



2016

# Annual Report

maternal infant  
child & youth  
research network



réseau de recherche  
en santé des  
enfants et des mères



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## Vision

Better health for mothers and children

## Mission

Catalyzing advances in maternal and child healthcare by connecting minds and removing barriers to high-quality health research

# Message

Joint message from the chair and scientific director

**The Canadian maternal and child health research community has a unique set of challenges. Centres that operate in isolation throughout the country leads to the duplication of efforts, limited clinical trial recruitment, and varying consistency in ethics review and data access and sharing.**

Investigators across the MICYRN organizations are pursuing vital research that will ultimately improve the diagnosis, prevention and treatment of many conditions affecting maternal and child health. Often, however, the expenditure of energy and resources required to develop funding applications, manage multijurisdictional studies, ensure access to data, and implement best practices takes away from time and resources that should be spent on research.

This past year, MICYRN has supported several projects that demonstrate the rewards of optimizing investment in research. A number of national initiatives were successful in securing significant funding, while international collaborations are giving Canada a voice in global strategies via Enpr-EMA, the Global Alliance for Genomics and Health, and the U.S.-based Pediatric Trials Network.

MICYRN assisted the investigator community with national conferences and workshop organization, and the Network's working groups continue to link many sites to collaborate on improving standards and guidance in maternal and pediatric research. MICYRN entered its third year of partnership with the highly successful Rare Diseases: Models & Mechanisms

Network, now being emulated internationally, and continued partnering with Can-SHARE on interoperable approaches to data sharing.

The 2016 annual report highlights how through our pillars of connecting, facilitating, catalyzing and informing, MICYRN is striving towards its vision of better health for mothers and children.

As always, we would like to thank those members and partners who generously gave their expertise, time and financial support to ensure our collective efforts continue to contribute to the advancement of maternal and child health research in Canada and beyond.



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**Stephanie Atkinson, PhD, DSc (Hon),  
FCAHS**  
Chair of the Board of Directors



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**Anne Junker, MD**  
Scientific Director

# Governance

MICYRN's leadership



In 2016, Drs. Jon Barrett and Suzanne Tough joined the MICYRN Board of Directors, bringing substantial knowledge and expertise to the team. Dr. Barrett is a specialist in maternal-fetal medicine, has held numerous leadership roles, and has been the recipient of several awards for his contributions to research. Dr. Tough sits on several national and international advisory boards, and is the lead scientist on the development of the Alberta child data repository, which will enable the re-use of research data to enhance the development of new knowledge and increase research productivity.

Drs. Alain Moreau, Martin Osmond and Aubrey Tingle stepped down from their positions on the Board, and we would like to thank them for their tireless efforts and contributions to MICYRN.

Dr. Osmond provided outstanding leadership in his capacity, helping to fundamentally shape MICYRN's long-term goals and objectives. Dr. Tingle served since 2009, and led the process of incorporating MICYRN as a federal, not-for-profit society and helped establish the Network's charitable status. Dr. Moreau's efforts helped in spurring the development of MICYRN's collaboration policy, which describes the tiers of collaboration that MICYRN engages in with the research community. Dr. Osmond remains as the member representative for CHEO-RI.

## 2016 Board of Directors

<b>Stephanie Atkinson</b> (chair)	McMaster University
<b>Alan Bocking</b> (vice-chair)	Lunenfeld-Tanenbaum Research Institute
<b>William Avison</b>	University of Western Ontario (Professor Emeritus)
<b>Jon Barrett</b>	Sunnybrook Health Sciences Centre
<b>Sandra Davidge</b>	Women and Children's Health Research Institute
<b>Katie Lafferty</b>	Canadian Partnership for Stroke Recovery
<b>Patrick McGrath</b>	IWK Health Centre
<b>Brent Scott</b>	Alberta Children's Hospital Research Institute
<b>Suzanne Tough</b>	University of Calgary

