provide the best care at their site. In MICYRN’s Coalition of Networks, there is ‘strength in numbers’, and a more effective body with which to address key issues affecting the ability to do research across multiple jurisdictions. In 2013, MICYRN invited four more networks in the areas of anaesthesia, inherited metabolic diseases, hepatology, and epilepsy to become affiliated. One of the areas of focus for the next year is working with networks to improve patient and family engagement in research studies. The following table shows the sites at which the networks affiliated with MICYRN are active.

Perinatal and Pediatric Networks /Study Sites	CFRI Vancouver	ACHRI Calgary	WHCRI Edmonton	SHR Saskatoon	MICH Winnipeg	Laurentian Sudbury	CHRI London	McMaster Hamilton	Sick Kids Toronto	Queens Kingston	CHEO Ottawa	CHU-St.Justine Montreal	MUHC McGill Montreal	Sherbrooke	Laval	IWK Halifax	Memorial St.John's
Maternal-Fetal	✓	✓✓					✓						✓			✓	
Perinatal	✓✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Neonatal Followup	✓✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
Arthritis	✓✓	✓	✓	✓	✓	✓	✓	✓	✓								
Neurodevelopment	✓✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓			✓	
Epilepsy	✓					✓	✓	✓	✓✓	✓	✓	✓	✓	✓	✓	✓	✓
Blood Disorders	✓	✓	✓	✓	✓	✓	✓	✓	✓✓	✓	✓	✓	✓	✓	✓	✓	✓
Cancer			✓✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Liver Disease	✓✓	✓	✓	✓	✓				✓		✓	✓	✓			✓	✓
Kidney Disease	✓	✓✓	✓		✓			✓	✓		✓	✓				✓	✓
Surgery	✓✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
Heart Defects	✓	✓	✓✓	✓	✓											✓	✓
Anesthesia	✓	✓						✓	✓		✓✓	✓	✓			✓	
Emergency	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓✓	✓	✓	✓	✓	✓	✓
Obesity	✓✓	✓✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Metabolic Diseases	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓✓		✓	✓	✓	✓	✓
Crohn's & Colitis	✓	✓	✓		✓				✓✓		✓	✓	✓			✓	✓
Immunization	✓✓	✓		✓	✓					✓			✓		✓	✓	✓
Drug Safety	✓✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Palliative Care	✓✓	✓	✓		✓		✓	✓	✓		✓	✓	✓			✓	✓
Network Lead =	✓✓																

con•nect

kə'nekt/ ◀

verb

1. bring together or into contact so that a real or notional link is established.

Making connections

In a country as vast as Canada, people often work in isolation and it can take a long time to convey discoveries made in one region that could improve therapies or aid in the studies elsewhere. Connecting researchers, healthcare professionals and staff through networks and regular lines of communication is essential to increasing the exchange of knowledge and the speed at which discoveries are put into practice nationally. A significant part of MICYRN's work is forging these connections.

Connecting Birth Cohorts

Prospective longitudinal birth cohort studies exist to investigate the effect of prenatal, pregnancy, and early postnatal exposures and interventions on maternal health, pregnancy outcomes, and long-term child health, social adjustment, and adult chronic disease. Many such studies are designed to investigate links between environmental and genetic factors and health and disease outcomes in both mother and child. In 2013 MICYRN'S Canadian Birth Cohort Inventory expanded, thanks to funding from the CIHR-Institute of Human Development Child & Youth Health to obtain additional information from known Cohorts, and to enroll new Cohorts. Nearly one million mothers and their offspring were identified across the 46 studies included in the original inventory and more than 90% of these studies remain active. Of 20 additional cohorts identified, five were new, rather than follow-on, studies and met the criteria for inclusion in the Inventory. The update also determined the systems and processes used to collect and store cohort data, in a step towards enabling data sharing between studies. The coming year will see more work towards harmonization of the Canadian cohorts, which will provide increased numbers to improve the statistical power and interpretation of outcomes across similarly designed studies; permit evaluation of similarities and differences across jurisdictions; and optimize the return on investment by extending the scientific impact of individual cohorts. The Birth Cohort initiative is overseen by MICYRN Board executive sponsors Stephanie Atkinson (satkins@mcmaster.ca) and Alan Bocking (ABocking@mtsinai.on.ca).

