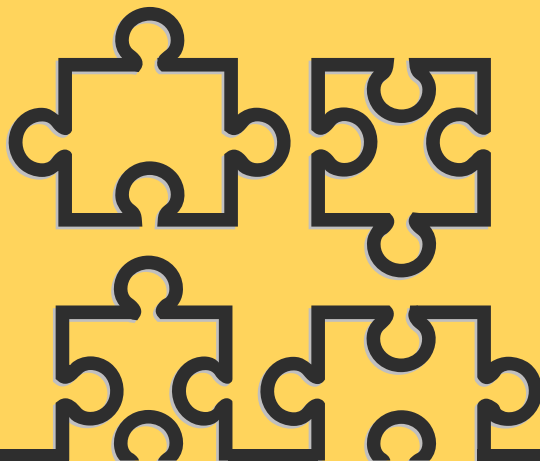


# 2019



ANNUAL ■■■

**MICYRN**

■■■ REPORT

Infrastructure connects  
provinces connect  
investigators connect  
research that lead to results.

**2019** A YEAR OF

# CONNECTING THE PIECES

TO IMPROVE HEALTHCARE RESEARCH

CONNECTING INFRASTRUCTURE

CONNECTING THE PROVINCES AND

**CANADA**

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# MICYRN Members

BC Children's Hospital Research Institute, University of British Columbia	BC
Women's Health Research Institute	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	SK
Children's Hospital Research Institute of Manitoba, University of Manitoba	MB
Children's Health Research Institute	ON
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
Department of Pediatrics, McMaster University	ON
Queen's University, Kingston General Hospital	ON
Children's Hospital of Eastern Ontario Research Institute	ON
Centre de recherche du CHU Sainte-Justine, Université de Montréal	QC
Research Institute of the McGill University Health Centre, McGill University	QC
Department of Pediatrics, Université de Sherbrooke	QC
Centre de recherche du CHU de Québec	QC
IWK Health Centre, Dalhousie University	NS
Janeway Children's Health and Rehabilitation Centre, Memorial University	NF

## MESSAGE FROM THE SCIENTIFIC DIRECTOR

In 2019 I visited members across Canada to discuss the landscape of maternal and child health research, and in the process gained a greater understanding of investigator needs between provinces. These visits also helped to establish how MICYRN could achieve its 2019 mandate—to develop a national collaborative infrastructure that enhances the number and quality of clinical trials conducted in Canadian children.

As the only national network of its nature, MICYRN addresses the obstacles and opportunities of being one country separated by jurisdictions, provinces, municipalities, and geography. There is resounding agreement that a national infrastructure is needed to streamline ethics (CHEER initiative), facilitate access to clinical trials, and expedite multijurisdictional studies. At the General Assembly, members and the Clinical Trials Consortium identified key indicators that would be meaningful and useful to focus on for clinical trial quality improvement and performance metrics.

With the COVID-19 outbreak in 2020 drastically changing demands on the research and healthcare community, the network's ability to respond quickly has become even more important. MICYRN is working to keep vital aspects of the health research community afloat while members turn their attention to immediate demands. The network's 2019 priority to better ensure facilitation of multijurisdictional clinical trials is a direct benefit to the rising need for clinical trials across sites and countries.

In this report we reflect on accomplishments of 2019 and strides made in connecting the pieces to improved research in Canada. Heading into 2020, we will see how those pieces can be applied to ensure MICYRN continues moving towards our shared goals in times of rapidly changing needs.



Thierry Lacaze, MD, PhD



## LETTRE DU DIRECTEUR SCIENTIFIQUE

En 2019 j'ai eu la chance de rendre visite à la plupart des site-membres de MICYRN pour présenter les priorités de l'organisation et mieux comprendre les besoins et difficultés propres à chaque site. Ces visites très fructueuses ont permis de déterminer comment MICYRN peut réaliser son mandat: développer une infrastructure de collaboration nationale qui améliore le nombre et la qualité des essais cliniques menés en Pédiatrie.

MICYRN continue de travailler avec le Consortium pour diminuer les obstacles et faciliter la recherche clinique en supportant notamment une harmonisation des revues d'Éthique grâce au projet CHEER. Lors de l'Assemblée générale de MICYRN en décembre 2019, les représentants des membres et le Consortium ont identifié des indicateurs clés qui seraient significatifs et utiles pour se concentrer sur l'amélioration de la qualité des essais cliniques et les mesures de performance à l'échelle nationale.