# By the Numbers

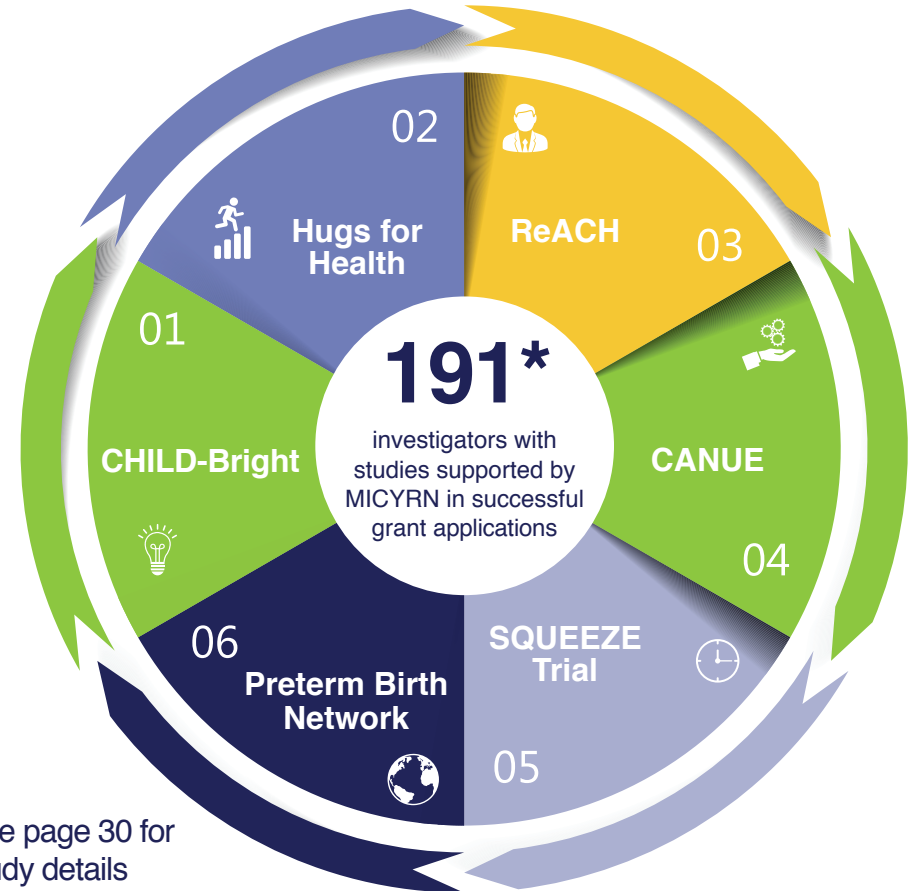


**3**  
Working Groups

**30** Experts advising on Clinical Research Informatics

**17** Experts advising on KidsCAN Trials Platform

**27** Experts advising on Research Ethics Board Review

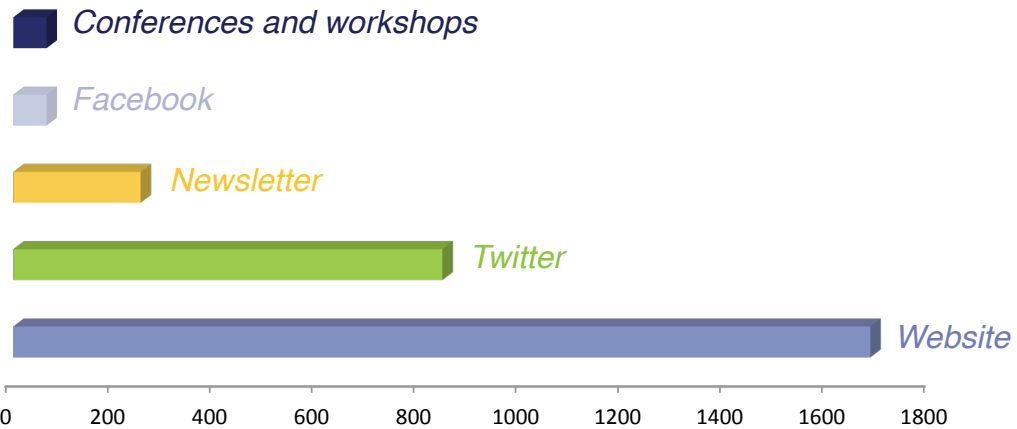


\* See page 30 for study details

# By the Numbers

# 2897

People reached through various communication platforms



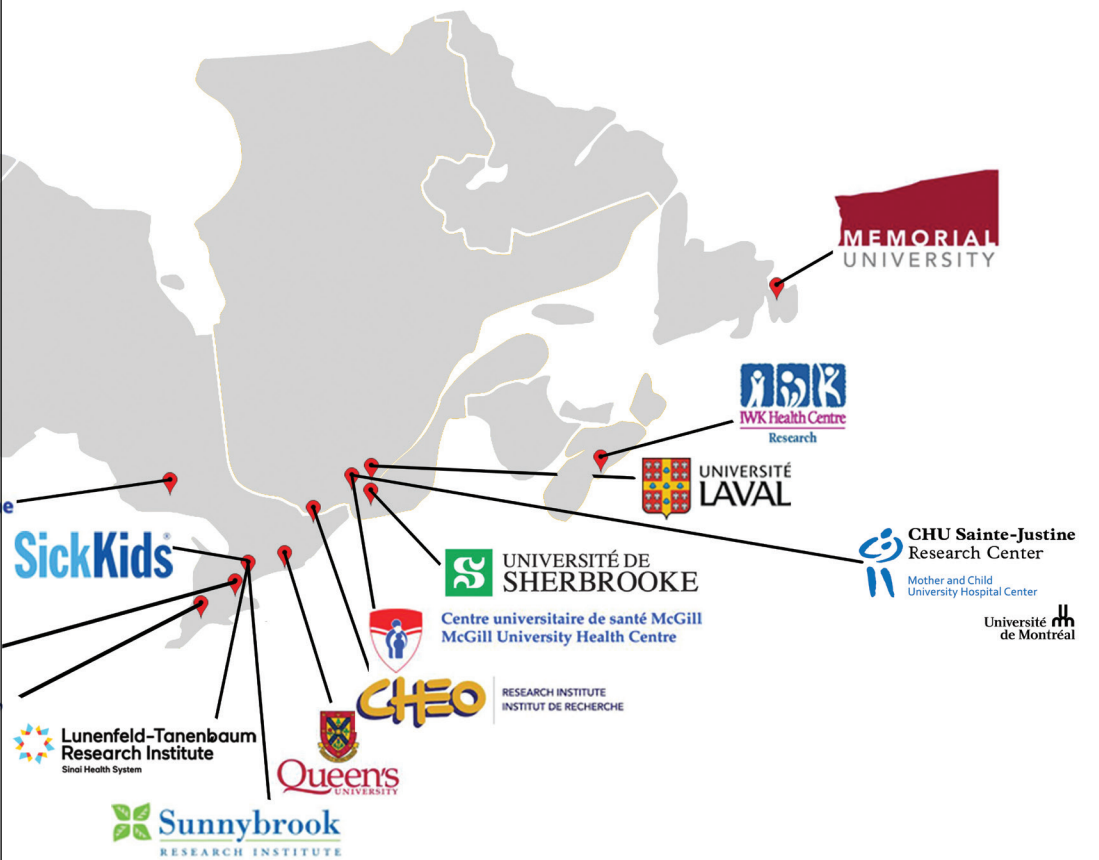
# At a Glance

Connecting **Facilitating**  
**Catalyzing** Informing



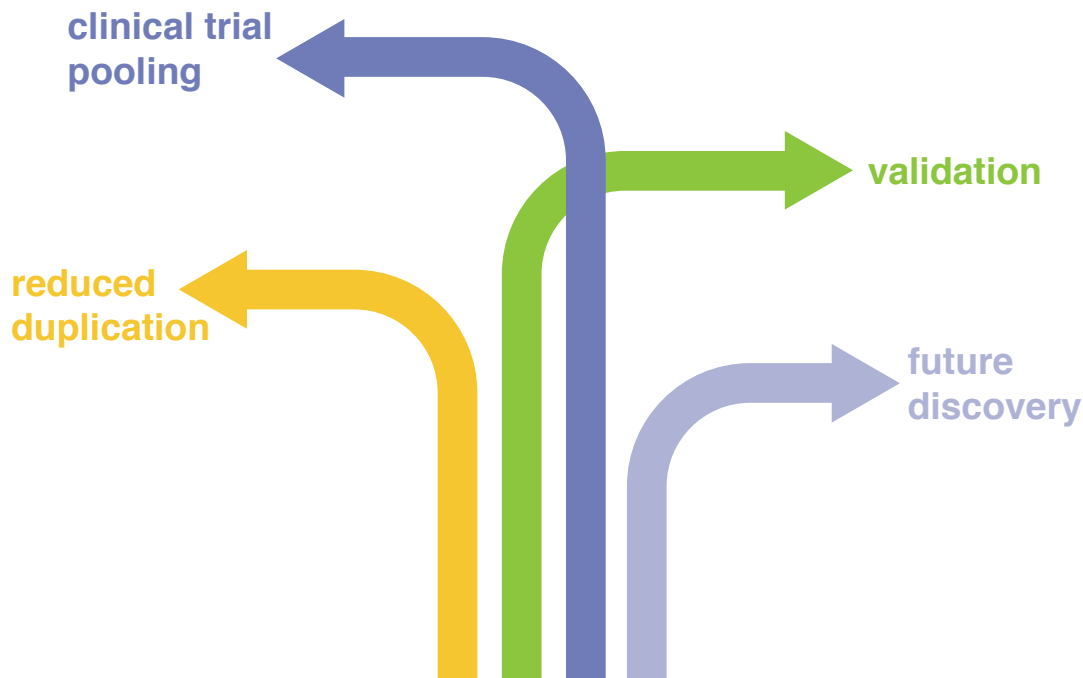
# Where We Are

# Who We Are



# Data Sharing

*It is essential for expedited translation of research results into knowledge, products and procedures to improve human health.*



**The issue isn't whether or not data should be shared, but rather how it is shared. MICYRN is working to improve opportunities for data sharing and harmonization, which has led to progress on several initiatives and partnerships.**

## Can-SHARE

Can-SHARE – the pan-Canadian arm of the Global Alliance for Genomics and Health (GA4GH) program – continued developing a framework for responsible, secure and effective sharing of genomic and clinical datasets across Canada, with international partners (PI Bartha Knoppers, McGill with Michael Brudno, SickKids RI and Jan Friedman, UBC). This big data program will ultimately accelerate progress in biomedicine and improve patient care; further the objectives of the GA4GH; and have an impact on other international bodies with investments in big data, including consortia where Canada plays a major role. Closer to home, this work should benefit every research team that operates across multiple jurisdictions and needs to share data.