Connecting...

Connections Made

Public Health Agency of Canada (PHAC): MICYRN now benefits from a secure web based collective of applications with an innovative IT architecture that PHAC has developed and administers to support document management, real-time data sharing and communication for national research initiatives that include the Canadian Longitudinal Study on Aging.

Maelstrom Research: Maelstrom Research provides a suite of methods, open-source software, and expert advice to support valid data comparison, integration, and harmonization across cohort studies. Created in 2012, Maelstrom Research emerged from the activities of the Public Population Project in Genomics and Society, (P³G), the Biobank Standardization and Harmonization for Research Excellence in the European Union (BioSHaRE-EU), and the Canadian Longitudinal Study on Aging (CLSA). MICYRN provided vital connections that resulted in the Maelstrom tools being used to conduct comparative analysis of data in registries developed by some of MICYRN's affiliated Canadian networks with those of colleagues in the USA and EU. Maelstrom is located at the Research Institute of the McGill University Health Centre. [www.maelstrom-research.org]

Ontario Brain Institute (OBI): The *Swiss Army Knife of Brain Research* is how the OBI's Data Center aptly describes the value of integrating data contributed from a wide range of disciplines to better understand brain disorders. MICYRN was invited to present at a Brain Data Harmonization Initiative Workshop, organized by the NeuroDevNet Network of Centres of Excellence (NDN) and the OBI in October 2013, which led to a white paper entitled "Brain Data Harmonization Initiative: A Call for the Brain Research Community to Develop Common Data Collection Standards to Facilitate Data Aggregation, Sharing and Analyses". MICYRN then contributed to a Brain Canada submission (April 2014), which proposes a pragmatic, feasible set of harmonization steps and deliverables that will benefit the neuroscience research community in Canada, and increase the impact of Canadian neuroscience internationally. [www.braininstitute.ca]

CIHR Institute of Genetics: MICYRN has enjoyed a growing relationship with the Institute of Genetics that fosters research to improve the diagnosis and treatment of people with rare diseases. Activities in 2013 included meetings with Health Canada towards a new regulatory framework for the authorization of orphan drugs used to treat rare disease; engagement in a number of workshops organized by the Canadian Organization for Rare Disorders to develop a Canadian Rare Diseases Plan; contribution to the rare diseases *orphanet* portal and a joint CIHR-MICYRN workshop held in Ottawa, January 30-31st, 2014 to discuss the design and conduct of clinical trials in small populations, and spearhead the development of a national platform for pediatric clinical trials.



FACILITATING



fa•cil•i•tate

fə'sili,tāt/ ◀

verb

1. make (an action or process) easy or easier.

Facilitating efforts

With 14 health care jurisdictions in Canada, clinician investigators face many barriers to collaboration that would advance the understanding and improve care of disorders. These include lack of standardization of care practices, variation in clinical information collected, privacy legislation that restricts data sharing, and a multitude of ethics reviews. MICYRN is committed to developing infrastructure that facilitates multi-jurisdictional research, across Canada and beyond.

Clinical Research Informatics

2013 saw five investigator-initiated clinical trials activated and running on the MICYRN clinical trials platform, which is hosted at Women & Children's Health Research Institute (WCHRI) in Edmonton, AB. A super-stable version of the REDCap™ software is maintained in an environment that meets requirements for data management in regulated clinical trials, and operates as a shared resource to make available infrastructure that would otherwise be difficult and costly for a single site to develop and maintain. MICYRN's Clinical Research Informatics (CRI) working group, which joins 23 individuals from 17 sites, completed consensus recommendations for clinical research information system infrastructure standards and systems functionality, and proposed terms of reference for the use of the trials platform, all of which

were endorsed by the MICYRN Board. These quality standards are the starting point for the MICYRN informatics platform, but also serve as a reference for other systems within individual MICYRN member organizations.

