

# New Directions

2018



clinical  
investigations

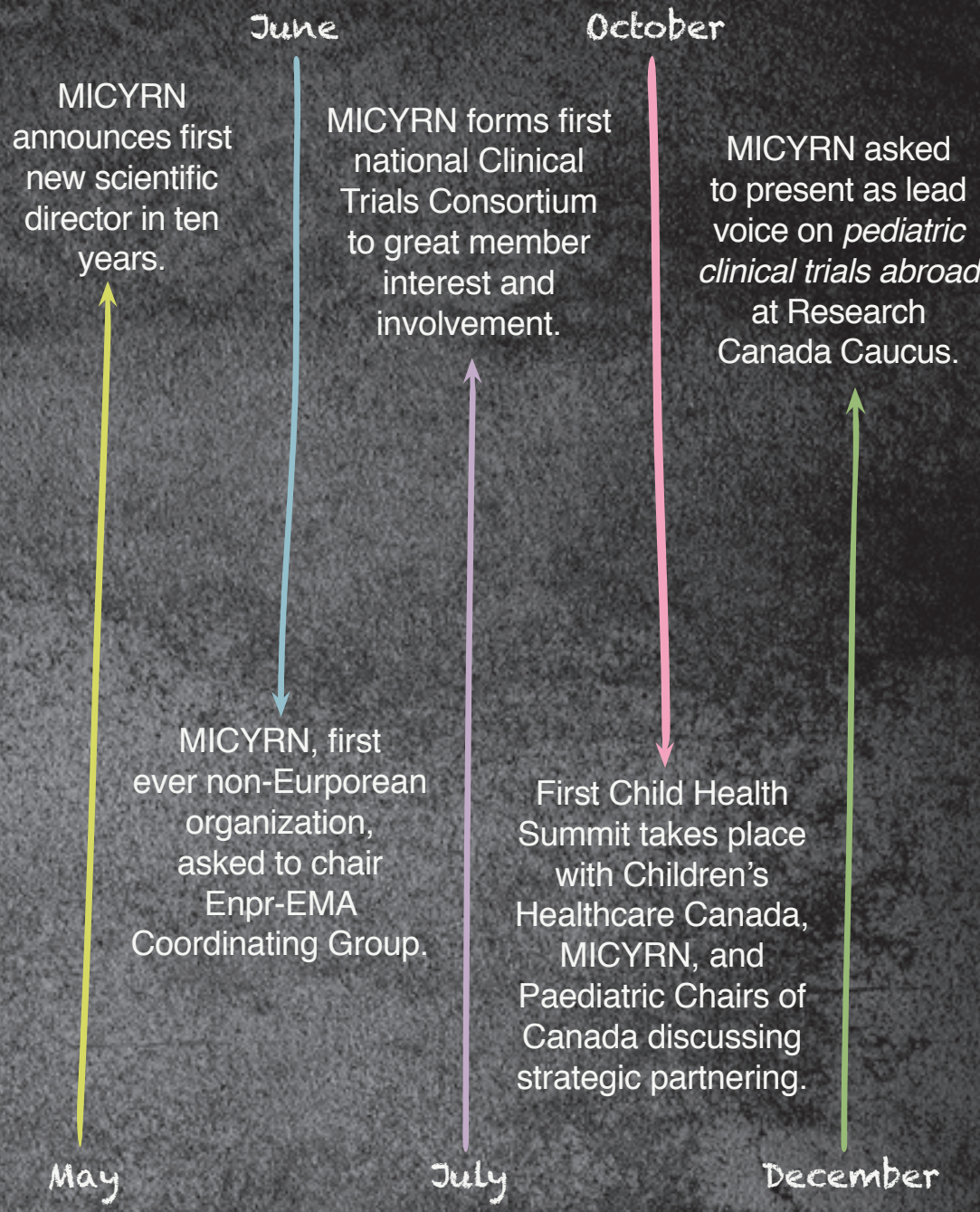
research-enabling  
partnerships

**MICYRN**

*better health for mothers and children*



# New directions in 2018



Enabling research

# People

## Enabling Research



## Governance

This year, Dr. William Avison completed his term on the MICYRN Board; he provided great insight into board issues, was the executive sponsor on MICYRN's clinical trials program, and the board member representative on the KidsCAN Steering Committee. Dr. Stephanie Atkinson also completed her final term with MICYRN. Over the years she has been a strong supporter of the network, and as vice-chair and then chair was instrumental in moving the maternal agenda forward. She spearheaded initiatives that led to a national birth cohort inventory that is now used by many investigators as a fundamental research tool to monitor children's health and development, and also link prenatal and early postnatal exposures to long-term outcomes.