It was the first year of a two-year partnership in which Can-SHARE provided MICYRN \$50,000 annually for projects to advance data sharing in the following key areas:

- Clinical research informatics systems and security
- Ethics review of data intensive studies
- Harmonization of data from





MICYRN's coalition of 46 Canadian pregnancy and birth cohort study investigators

- The Rare Diseases: Models & Mechanisms Network

MICYRN member organizations will benefit from policies developed on consent, privacy and security, research on children, accountability (for data sharing), and ethics review equivalency.

## Ethics

The Public Population Project in Genomics and Society (P3G) Pediatric Platform, which was supported in its development through MICYRN funding, dissolved in 2016 and joined the GA4GH Pediatrics Task Team to unify efforts. Members of the GA4GH worked to develop tools, policies and resources that

MICYRN's ethics initiative has been recognized nationally in the joint Health Canada – Canadian Clinical Trials Coordinating Centre 2016 report of recommendations on REB accreditation, and was highlighted internationally in a 2016 publication in Science – “Ethics review for international data-intensive research”. This is raising the profile of work that MICYRN-related REBs are doing to improve the quality and consistency of ethics review.

address ethical, legal and societal issues (ELSI) in international pediatric research, which is critical to making the large-scale collection of genome sequencing and clinical outcomes data possible. A number of these resources are useful for clinician scientists looking for assistance in developing consent templates, including:

- Legacy Consents and International Data Sharing: covers situations where researchers have collected data using older legacy consents
- Clauses for International Data Sharing: addresses situations where researchers wish to add clauses on international data sharing to their existing consent documents

- Generic International Data Sharing Prospective Consent Form: provides a generic template for studies moving forward prospectively

## Birth Cohorts

Drawing on MICYRN's coalition of pregnancy and birth cohort investigators, the Research Advancement through Cohort Cataloguing and Harmonization (ReACH) initiative (lead PI Isabel Fortier, RI-MUHC) has made swift headway after receiving a CIHR operating grant to develop a Canadian Cohort Registry to support research into the developmental origins of health and disease. The registry is a web-based catalogue through which investigators can access data across multiple cohorts that have studied similar features in expecting parents, including socio-demographic characteristics, lifestyle behaviours and diseases, and outcomes in their children.



## i2b2

Informatics for Integrating Biology & the Bedside (i2b2) is a scalable open-source informatics framework that enables secondary usage and sharing of clinical data for discovery research. In a project designed to gain experience with this system, a fully functional i2b2 instance was set up for pediatric diabetes data. It will draw clinical data from diabetes clinic databases in several provinces, validate this against provincial administrative health data, and transform it in an analysis-ready dataset, browsable through the i2b2 interface. A notable success this year was definition of a harmonized data dictionary based on the European SWEET juvenile diabetes database. Canadian data is being mapped to this harmonized dictionary, which will enable Canadian investigators to directly share data with their European counterparts.

Partnered through MICYRN, informatics leads at WCHRI (through the support of the Stollery Children’s Hospital Foundation) and BCCHR worked with their pediatric diabetes researchers and provincial health data administrators.



Along with Dr. Lawrence Richer (WCHRI), the project was spearheaded by Dr. Elodie Portales-Casamar (BCCHR) who leads the MICYRN Informatics working group. Dr. Portales-Casamar was also part of a BCCHR team that won best poster prize describing an administrative toolbox that has been developed to best support REDCap users at the 2016 REDCap conference. The MICYRN REDCap version houses 25 projects across six research organizations.

### CANUE

The Canadian Urban Environmental (CANUE) Health Research Consortium, brings together investigators managing some of the largest health and cohort databases in Canada to build an unprecedented capacity to study how multiple environmental factors are linked to a wide range of health outcomes. MICYRN links our coalition of pregnancy and birth cohort investigators to CANUE, and Drs. Stephanie Atkinson (MICYRN board chair and ReACH co-PI) and Megan Azad (CHILD cohort study co-lead) are co-chairs of the CANUE Maternal-Fetal-Child Integrated Research Analysis working group. Over 100 CANUE investigators attended a workshop at the



“Birth cohorts (ReACH) and environmentalists (CANUE) are joining forces to leverage CIHR research funding and advance maternal and child health research.”

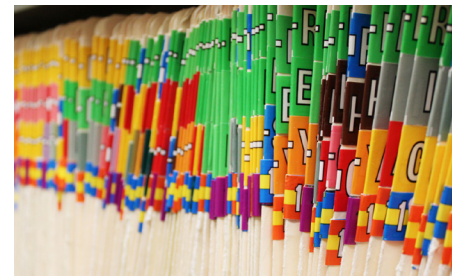
Dr. Stephanie Atkinson

end of the year, where they discussed common interests on environmental exposures and outcomes and possible approaches to link the pregnancy and birth cohort databases being created through the ReACH project with CANUE databases.