Avec l'épidémie COVID-19 et ses multiples impacts sur la communauté de la recherche et des soins de santé, la capacité du réseau à réagir rapidement est devenue plus importante que jamais. MICYRN s'efforce de maintenir les activités autour des priorités établies pour 2020 pendant que les membres portent leur attention sur les demandes immédiates.

Ce rapport résume les réalisations de 2019. Depuis l'assemblée générale, des progrès importants ont été réalisés pour plusieurs des priorités définies pour 2020. Malgré les difficultés récentes liées à la crise sanitaire, MICYRN continue d'apporter son soutien aux investigateurs et unités de recherche clinique.



Thierry Lacaze, MD, PhD



# Governance

Dr. Sandra Davidge assumed the role of board chair in 2019. Dr. Davidge has sat on the MICYRN Board of Directors since 2011, making immense contributions to the Network in that time, and we are grateful to her for taking on this leadership position. She assumed the position from Dr. Brent Scott, who has been integrally involved in MICYRN since its 2006 inception. We are appreciative to Dr. Scott for continuing to serve on the Board for the next year in the capacity of past chair. Dr. Ekat Kritikou accepted a two-year term as vice chair, bringing with her extensive experience in strategic partnerships and research strategy. MICYRN also welcomed Drs. Darryl Adamko, Jason Berman, Rulan Parekh, and Wyeth Wasserman as new members of the board.

## 2019 BOARD OF DIRECTORS

**Sandra T. Davidge, PhD (Chair)**

Women and Children's Health Research Institute (WCHRI)

**Ekat Kritikou, PhD (Vice Chair)**

CHU Sainte-Justine Research Center

**Darryl Adamko, MD, FRCPC**

University of Saskatchewan

**Jason Berman, MD, RCPC, FAAP**

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

**Terry Klassen, MD, MSc, FRCPC**

Children's Hospital Research Institute of Manitoba (CHRIM)

**Charlotte Moore Hepburn, MD, FRCPC, FAAP**

Canadian Paediatric Society

**Rulan Parekh, MD, MS, FRCPC**

Sick Kids Research Institute

**Dr. Brent Scott (Past Chair)**

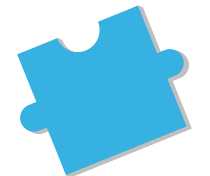
Professor Emeritus, Department of Pediatrics, University of Calgary

**Suzanne Tough, MSc, PhD**

University of Calgary

**Wyeth Wasserman, PhD**

BC Children's Hospital Research Institute (BCCHR)



# Facts and Figures

## PIECES TO HEALTHIER CHILDREN IN 2019

**ACCESS TO EXPERTISE** 

**INCREASED COMMUNICATION** 

**BETTER MEDICINES** 

**EFFECTIVE COLLABORATION** 



**IMPROVED RESEARCH** 

**GREATER EVIDENCE** 

### IMPROVED RESEARCH

**CONNECT**  Facilitated regular meetings and calls between research experts across Canada

**IMPLEMENT**  Developed materials, processes and tools as recommended by working groups

**ASSESS**  Surveyed community needs and obstacles to research success

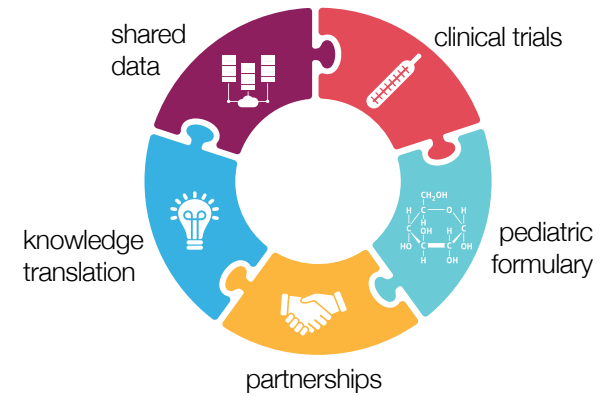
**SUPPORT**  Provided assistance to teams and groups to bridge support gaps