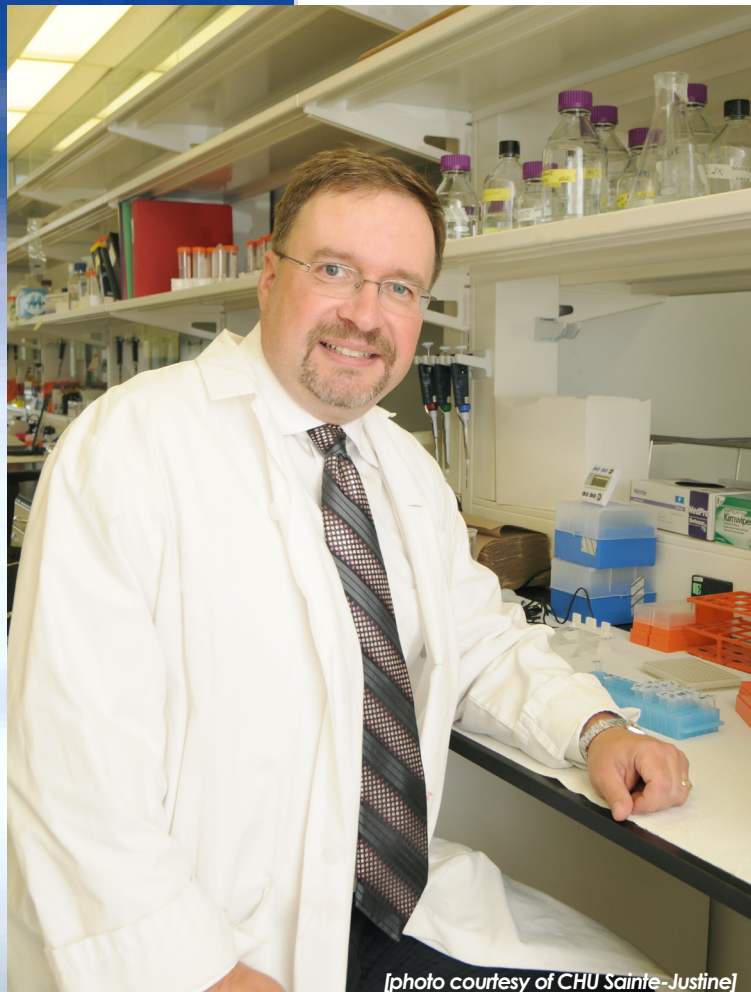
Areas of focus for the next year include expanding the use of REDCap™ Trials platform for MICYRN studies and continued opportunities for the CRI working group to collaborate nationally on the development of other best practice standards and frameworks.

The Clinical Informatics initiative is overseen by MICYRN Board executive sponsors Sandra Davidge (sandra.davidge@ualberta.ca) and Brent Scott (scott@ucalgary.ca). The Project Lead is Lawrence Richer, Director for Clinical Research at WCHRI (lricher@ualberta.ca).

Public Population Project in Genomics (P³G)

The P³G International Pediatric Platform is supported by MICYRN, the Center for Genomics and Policy (CGP) at McGill University, and the CARE for RARE project (PI Kym Boycott, CHEO RI). Led by Ellen

Wright Clayton (Vanderbilt University, USA) and coordinated by Minh Thu Nguyen at the CGP, the Platform (provides research tools for researchers and REBs concerned with pediatric biobanking. In August, the Platform published its article, "Return of whole-genome sequencing results in pediatric research: a Statement of the P³G International Pediatric Platform" online (www.p3g.org/p3g-international-paediatric-research-programme); and held its second annual meeting in September in Montreal to discuss the dissemination strategy for the position statement.