### Looking Forward

MICYRN is raising awareness about child health information collected by community-based practitioners. The Canadian Primary Care Sentinel

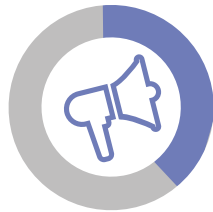
Surveillance Network (CPCSSN) is a pan-Canadian research initiative that started in 2008 with a grant from the Public Health Agency of Canada (PHAC), and forms the backbone of the CIHR Pan-Canadian SPOR Network in Primary and Integrated Health Care Innovations. Health information from over one million Canadians with chronic diseases is collected from electronic health records of the more than 1000 CPCSSN-affiliated practitioners, including pediatricians in Manitoba



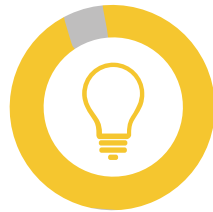
and Alberta. CPCSSN is the 2013 winner of the Privacy Innovation Award from the International Association of Privacy Professionals (IAPP). There is an opportunity for the pediatric community to apply this award-winning system to the collection of pediatric patient data to improve on indicators of child health across the country, and contribute to research that will ultimately improve the care of children.

# Rare Diseases

*There is a dire need to increase awareness of rare diseases, improve diagnosis, provide therapies and support families.*



**30% of children's hospital admissions are for rare diseases**



**95% are currently without established therapy**



**75% of rare diseases present in childhood**



**50% of children's hospital expenditures are attributed to rare diseases**

**Finding cures and effective therapies is critically important given that the majority present in childhood and are currently without treatment. With causative genes being discovered at a remarkable rate, diagnosis and treatment is becoming more of a reality for patients and their families.**

## Rare Diseases Research Planning Workshop

More than 40 participants representing investigators, patients, and industry came together at a planning workshop in October hosted at BCCHR. Led by Drs. Kym Boycott (CHEO-RI), Alex MacKenzie (CHEO-RI), and Anne Junker (BCCHR), the group discussed challenges and barriers for Canadians with rare diseases, research initiatives underway, and how to take advantage of emerging funding opportunities to drive new



*October rare diseases research planning workshop*

initiatives and build on Canada's considerable strength and international reputation in this field.

The workshop was made possible by an unrestricted cash grant from Pfizer Canada, with in-kind support from MICYRN, the Care4Rare Canada Consortium, CHEO-RI, and BCCHR.

### Research Canada Caucus

In May 2016, Research Canada held a caucus that brought together some of Canada's leading child health researchers with parliamentarians. Showcasing rare diseases as one of five important areas of pediatric research and child health,



Clara van Karnebeek and Kym Boycott (RDMM), Francois Bernier (ACHRI), Alex MacKenzie (CHEO-RI), Wyeth Wasserman (BCCHR)

Drs. Clara van Karnebeek (BCCHR), Kym Boycott (CHEO-RI), Francois Bernier (ACHRI), Alex MacKenzie (CHEO-RI), and Wyeth Wasserman (BCCHR) highlighted Canadian leadership in the genetics of rare diseases. Dr. Martin Osmond (Research Canada Board Director, CHEO-RI Scientific Director, and MICYRN member representative) provided opening remarks and introductions.

### Rare Diseases: Models & Mechanisms Network



The Rare Diseases: Models and Mechanisms Network (RDMM) completed its second full year of connecting clinicians who have identified genetic causes for rare diseases with researchers using model organisms to study those genes. RDMM catalyst grants enable clinicians to validate findings and assist model

organism scientists pursuing studies of disease pathogenesis and treatment. Fourteen grants were awarded in 2016, with one co-supported by Dravet.ca to a team studying genes in this severe epilepsy syndrome. In 2016, the RDMM established key collaborations with the USA Model Organism Screening Centre, the NIH Undiagnosed Diseases Program, and with groups in Australia and the EU working to emulate the Network. MICYRN's coordinating centre staff maintained the grant review process, for which they developed, and provided administrative and communication support including quarterly newsletters and the annual report.

“Model organisms are Nature's gift to health research. They will be critical in functionalizing human genetic variants that cause disease, and in paving the way to developing rational therapies and disease prevention strategies for decades to come!”

Dr. Phil Hieter, RDMM lead-PI

# Clinical Trials

Evidence is greatly needed to improve treatment for pregnant women and children.



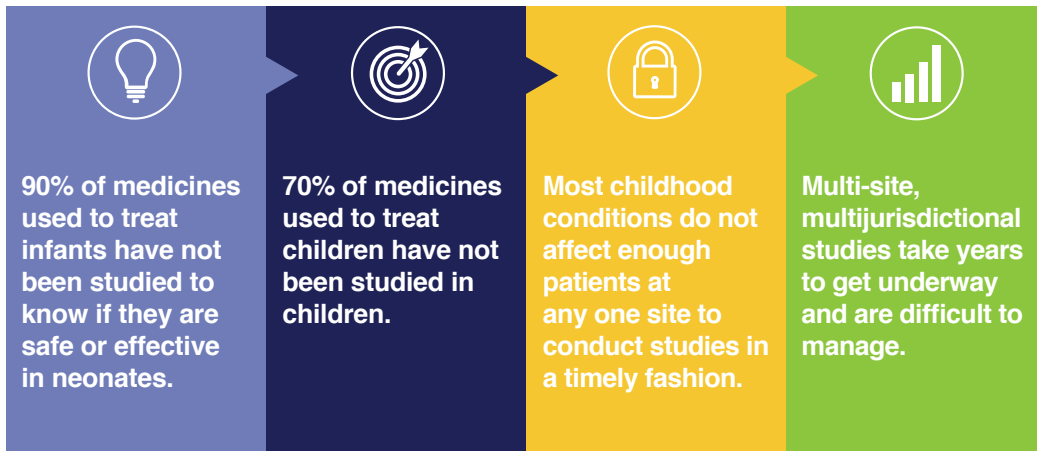
**Overlooked for decades because of perceived ethical issues, children are often prescribed medications not properly studied on them. This means we do not know the right dose to use, whether the drug is safe or even effective in treating the condition, and usually do not have 'child-sized' medicines.**