**FUND**  Ensured new and sustained funding by assisting in grant application development

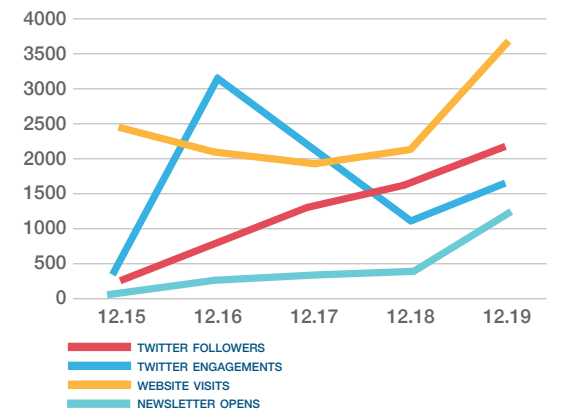
**COLLABORATE**  Shared news and opportunities from national/international meetings with MICYRN members



### GREATER EVIDENCE



### INCREASED COMMUNICATION



### EFFECTIVE COLLABORATION



4 countries | 18 cities | 32 meetings



To determine areas where MICYRN can help improve maternal and child healthcare research, the scientific director met more than

**200**

- investigators
- policy makers
- hospital administrators
- health care research stakeholders

### ACCESS TO EXPERTISE



The point-of-contact database provides industry, investigators and sites access to expertise, connections and opportunities to advance research.



### BETTER MEDICINES



*CHILDREN ARE NOT LITTLE ADULTS*  
**WHO, 2008**

Child healthcare researchers have known for years the urgency around developing formulations for children. MICYRN is assisting those who are working to improve access to child-friendly medicines.

### PIECES TO THE PUZZLE



# Engagement

collecting  
the  
pieces

## MICYRN GENERAL ASSEMBLY

In December, representatives came from across the country to discuss MICYRN's future priorities. International guest speakers shared lessons learnt in the implementation of shared quality and performance improvement management process for multi-site clinical trials. National guest speakers discussed facilitating multi-jurisdictional research, as well as the needs of the maternal and child health research community across Canada.



*MICYRN General Assembly discussions*

## INTERNATIONAL CONNECTIONS

MICYRN was once again the representative for Canada advising on Enpr-EMA's International Collaboration Working Group, which also includes representation from Australia, the EU, Japan, and USA. The group, co-chaired

by Thierry Lacaze, is working to assist those conducting multiregional studies by developing a guidance document related to the clinical trial authorisation processes in the different regions. An environmental scan of clinical trial applications and research ethics review processes was also developed to determine international differences and similarities between the regulatory and ethics pathways for pediatric clinical trials. The project is a collaboration between regulators and pediatric networks (Enpr-EMA, PTN, i-ACT, MICYRN).

## ANNUAL CHILD HEALTH SUMMIT

After building momentum in the first Child Health Summit meeting held in 2018, the executive and boards of Children's Healthcare Canada, Paediatric Chairs of Canada and MICYRN met again in partnership with the Goodman Pediatric Formulations Centre to discuss key topics, including future planning for the Safer Medications for Children agenda. Group discussions addressed regulatory policy, advocacy, and research issues around supporting the pediatric drug agendas.

Strengthened partnerships with the Canadian Paediatric Society, Children's Healthcare Canada and Goodman Pediatric Formulations Centre is ensuring aligned priorities and greater advocacy to improve funding and opportunities for child health research.



# Collaboration

comparing  
the  
pieces

## HARMONIZING ETHICS REVIEW ACROSS CANADA

MICYRN and Clinical Trials Ontario (CTO) submitted a SPOR grant application to CIHR to support harmonized pediatric clinical trial ethics review across the provinces. The Collaboration for Child Health: Efficiency and Excellence in Ethics Review and Research (CHEER) project, which was successfully funded, will develop a cross-province streamlined ethics review process for multi-site studies with the goal of achieving a single ethics review for child health studies. MICYRN will play a role in developing the education program, including online topic-focused modules; educational content for research teams, trainees, and REB members; and webinars with topics of broad interest for researchers, administrators, REBs, and patients and families.



*Thierry Lacaze at YPAG presentation*

## NATIONAL YPAG INITIATIVE

The National Young Persons' Advisory Group officially launched in 2019 with six participating sites across Canada. In addition to advising investigators on research as it relates to youths, participants also act as young ambassadors to their peers to increase awareness of the importance of youth in research. At the 96th annual

Canadian Paediatric Society Conference, the group presented a poster on their history and projects since 2012.

## C4T WORKSHOP

MICYRN assisted in the facilitation of a workshop for clinicians, researchers, regulators, industry, and patient families to discuss the need to build and evaluate evidence for dosing, comparative effectiveness, and long-term safety of medicinal cannabinoids in children. The Canadian Childhood Cannabinoid Clinical Trials (C4T) group, led by Dr. Lauren Kelly, was formed to support the evaluation of cannabinoid products for use in children with health concerns. MICYRN provided C4T administrative and executive director support.