[photo courtesy of CHU Sainte-Justine]

Sainte-Justine University Hospital Research Center's
Director of Research, Dr. Alain Moreau

Ethics

Currently, it can take upwards of two years for a research project to be approved to get underway at all participating sites in Canada. Investigators often have to respond to marked differences in the opinion of different REBs, in part because rapid advances in science and technology make it difficult for institutions to develop responses to emerging ethics issues. MICYRN's ethics group connects the chairs of the eight self-standing reproductive and child health research ethics boards (REBs) in Canada, and other experts

in law and ethics. The aim is to improve the quality and consistency, and to streamline the process, of ethics review of multi-site studies. Two important protocols for which a consensus opinion was achieved in the past year included: Permission to Contact, which enables a greater number and diversity of patients to be provided the opportunity to be involved in research; and the Pharmacokinetics of understudied drugs prescribed to children as standard of care (POPS). (See the following.)



Staff at the BC Children's Hospital [photo courtesy of CFRI]

Towards Safe and Effective Treatment for Canadian Children

MICYRN is coordinating the engagement of Canadian sites and investigators in an international project sponsored by the USA National Institutes of Health Eunice Kennedy Shriver Institute of Child Health and Human Development (NICHD). The purpose of the study is to characterize the pharmacokinetics (absorption and metabolism) of drugs that are regularly prescribed to children per standard of care, but for which there is insufficient information to guide safe use. The POPS study was initiated to address a problem that is receiving global attention: the substantial "off-label" use of drugs in children. This includes the use of a drug for the treatment of diseases not listed on the product label, use outside of the licensed age range, dosing that does not adhere to approved dosing guidelines, or the use of an unapproved route of administration. Approximately 25 percent of drugs prescribed in the emergency room setting and over 50 percent of drugs administered in the hospital are unapproved or used off-label in children. The data collected through POPS will provide valuable dosing information about drugs commonly used in different pediatric age groups, as well as special pediatric populations (i.e. extremely premature, obese).

Four MICYRN members have indicated a strong interest in participating in this study: CHEO RI (Ottawa), Sick Kids (Toronto), Ste Justine (Montreal) and the Manitoba Institute for Child Health (Winnipeg).

Contemporaneous to the approach of MICYRN to open Canadian sites, the UK-Medicines for Children Research Network (UK-MCRN) was approached by the POPS team based at the Duke University Clinical Research Institute. International connections that have developed through MICYRN's membership in the European Network for Pediatric Research of the European Medicines Agency (EnprEMA) are helping to facilitate discussions with the UK-MCRN around harmonized procedures.

It is hoped that POPS will set the stage for streamlining the development and conduct of pediatric clinical trials in Canada, and ensure that Canadian children are provided the opportunity to participate in international studies of new and potentially life-altering therapies.

CATALYZING



Manitoba Institute of Child Health researcher at work [photo courtesy of MICH]

cat•a•lyze

'katl, ɪz/ ◀

verb

1. cause or accelerate (a reaction) by acting as a catalyst.

Catalyzing ideas

Often strong ideas and proposals need assistance in order to move from theory to action. A key MICYRN objective is to act as a catalyst to build capacity, and stimulate and inform future research.

Engaging Young Persons as Advisors for Research

KidsCan

As of 2012, there were no active Youth Research Advisory Groups (YRAG) operating in Canada. While young people can lay the groundwork for brilliant scientific careers by early involvement in research, researchers can also benefit from the novel ideas of youths and their ability to find realistic solutions to problems their demographic faces. The KidsCan initiative served to establish and sustain a YRAG to act as research partners and make clinical research studies more youth friendly by incorporating their suggestions and unique perspective. KidsCan and its showcase project, MobileKids, are funded by a Peter Wall Innovative Solutions grant and a BC Michael Smith Foundation for Health Research Knowledge Mobilization award. MobileKids saw the development of a game for mobile devices that requires exercise to provide currency to play the game.