In 2018, Drs. Ekat Kritikou (CHU Sainte-Justine), Martin Osmond (CHEO-RI), and Charlotte Moore Hepburn (Canadian Paediatric Society) joined the Board, bringing with them extensive and broad experience to the team.

## 2018 MICYRN Board of Directors

### **Brent Scott, MDCM, FRCPC (Chair)**

Alberta Children's Hospital Research Institute (ACHRI)

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

Women and Children's Health Research Institute (WCHRI)

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

Children's Hospital Research Institute of Manitoba (CHRIM)

### **Ekat Kritikou, PhD**

CHU Sainte-Justine Research Center

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

Canadian Paediatric Society

### **Martin Osmond, MD**

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

### **Suzanne Tough, MSc, PhD**

University of Calgary



## New Scientific Director

After ten transformative years of service, Dr. Anne Junker stepped down in 2018 as the scientific director of MICYRN. Under her leadership, the network evolved from working groups that performed initial environmental scans to a federally incorporated non-profit society that has formal affiliation agreements with over 20 Canadian pediatric specialty research networks. Anne gave Canada a global voice in rare diseases and pediatric clinical trials research; formed a collegial national federated ethics board offering review to many studies; and brought Canada's willing collaboration to the establishment of a global pediatric clinical trials network spearheaded by groups in the EU and USA.



Anne Junker



Thierry Lacaze

In May, Dr. Thierry Lacaze (ACHRI) assumed MICYRN's scientific leadership. With vast experience in trials, he is moving the national clinical trials for children agenda forward, focusing on the development of a national hub to coordinate research, training, and knowledge transfer in the safe, therapeutic use of medicines for children. He has extensive experience in leadership roles—in 2006 he was the inaugural director of WCHRI, and in 2010 recruited as a senior scientist at CHEO-RI, where he was the Clinical Research Unit's scientific director from 2011-15. Since 2016, Thierry has been the section head of Neonatology at the Cumming School of Medicine, and regional program director of Neonatology at Alberta Health Services. His areas of study include clinical trials with an emphasis on medications.

## New Clinical Trials Associate Director

In response to a call from members to establish an initiative that will develop pediatric clinical trial infrastructure across the country, Breanne Stewart (Northern Alberta Clinical Trials + Research Centre) was brought on to assist MICYRN as the network's clinical trials associate director. She plays a critical role in ensuring MICYRN is able to build child/family-centric research and education capabilities, and provides support to the Clinical Trial Consortium to streamline and improve clinical trial processes and systems, enhancing the quality and efficiency of regulated and non-regulated trials.



## New Directions

It has been almost one year since I joined MICYRN as the scientific director, and in that time have had the opportunity to cross the country and reconnect with the community, meeting many of our members from Vancouver to Halifax. One similarity between the different jurisdictions is the energy and involvement around the new clinical trials agenda. I look forward to the year ahead and connecting with other investigators as MICYRN—with the support of the research institutes, academic departments, children's hospitals and their foundations—will address the need identified by the Consortium for increased access to high-quality clinical trials supported by the development of an efficient, safe, and family-centred national infrastructure.

## Nouvelles directions

En Mai prochain, cela fera un an que le Conseil d'Administration de MICYRN m'a nommé directeur scientifique. Ma première tâche a été de renouer avec la communauté, de Vancouver à Halifax, pour mieux comprendre les attentes et les besoins des chercheurs. J'ai été frappé par le volonté partagée par les centres hospitaliers universitaires de construire une infrastructure nationale, en suivant l'exemple d'autres pays, pour optimiser la recherche clinique en santé mère-enfant. Cette année, MICYRN, avec le soutien des instituts de recherche, des départements universitaires, des centres hospitaliers et leurs fondations, poursuivra ses efforts sur les priorités établies par le Consortium, en construisant les différents éléments nécessaires à des essais cliniques de haute qualité.

Thierry Lacaze, MD, PhD

# Infrastructure Enabling Research



## Clinical Trials Consortium

In response to member consensus that the network prioritizes the development of a collaborative national infrastructure to support clinical investigations with an emphasis on multicentre clinical trials, MICYRN established a Clinical Trials Consortium.