## International Partnerships

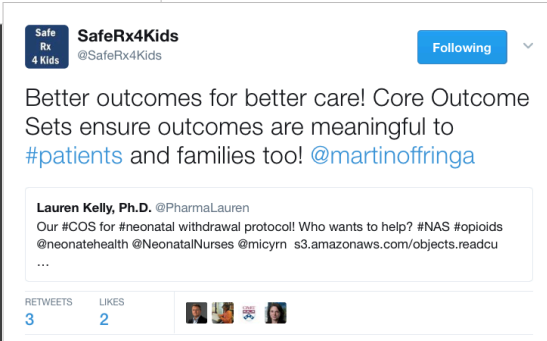
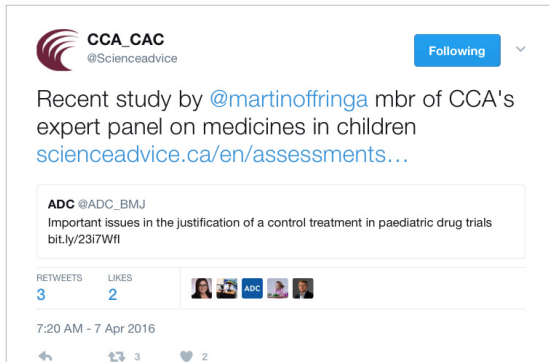
The final business plan for the KidsCAN network – a Canadian coordinating and advisory infrastructure network to ensure best therapies for children – was released early in the year and presented to the MICYRN Board of Directors. KidsCAN lead, Dr. Thierry Lacaze-Masmonteil (ACHRI) and Dr. Shoo Lee (CIHR/IHDCYH), attended a Brussels workshop organized by the EU Innovative Medicines Initiative (IMI) in partnership with the pharmaceutical industry association, with the aim to speed up the development of better and safer medicines for patients. An IMI2 submission was developed to establish a pan-European Pediatric Clinical Trials Network, led by Dr. Mark Turner (Institute of Translational Medicine, University of Liverpool) who is co-chair of the European Network of Paediatric Research at the European



Dr. Thierry Lacaze-Masmonteil, ACHRI



Medicines Agency (Enpr-EMA). Like Canada, most national and specialty networks lack sufficient funding for sustainable infrastructure. MICYRN is linked to these efforts as a member of the coordinating group of Enpr-EMA, and provided a letter of support to the EU application indicating the importance of trials infrastructure and detailing work in Canada via KidsCAN. Anne Junker represented Canada



Collaborative online discussion helps drive the exchange of information and knowledge dissemination. It increases the reach of published studies and ultimately has the ability to affect policy decisions.

*“Social media democratizes the way researchers connect and share their findings.”*

Dr. Julie Robillard, UBC

and MICYRN as a member of the coordinating committee of the Global Pediatric Trials Consortium, which has incorporated as the Institute for Advanced Clinical Trials (iACT).

There is renewed urgency in Canada to address the need for a national strategy on pediatric clinical trials. With international developments leading the way in developing multi-national infrastructure to support global pediatric trials, Canada must contribute and participate for the health of our children.

### Adaptive Pediatric Clinical Trials

Nominated lead, Dr. Terry Klassen (CHRIM), developed a submission to the CIHR SPOR Innovative Clinical Trials competition to address challenges in current trials, especially how they fail to inform decision making, and proposed innovative methods as potential solutions. The proposal combines comparative effectiveness with implementation research and presents an integrated set of four innovative multi-centre clinical trials in pediatric emergency medicine, supported by core methodological expertise, data management,



and network coordination. This initial step is intended to lay the groundwork for KidsCAN. Driving the establishment of KidsCAN is the recognition of considerable cost-savings in the provision of sustained infrastructure compared to setting up each trial independently and having to repeat the full expenditure of establishing resources with each new study. There is strong backing across the MICYRN membership to form the required infrastructure.

The MICYRN ethics working group will be involved in addressing challenges in ethics review of multi-site trials, while the coordinating centre will offer its suite of services to support the program.



# Research Teams

Collaborative teams and networks achieve efficiencies and optimize investment in research.