There were 14 youths, aged 14-18, on the advisory group in 2013. Over the course of the year they met regularly to talk about various aspects of research that involve young people. During these meetings, members took part in activities and gained knowledge and skills that enabled them to act as Young Ambassadors. They also provided feedback to the MobileKids project on areas including:

- Wearability of activity sensors for device selection
- Software decision-making (IOS versus Android)
- Beta-testing of MobileKids game
- Subject recruitment assistance for pilot study
- Activity challenge suggestions and timer variability for MobileKids game activities
- Media representation
- Post-study survey development
- Research study protocol design

KidsCan, which began as a pilot project in Vancouver, has started to spread to other Canadian centers and connections are developing with international groups in the USA and UK. Recruitment began for the 2014-2015 KidsCan group, while the current advisors are lined up to shape pediatric versions of the trials reporting CONSORT statement and trials protocol SPIRIT statement in a CIHR-funded project (PI Martin Offringa, Sick Kids Research Institute); and methods for achieving pediatric assent spearheaded by the Global Alliance for Pediatric Therapeutics with premiere pharmaceutical companies.

This year, the KidsCan program and MobileKids, were featured in the *Ottawa Citizen*, *National Post*, *Montreal Gazette*, *Windsor Star*, *Saskatoon Star-Phoenix*, *Regina Leader-Post*, *Edmonton Journal*, *Calgary Herald*, *Vancouver Sun*, and *The Province*. They were also selected for presentations and workshops at international academic and healthcare and technology conferences for the coming year.

Catalyzing...



"The integrated structure of the KidsCan program has broadened my view of the reality of health science research and has inspired me to share this passion with other youth in my community."

Vivian



"I've always been interested in research studies-having the opportunity to be in a group that helps make decisions for a study that influences my demographic is the best experience ever. It's also a great way to meet students with the same interests as myself!"

Alex

Catalyzing...



Members of the KidsCan Youth Advisory Group at the Child and Family Youth Research Institute in Vancouver, British Columbia.

See what the kids think and access their YouTube video here: [www.cfri.ca/kidscan/home]

Council of Canadian Child Health Research Support

MICYRN entered into an agreement with the Council of Canadian Child Health Research (CCCHR) to provide executive director support and engage the resources of the MICYRN coordinating centre. In June, CCCHR held a successful Joint CCCHR/CCHCSP Trainee Symposium, supported by MICYRN's Executive Director, Stephen Barbazuk. Dr. Jonathan McGavock of University of Manitoba led a successful workshop on "Getting Your First Grant."

Other services included managing CCCHR finances, updating the website, and arranging teleconferences. The Executive Director collaborated with the Executive Committee, facilitating the establishment of annual objectives and long term-goals that support CCCHR's strategic directions, while implementing processes to track and report results.

Rare Diseases Catalyst Network

The "genomics revolution" has led to heightened awareness of rare diseases. There are over 7000 rare diseases that collectively affect one in 12, or approximately 2.7 million Canadians and their families; 80 percent have a genetic basis and 75 percent present in childhood. Rare diseases cause chronic illness, disability, and often premature death while consuming a disproportionate share of spending in health care, education and social support. The CIHR Institute of Genetics and Genome Canada are providing a \$2.3 million funding opportunity to create a national Rare Diseases Catalyst Network, which will connect Canada's clinical gene discovery teams with over 500 basic scientists who use model organisms like yeast and fruit flies to improve understanding and potentially identify therapeutic and disease management strategies to the benefit of patients and their families. MICYRN's administration will provide the Collaboration Core for the Network, and, through our member organizations, work to develop and implement innovative knowledge translation strategies to link the clinical and laboratory communities together.

INFORMING



WCHRI director, Dr. Sandra Davidge, speaking at 2013 Research Day [photo courtesy of WCHRI]

in•form

in'fôrm/ ◀

verb

1. give (someone) facts or information; tell.
2. give an essential or formative principle or quality to.

Informing stakeholders

The exchange of knowledge is crucial to raising awareness of issues and promoting changes in funding, health care practice, policy and legislation in order to advance healthcare and improve patient outcomes. MICYRN is committed to sharing new information and discoveries, contributing to national discussions, and reaffirming established knowledge in health research and the healthcare system to researchers, practitioners, students, patients, and the community at large.