The group, which is comprised of scientific and operational leadership at each of MICYRN's child health research organizations, has established five initial goals. These include:

- **Pediatric Trial Units:** Support the development of Clinical Trial Unit (CTU) capability across member organizations; build and maintain a national CTU database with information relating to clinical trials infrastructure, capability, competency, readiness,



coordination, and performance measurement; and create a registration process for Pediatric CTUs, which includes:

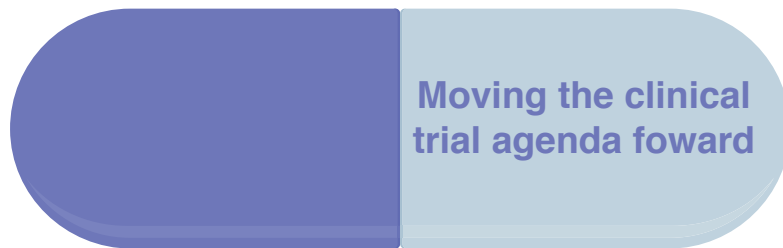
- 1) expertise continuity and stability
  - 2) infrastructure
  - 3) quality assurance
  - 4) information systems
  - 5) statistical input
  - 6) clinical research services
  - 7) education, training and patient involvement (making hospital more “research friendly”)
- **Multicentre Trial Guidance:** Develop star guidelines and procedural working documents in the conduct of multicentred trials; initial guidance topics include: placebo development/ labelling of study drug, master agreements for contracts, roll out of training to sites, and data collection and management
  - **Point of Contact:** Create a single clinical trials access point of information, resources and expertise for both industry and academic research (sponsors, other sites, and investigators); and develop points of contact with thought leaders across specialty networks to provide advice and expertise in areas such as study evaluation, protocol design, and review

- **Health Canada CTA Process:** Work with Health Canada on key guidance issues to better support sponsors in clinical trials applications to Health Canada
- **Ethics Harmonization Workshop:** Support the development of ethics harmonization for multijurisdictional studies in partnership with Clinical Trials Ontario and IHDCYH

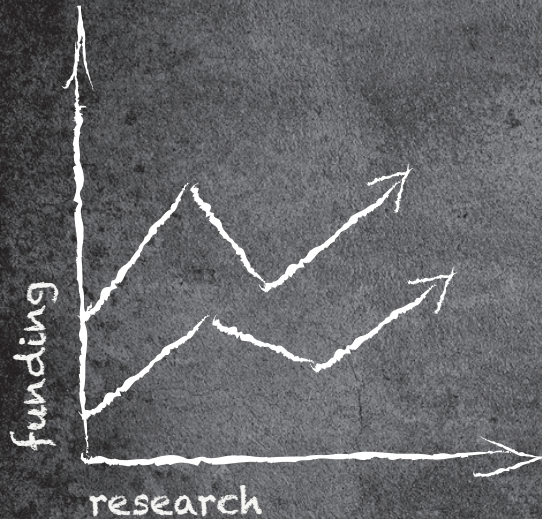
## KidsCAN Trials

KidsCAN Trials—a program of MICYRN—is working to ensure better medicines for children. In 2018, the program was involved in assisting the Canadian Paediatric Society and Goodman Pediatric Formulations Centre on the development of a policy paper, *Improving Paediatric Medications: A prescription for Canadian children and youth*.

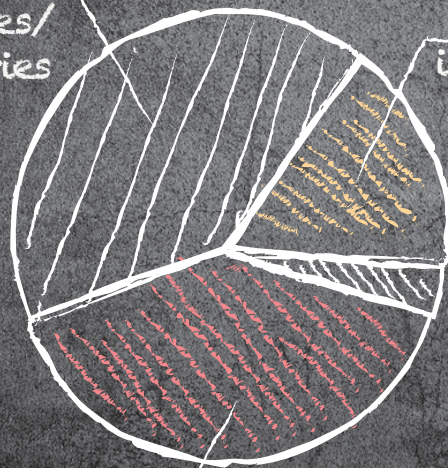
There has been difficulty finding information on dosing for children, so a national formulary/compendium would provide a valuable resource on drug dosing for physicians. There were extensive discussions with partners to provide a platform for the distribution of this information. Survey development, led by Dr. Geert 'tJong (CHRIM) and partnering with KidsCAN for dissemination assistance, was conducted to obtain information from potential users to learn what they would like to see from this type of source. A steering committee will be created to help determine next steps towards developing this national formulary.