CANUE working group: Alvaro Osornio Vargas, Piush Mandhane, Anita Kozyrski, Stephanie Atkinson (MICYRN chair), Meghan Azad, PJ Subbaro, Eric Lavigne (missing: Ayaz Hyder)

MICYRN is unique in the world for the collaborative engagement of multiple stakeholders and provision of research support.

Valuable connections made through MICYRN's collaborative membership, partners and key stakeholders are helping to develop the best research teams possible. The Network is also building international partnerships with other network coalitions to foster further collaboration.

## The Research Process

## Four Stages of Assistance



## Networking

Care4Rare, a nation-wide research program focusing on the improvement of both the diagnosis and treatment of rare diseases, led out of CHEO-RI, joined the affiliation this year bringing the number of research networks connected through MICYRN to 21. These networks are devoted to addressing the most significant problems related to their specialty, ensuring that Canadians have early access to new diagnostic tests, interventions and care models.

MICYRN hosted a breakfast meeting for researchers and network affiliates on how investigators are using social media for professional engagement. Attendees from several networks participated in a round table discussion after viewing a CAPHC webinar with presenters from CHEO on healthcare research and social media.

## Successful Teams

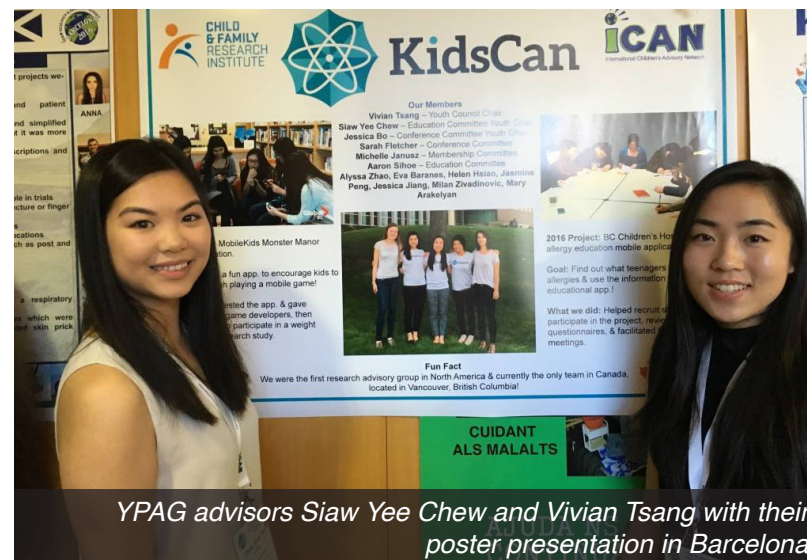
In-kind support of MICYRN core staff was proposed in project grant applications of several successful research teams (table page over). The MICYRN coordinating centre's staff brings complementary skill sets in the areas of administrative and

logistical support, communications and stakeholder engagement, and project and business management. The obvious benefit of this is a savings of time and resources to the teams, leaving more capacity for research.

Study	Home Institute	Lead PI	Funding Agency
Hugs for Health: Healthy Bugs for Healthy Babies	McMaster University	Deborah Sloboda	CIHR – \$1.5M
Research Advancement through Cohort Cataloguing and Harmonization (ReACH)	Research Institute of the McGill University Health Centre	Isabel Fortier	CIHR – \$1.3M
Improving Outcomes for Preterm Infants and their Families: A Canadian Collaborative Network	Sinai Health System	Prakeshkumar Shah	CIHR – \$4.25M
SQUEEZE Trial ( <i>studying septic shock in pediatric patients</i> )	McMaster University	Melissa Parker	CIHR – \$1.94M
CANadian Urban Environmental (CANUE) Health Research Consortium	University of Toronto	Jeffrey Brook	CIHR – \$4.165M
CHILD-BRIGHT Network ( <i>brain-based developmental disabilities research</i> )	Research Institute of the McGill University Health Centre	Annette Majnemer	CIHR – \$12.5M (with matching funds)

### Youth Advising Researchers

KidsCan, the young persons’ advisory group (YPAG) in Vancouver and currently the only research YPAG in Canada, had a very busy year presenting at conferences including the International Children’s Advisory Network (iCAN) Summit in Barcelona, the Paediatric Academic Society Meeting in Baltimore, and the International Congress of Pediatrics in Vancouver. At the 2016 Paediatric Academic Society Meeting, Vivian Tsang (lead) and Siaw Yee Chew were exhibitors for the iCAN booth; and,



YPAG advisors Siaw Yee Chew and Vivian Tsang with their poster presentation in Barcelona

in collaboration with the University of Connecticut and iCAN, distributed surveys to researchers and clinicians about their opinions on medical marijuana. KidsCan continues to provide feedback on national studies and in 2016 made the following contributions to MICYRN member organization research:

- Advised on the ‘Impact of Transitioning to Secondary Schools on Health Behaviours’ study (PI Louise Mâsse, BCCHR)
- Partnered with the BC Children’s Hospital Allergy Clinic in development of a food allergies mobile app (PI Edmond Chan, BCCHR)
- Presented at BCCHR’s annual Mini Med School to recruit new advisors
- Assisted in the orientation of new advisors for the CHILD-BRIGHT SPOR Network
- Provided a young person’s perspective on CIHR training modules designed to orient patient/public research advisors



# Engagement

*Connecting, collaborating and communicating for a mutually beneficial exchange of knowledge and understanding.*



**With the rise of new communication platforms, investigators looking to increase the reach and exposure of their findings must develop an understanding of how social media is affecting research engagement and dissemination today.**



## Social Media

With a significant range in MICYRN organizations' social media engagement levels, MICYRN has been working to develop its own following and connections to communicate not only the Network's developments, but also assist in increasing the reach of study findings for investigators at member organizations.