MICYRN COMMUNICATIONS

Website

The MICYRN website was revitalised in 2013 and is now an important source of information on maternal, infant, child and youth research and initiatives within the Network. Upcoming events and conferences are posted, along with the latest MICYRN and member news. Key initiatives are highlighted, and investigators can obtain information on the birth cohort and network inventories. Reports from MICYRN and affiliated partners are uploaded here for easy access. The exchange of information is integral to the Network's function.

Newsletter

The MICYRN Newsletter was established as a quarterly publication with the objective to update the pediatric community on advancements, news, and opportunities in a timely fashion. Members are encouraged to submit any upcoming event of conference details for publication.

Stakeholder Communications

A significant function of a network is to provide rapid and vast dissemination of relevant information. MICYRN is establishing a two-prong approach, maintaining an email database of categorized contacts to funnel information, as well as developing collaboration sites for its various working groups through the PHAC Canadian Network for Public Health Intelligence (CNPHI) system, where members can go to post documents, offer feedback and access updates.

Workshops, Presentations and Conferences

MICYRN responded to a number of invitations to attend and present at national conferences and workshops in 2013, lending a strong voice to discussions on the direction of a national plan for child health and research. These discussions centered on key issues shaping research strategies, commitment of resources, and changing policy. MICYRN presented at and/or attended the following events.



CREDIT: [FreeDigitalPhotos.net/ddpavumba]

Meetings Organized

- National Canadian Association of Research Ethics Boards symposium: Ethical Issues presented by Reproductive & Child Health Research: Incidental Findings and Return of Results with Denise Avard, Research Director for the Centre of Genomics and Policy and Associate Professor at the Faculty of Medicine, Department of Human Genetics at McGill University (Calgary, April 25)

Invited Presentations

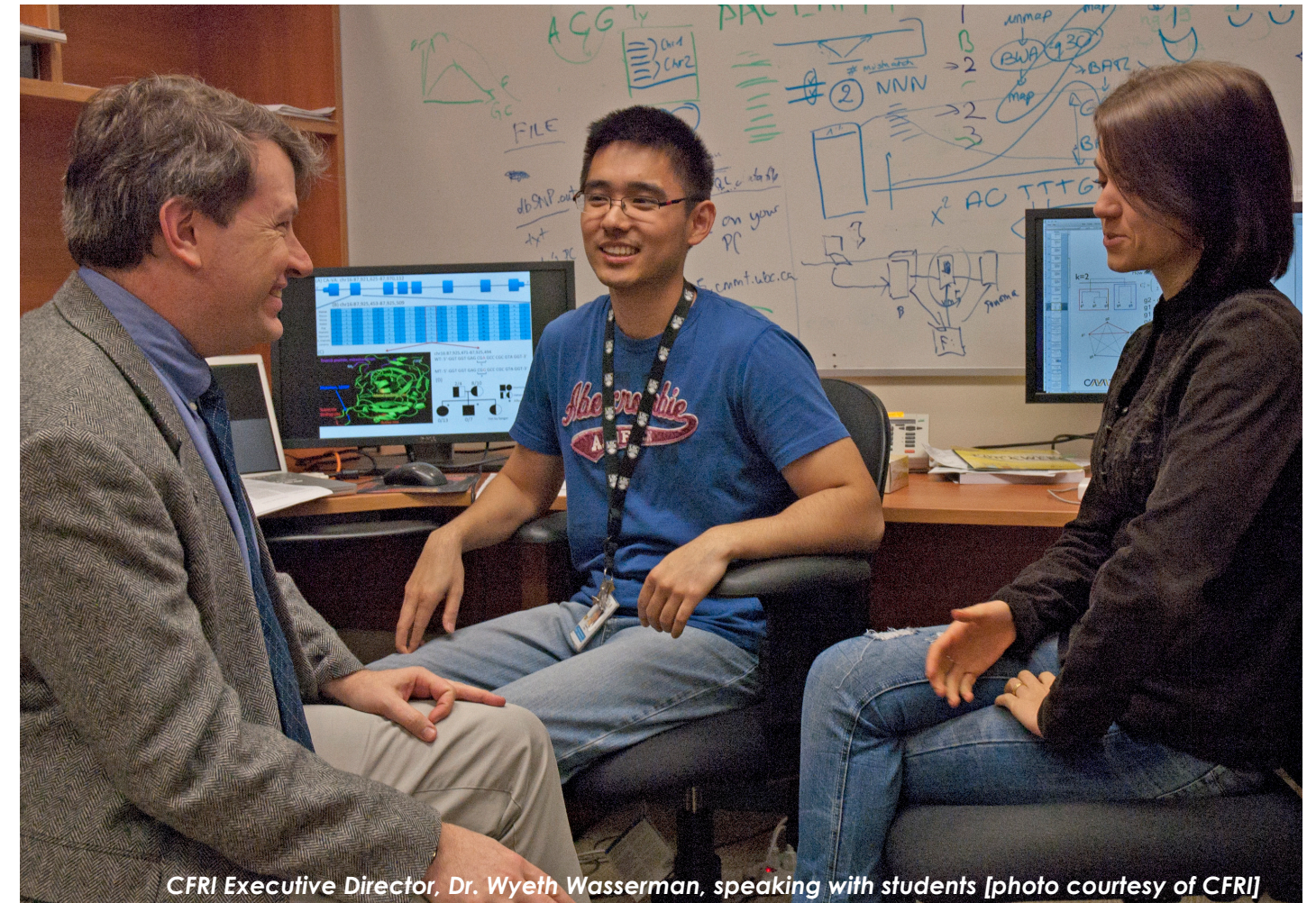
- Western Canadian Clinical Trials Network inaugural meeting, "Pediatric Clinical Trials" (Saskatoon, April 11-12)
- Council of Canadian Academies Mind the Gap: Pediatric Therapeutics Review Panel State of the Nation for Pediatric Clinical Trials in Canada (Toronto, May 27)
- Canada Brain Code invitational workshop MICYRN Clinical Research Informatics: Opportunities for Front-end Data Harmonization (Toronto, October 23)