# Funding Enabling Research



salaries/  
bursaries



indirect  
costs

administrative  
support

research  
support

## Rare Diseases: Models & Mechanisms Network

In 2018, RDMM's application for renewal was granted \$1.68M over four years. MICYRN continues to provide administrative, communication, and engagement support to the network. With 75% of rare diseases presenting in childhood, MICYRN is committed to supporting investigators working to potentially identify therapeutic and disease management strategies to help patients and their families. This renewal builds on the previous four-year grant, which funded 78 projects, nine that were awarded additional funds, resulting in twelve original scientific publications.

## MICYRN Sponsor's Speakers

At the 16th annual CCHCSP Symposium, Engaging EQ for Excellence, MICYRN sponsored Dr. Kathryn Sibley's (CHRIM) knowledge translation workshop. The session explored how KT questions can be incorporated into existing health research programs, and also identified opportunities, resources, and potential next steps for embedding KT research questions in one's own child health research programs.

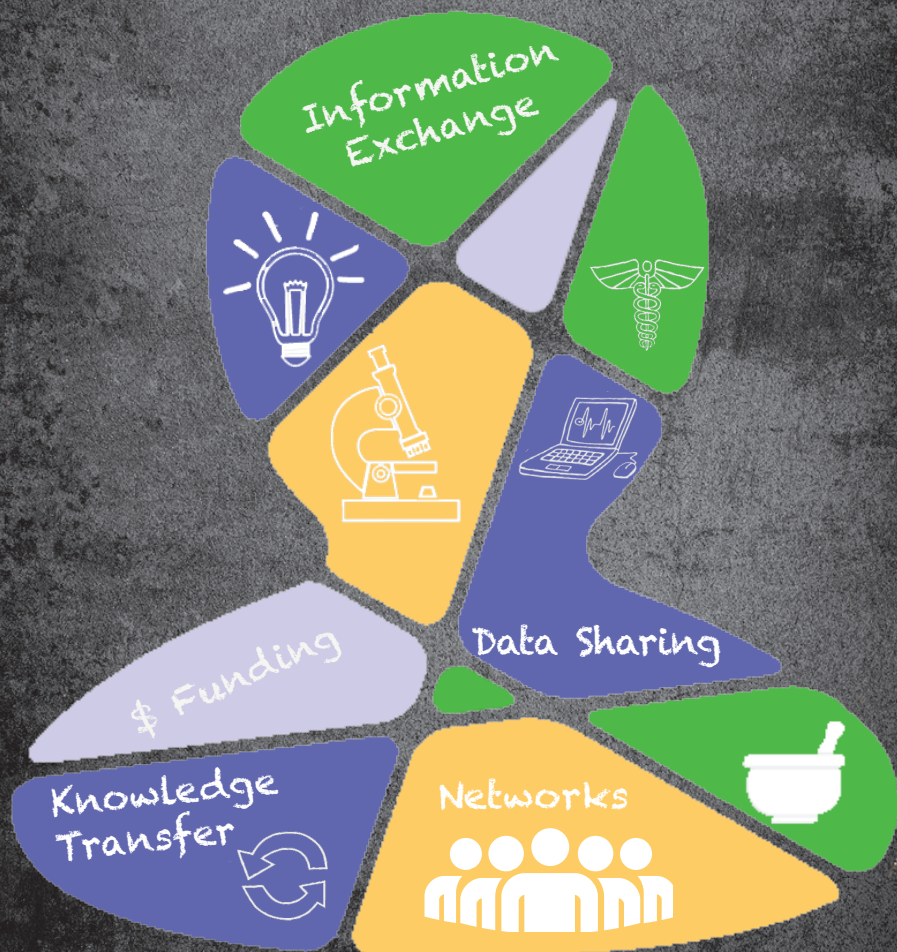


CCHCSP Symposium, tweetorial session

## Commitment to Research Support

MICYRN held its annual strategic planning retreat where attendees reviewed the current state of child and maternal health research in Canada and prioritized the network's activities in response. Members determined MICYRN should continue to facilitate and support the research of investigators at member sites through infrastructure development.