*Stephen Barbazuk*

## KIDSCAN TRIALS

The KidsCan Trials program brings leaders together to work on improving medicines for children and evidence through clinical trials. Innovations in Pediatric Clinical Trials (iPCT) is developing innovative methods for trials, sharing a centralized management structure and recruiting in pediatric ERs in four provinces. Members of the KidsCan Steering Committee were involved in the development of an important policy statement, "Improving medications for children: A prescription for Canadian children and youth", spearheaded by CPS and the Goodman Pediatric Formulations Centre.

# Delivering on Needs

pieces  
of the  
puzzle

## SITE-READINESS AND CONTACT DATABASE

MICYRN developed a Clinical Trials Unit database to provide information on member site readiness. The Clinical Trials Consortium determined a minimum set of criteria to consider a unit ready to participate in both academic- and industry-sponsored trials. A Point of Contact database was also developed, allowing MICYRN to function as a national access point for stakeholders looking for child health investigators able to provide scientific expertise on study and protocol design and willing to participate as a site for upcoming multicentre child health clinical trials.

## NETWORK OF LAWYERS

At the General Assembly, an overview was presented on a network of lawyers established across the MICYRN organizations to discuss practical ways to facilitate timely approval of investigator-initiated, multicentre, multi-jurisdictional clinical trial agreements. The group developed a Study Terms of Reference checklist to assist teams in clinical trial organization prior to the drafting of the initial contract, and is also drafting a “Heads of Terms” agreement outlining each jurisdiction’s essential items and hard limits to be used as a guidance for future contracts.



Breanne Stewart

## MULTICENTRE TRIAL GUIDANCE – TOOLS AND RESOURCES

Star guidelines and procedural working documents in the conduct of multicentre trials are under development and being shared in the MICYRN E-Library. Resources include templates, checklists and guidance documents.

## SUPPORTING THE COMMUNITY

**Molly Towell Perinatal Research Foundation:** MICYRN assumed website and communication support in addition to executive administrative assistance, saving the Foundation resources to further fund research grants.

**National Pediatric Resident Research Competition:** MICYRN assumed administrative and coordination support of this highly successful annual meeting, ensuring minimal strain on staff and organizations as it rotates hosting institutes.

**REDCap Conference:** MICYRN supported a number of member organizations in sending their REDCap administrators and data managers to the conference. MICYRN also sponsored the Canadian REDCap Administrators satellite meeting.

**CNPRM:** For the 2019 Canadian National Perinatal Research Meeting, MICYRN expanded its support of providing the judging tools to include administrative, communications, abstract submission and on-site assistance.

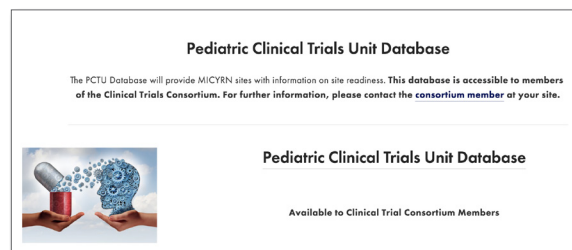
**RDMM:** MICYRN continues to support the Rare Diseases: Models & Mechanisms Network. Christine Oriel also contributed to the publication of a paper about the Network in the *American Journal of Human Genetics*.

# National Infrastructure

## CLINICAL TRIALS CONSORTIUM

MICYRN's Clinical Trials Consortium (CTC) has been working steadily over the past year on advancing several national initiatives to improve clinical trials for children and generate evidence for treatment. It was recognized that contributions at the local site level will be imperative if this is to be successful at the national level. Significant achievements include development of:

- multicentre trial guidance
- CTU database
- study contract streamlining efforts: assembling a network of lawyers
- ethics harmonization grant submission
- MICYRN's response to the Health Canada Agile Regulations Paper
- quality improvement and performance measurement initiative



connecting  
the  
pieces

## PEDIATRIC CLINICAL TRIAL INFRASTRUCTURE

MICYRN started the process of developing the first ever national infrastructure in Canada to support pediatric clinical trial investigations with an emphasis on

multicentre clinical trials. This infrastructure includes a system for connecting sites determined to be trial ready; streamlining ethics review and the application process; pooling resources and expertise; and supporting the development of new research methods. The first point of contact database for investigators, industry, and academia was also developed in 2019.