Invited Participation

- CIHR Institute of Human Development Child & Youth Health IHDCYH Strategic Planning: New Directions (Toronto, February 27-28)
- European Medicines Agency-sponsored invitational workshop: "Developing Collaborations between Inter/National Pediatric Research Networks" (Canary Wharf, London UK, March)
- CIHR Signature Initiative RFA development workshop: Developmental Origins of Health and Disease, (Toronto, September 19-20)
- Canadian Organization for Rare Diseases, Plan to Plan the Canadian Rare Diseases Plan Working Group Chair and presented on Centers of Excellence & Reference Networks (Ottawa, September 29-30)
- Canadian Organization for Rare Diseases, National Consultation for the Canadian Rare Diseases Plan Working Group Chair (Toronto, November 11-12)

Annual Society meetings attended

- Canadian Association of Research Ethics Boards (Calgary, April 25-27)
- Redcap Consortium (Philadelphia, June 24-26)
- Canadian Child & Youth Health Coalition Annual Symposium: Social Pediatrics (Toronto, October 20)
- Canadian Association of Pediatric Health Centers (CAPHC) (Toronto, October 21-23)



CFRI Executive Director, Dr. Wyeth Wasserman, speaking with students [photo courtesy of CFRI]

LOOKING FORWARD

Initiatives in Development

Accountability Framework

There is increasing demand to justify the investment in health research by demonstrating impacts on health, health care and health system sustainability. With greater competition for resources, and a trend away from traditional research metrics (e.g. citation metrics, publication in influential journals, presentations) it has become crucial for research organizations to develop ways to show accountability to their funders and governors.

MICYRN has started working with its member organizations to develop and implement an evaluation framework to enable a coordinated approach to demonstrating accountability and communicating the impact of health research to key stakeholders.