# Partnerships Enabling Research



## European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA)

At the Enpr-EMA annual workshop Thierry Lacaze represented MICYRN—the only Canadian organization and, along with the Pediatric Trials Network (Duke University), one of only two non-European members on the Coordinating Group. Working groups made up of volunteers from Enpr-EMA members address public-private partnership, ethics, participation of young patients in research, GCP training, and trial preparedness. Thierry chairs the working group on international collaboration (US, Europe, Canada, Australia, and Japan).

## Child Health Summit

MICYRN participated in a first ever Child Health Summit with members of the MICYRN Board of Directors, Paediatric Chairs of Canada, and Children's Healthcare Canada to identify opportunities for collaborating on child health priority issues. The group agreed that one of MICYRN's primary objectives—development of a collaborative national infrastructure to support clinical investigations—aligns with one of the priorities in Children's Healthcare Canada's 2019-2021 Strategy. Multicentre clinical trials will enhance Canadian child health through increased access to high-quality clinical trials supported by an efficient, safe, and family-centred national infrastructure. A number of areas for collaboration were identified, including:

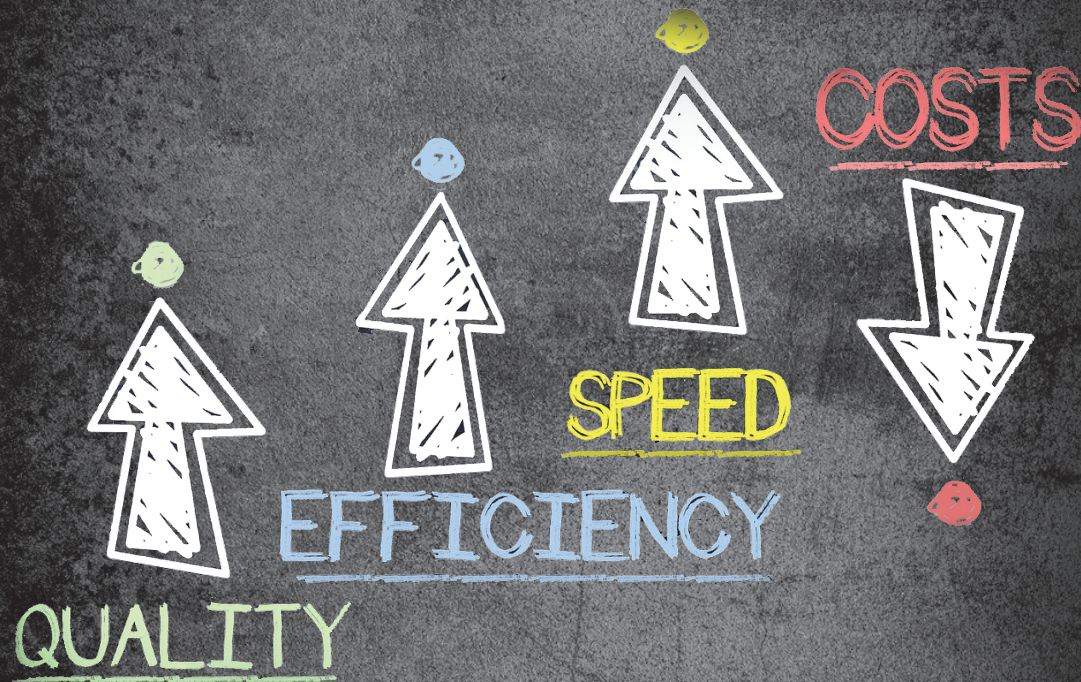
- Coordinated advocacy
- Patient and family engagement
- Data and patient databases – data sharing across jurisdictions
- Knowledge translation and dissemination
- Clinician investigator/scientist support
- Clinical trial support



*MICYRN strategic planning session post Child Health Summit*



# Services Enabling Research



## KidsCan Young Persons' Advisory Group

The Vancouver-based KidsCan Young Persons' Advisory Group (YPAG) presented work from Canada at the 2018 International Children's Advisory Network Summit in Scotland. The group's projects included an ongoing collaboration with the BC Health Research Connection Project on the newly initiated REACH Platform to engage members of the public in research, as well as a province-wide study to create a network of physicians to bridge the gap between paediatric patients with IBD transitioning to adult care. During the conference, the team also conducted research studies in efforts to survey the educational resources different youth advisory groups use around the world to train their members, as well as the need for standardized educational materials to allow efficient international collaboration.

MICYRN is partnering with the KidsCan YPAG to spearhead a Canada-wide research advisory group as a resource for clinicians and researchers to engage with youth in patient-oriented research, which will be led by Vivian Tsang.