## QUALITY IMPROVEMENT AND PERFORMANCE MEASUREMENT INITIATIVE

The CTC started an initiative to understand underlying sources of inefficiencies in the clinical trials process, and where improvements have the potential to increase the timeliness, feasibility, and number of academic- and industry-sponsored



*MICYRN General Assembly discussions*

pediatric clinical trials in Canada. MICYRN connected with each of the child health centres individually to create a list of indicators for quality improvement and performance measurement. At the General Assembly, the CTC selected four priority indicators: the number of child health investigators; time from site initiation to first patient enrolled; percentage of targeted participants enrolled; and study start-up time.



# Informing

sharing  
the  
picture

## NEW WEBSITE LAUNCHED

MICYRN launched an updated website in 2019 that features a number of services and support systems for investigators establishing clinical trials for children across Canada. New features include:

- E-library providing templates and support to investigators developing trials
- CTU database of Canadian site information accessible to consortium members
- Blog to feature new research and publications from member investigators

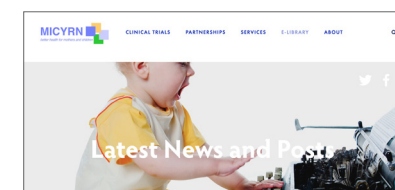
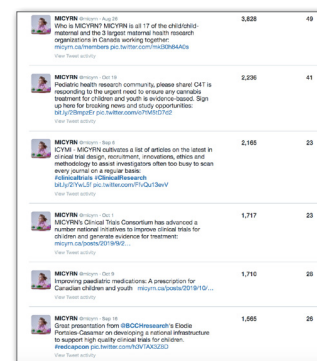


## PUBLICATIONS

MICYRN launched a features blog and news section to highlight recent and noteworthy research and publications. A number of impactful articles published by member investigators are highlighted to increase the exposure of important work that might not normally receive extensive coverage, and in the process improve their altmetrics to help further circulation. For investigators often too busy to scan every journal each month, MICYRN's Clinical Trials Pub Blast categorizes and links to the latest studies and articles addressing methodology, innovations, recruitment, medicines, and ethics.

## PROMOTING COMMUNITY NEWS

MICYRN launched a website features blog and news section to highlight recent and noteworthy research and publications by investigators at member organizations. In 2019, the Network's Twitter account became regularly sought out to share educational materials, events, and new research from members and their investigators.



THESE MICYRN MEMBERS AND THEIR FOUNDATIONS PROVIDED THE CONTINUED FINANCIAL SUPPORT NEEDED TO SUSTAIN THE NETWORK'S WORK AND ADVANCE NATIONAL INITIATIVES IN 2019.

# THANK YOU!



## Financial Statements

STATEMENT OF OPERATIONS	2019/2020* (CAD\$)	2018/2019 (CAD\$)	2017/2018 (CAD\$)
<b>REVENUE</b>			
Member contributions	\$ 305,000	\$ 363,500	\$ 261,000
Other sources	\$ 61,770	\$ 147,420	\$ 77,225
<b>TOTAL REVENUE</b>	<b>\$ 366,770</b>	<b>\$ 510,920</b>	<b>\$ 338,225</b>

STATEMENT OF RESULTS	2019/2020* (CAD\$)	2018/2019 (CAD\$)	2017/2018 (CAD\$)
<b>EXPENSES</b>			
Coordinating centre operations	\$ 20,394	\$ 24,464	\$ 23,377
Salaries and benefits	\$ 286,977	\$ 277,045	\$ 266,228
Conferences and workshops	\$ 47,979	\$ 50,260	\$ 12,936
Platform salary	\$ 78,142	\$ 24,000	\$ 3,000
<b>TOTAL EXPENSES</b>	<b>\$ 433,492</b>	<b>\$ 375,769</b>	<b>\$ 305,541</b>

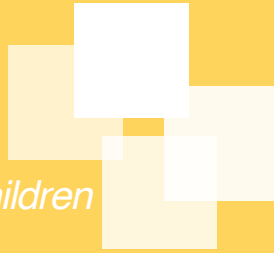
\* Unaudited

## EXECUTIVE STAFF

Stephen Barbazuk	Executive Director
Thierry Lacaze	Scientific Director
Christine Oriel	Administrative Assistant
Andrea Rudy	Engagement Associate
Breanne Stewart	Associate Director, Clinical Trials

# MICYRN

*better health for mothers and children*



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