CHEO Research Institute researcher at work [photo courtesy of CHEO]



A Canadian Strategy for Reproductive and Child Health Clinical Trials

In 2012, the Minister of Health, on behalf of Health Canada, asked the Council of Canadian Academies (CCA) to convene an Expert Panel and provide an evidence-based and authoritative assessment on the State of Therapeutic Products for Infants, Children, and Youth. The full report, available in September 2014, will give insight into what is currently in place and what is needed in Canada for ethical development of safe and effective pharmaceuticals and biologics labeled as pediatric therapies. This review comes at a time when Health Canada is working to respond to new and emerging science, medicines and technologies by modernizing 50-year-old regulations in the Food and Drugs Act. This work includes a focus on the regulatory framework for rare disease therapies, and the “off label” use of medications, both issues highly applicable to children. There is also a high demand to improve Canada’s global standing generally, in terms of clinical trials.

An action plan to help attract more clinical trials to Canada was set in 2011 by the Canadian Institutes of Health Research, the Association of Academic Health Organizations (ACAHO) and industry (Rx&D). And over the last two years, the Senate Standing Committee on Social Affairs, Science and Technology has undertaken four reviews on components related to prescription pharmaceuticals in Canada.

MICYRN is helping to develop a Canadian strategy for clinical trials that would include a national network with consistent long-term and integrated infrastructure. This network would coordinate efforts taking place in each province to develop support for patient-oriented research, and leverage activities in Canada and involving Canadians internationally to improve research in children.

Financial Report

Statement of Results	2013/2014 (CAD\$)	2012/2013 * (CAD\$)
REVENUES		
Member Contributions	\$ 205,000	\$ 170,000
Grants	30,000	9,012
Other Sources	20,000	0
Total of revenues	\$ 255,000	\$ 179,012

Statement of Results	2013/2014 (CAD\$)	2012/2013 (CAD\$)
EXPENSES		
Coordinating Centre Operations	\$ 35,281	\$ 48,613
Salaries and Benefits	152,000	163,549
Conferences and Workshops	27,614	38,658
Research Awards	0	60,000
Total of expenses	\$ 214,895	\$ 310,820

* Audited financial statements

MICYRN 2013 Board of Directors

Aubrey Tingle (chair)
MICYRN

Stephanie Atkinson (vice-chair)
McMaster University

Alan Bocking
Lunenfeld-Tanenbaum Research Institute, Mt.Sinai

Sandra Davidge
Women and Children's Health Research Institute

Victor Han
Children's Health Research Institute

Katie Lafferty
Canadian Partnership for Stroke Recovery

Martin Osmond
Children's Hospital of Eastern Ontario Research Institute (CHEO)

Brent Scott
Alberta Children's Hospital Research Institute

MICYRN 2013 Member Institutes

Child & Family Research Institute (CFRI)	BC
Women's Health Research Institute	BC
Women & Children's Health Research Institute (WCHRI)	AB
Alberta Children's Hospital Research Institute (ACHRI)	AB
Royal University Hospital, Saskatoon Health Region	SK
Manitoba Institute of Child Health (MICH)	MB
Children's Health Research Institute (CHRI)	ON
The Hospital for Sick Children	ON
Lunenfeld-Tanenbaum Research Institute, Mount Sinai Hospital	ON
Sunnybrook Health Sciences Centre, Centre for Mother, Infant, & Child Research	ON
Laurentian University	ON
McMaster Children's Hospital, McMaster University	ON
Kingston General Hospital, Queen's University	ON
Children's Hospital of Eastern Ontario (CHEO) Research Institute	ON
Centre de recherche du CHU Sainte-Justine, Université de Montréal	QC
Research Institute at the Montreal Children's Hospital, McGill University	QC
Centre d'excellence en recherche de l'Université de Sherbrooke Mère-Enfant	QC
Centre de recherche du CHU de Québec, Université Laval	QC
IWK Health Centre, Dalhousie University	NS
Janeway Children's Health and Rehabilitation Centre, Memorial University of Newfoundland	NF

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