## Website and Newsletter

MICYRN's website and quarterly newsletter continue to be significant channels for sharing updates to community members. In 2016, a new feature was added to the newsletter to profile one member organization in each issue, highlighting their focus and objects and sharing recent studies to increase awareness of the work being done across the country.

## National Meetings

**Annual General Meeting:** The 2016 AGM meeting in Niagara Falls was well attended by representatives of MICYRN's member organizations, as was the strategic planning session that followed, which included invited guests. Participants examined maternal and child health research trends and current opportunities to determine how best to support investigators and enhance their research capacity and impact.



**Participants taking a break at the 2016 AGM and Strategic Planning Retreat in Niagra Falls**

*(clockwise from top right)*

*Martin Osmond (CHEO-RI), Thierry Lacaze-Masmonteil (ACHRI), Lawrence Richer (WCHRI), Terry Klassen (CHRIM), and Martin Offringa (SickKids)*

**Canadian National Perinatal Research Meeting (CNPRM):** MICYRN was recognized as a gold sponsor of the annual meeting of perinatal researchers. MICYRN’s coordinating centre staff developed an online system to support the submission and review of approximately 200 abstracts for the 2017 conference. Aided by Dr. Elodie Portales Casamar and Ashley McKerron (BCCHR Informatics), they also developed a web-based system to facilitate judging of posters and subsequent tallying for awards.

**HCSMCA National Symposium:** In conjunction with Quality Forum 2016, the first national Health Care Social Media Canada conference was held in Vancouver and attended by Andrea Rudy, MICYRN’s engagement associate. Over 160 members of the media, health care experts and patient advocacy groups came together for a day of workshops to discuss how digital communication can improve care.

## Member Organizations

BC Children’s Hospital Research Institute Provincial Health Services Authority	BC
Women’s Health Research Institute Provincial Health Services Authority	BC
Women and Children’s Health Research Institute University of Alberta	AB
Alberta Children’s Hospital Research Institute University of Calgary	AB
University of Saskatchewan Royal University Hospital	SK
Children’s Hospital Research Institute of Manitoba University of Manitoba	MB
Children’s Health Research Institute SickKids Research Institute	ON
Lunenfeld-Tanenbaum Research Institute Sinai Health System	ON
Sunnybrook Health Sciences Centre Centre for Mother, Infant, & Child Research	ON
Laurentian University	ON
McMaster Department of Pediatrics, McMaster University	ON
Queen’s University, Kingston Health Sciences Centre	ON
Children’s Hospital of Eastern Ontario Research Institute	ON
Centre de recherche du CHU Sainte-Justine Université de Montréal	QC
Research Institute at the Montreal Children’s Hospital McGill University, Montreal Children’s Hospital	QC
Maternal and Child Health Research Center Université de Sherbrooke	QC
Université Laval Centre de recherche du CHU de Québec	QC
IWK Health Centre Dalhousie University	NS
Janeway Children’s Health and Rehabilitation Centre Memorial University of Newfoundland	NF

# Financial Statements

Statement of Operations	2016/2017* (CAD\$)	2015/2016 (CAD\$)	2014/2015 (CAD\$)
<b>REVENUE</b>			
Member contributions	\$ 220,000	\$ 225,000	\$ 375,000
Other sources	\$ 114,636	\$ 87,003	\$ 82,265
<b>Total Revenue</b>	<b>\$ 334,636</b>	<b>\$ 312,003</b>	<b>\$ 457,265</b>

Statement of Results	2016/2017* (CAD\$)	2015/2016 (CAD\$)	2014/2015 (CAD\$)
<b>EXPENSES</b>			
Coordinating centre operations	\$ 26,388	\$ 37,569	\$ 32,011
Salaries and benefits	\$ 243,542	\$ 235,822	\$ 211,732
Conferences and workshops	\$ 16,121	\$ 29,370	\$ 21,755
Platform salary support	\$ 18,827	\$ 17,118	\$ -
<b>Total Expenses</b>	<b>\$ 304,878</b>	<b>\$ 319,879</b>	<b>\$ 265,498</b>

\* Unaudited

# 2016 Funders



## Thank you!

*Better health for  
mothers and children*

# Executive Staff

**Anne Junker, Scientific Director**

Stephen Barbazuk, Executive Director  
Christine Oriel, Administrative Assistant  
Andrea Rudy, Engagement Associate



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