Vivian Tsang (KidsCan) at the iCAN Summit in Edinburgh

## Engagement

With the vast number of articles published monthly, MICYRN recognized that investigators often do not have the time to scan every journal for the latest articles addressing trial methods, innovation, recruitment, reviews, large trials, medicines and ethics. In response, MICYRN began curating, synthesizing and then circulating a list of articles that address these areas for interested members of the community every few months. A number of impactful articles published by member investigators are blogged about on MICYRN's website, increasing exposure to important work and improving their altmetrics, helping with further circulation.

MICYRN initiated dialogue with communication leads at member organizations to explore ways to improve the visibility of investigator research. Outcomes included directives to increase the use of social media to improve exposure, blog articles to increase altmetric scores, and the future implementation of a new studies section in the quarterly newsletter. MICYRN's new website will also be an improved platform to increase the coverage of member publications.



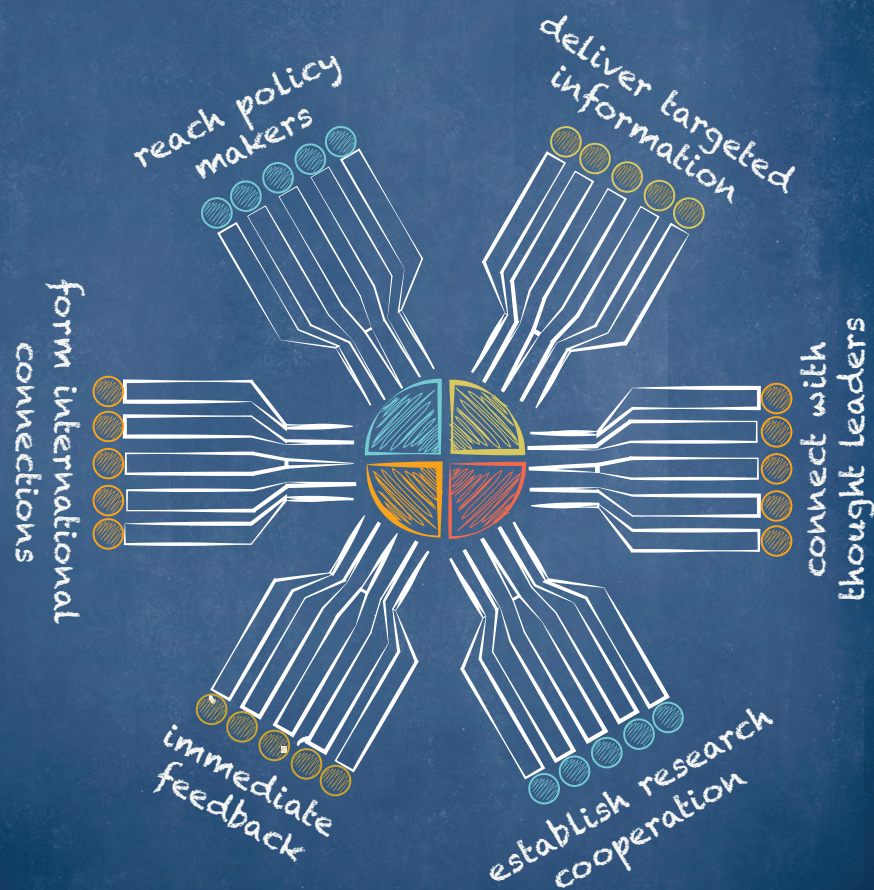
## Organization Support

Smaller organizations and teams supporting workshops and conferences often do not have a full complement of resources to ensure the best use of funds for their agendas. MICYRN has often provided a suite of services to reduce expenditures on operational support so more funding goes towards research and the support of research. In 2018, MICYRN signed memorandum of understandings with the Molly Towell Perinatal Research Foundation and the Canadian National Perinatal Research Meeting to provide administrative, project management, and communication services.



# Workshops

## Enabling Research



## Development of Canadian Childhood Cannabinoid Clinical Trials Workshop

Cannabinoids are increasingly being used in Canadian children for a variety of conditions including neurological disorders, cancer and chronic pain. This has accelerated from a small series of case reports and anecdotal online reviews in parent communities where families often desperately seek effective treatments for complex conditions. With Canadian legalization of cannabinoids in 2018, there is an urgent need to develop systematic approaches to building and evaluating the evidence for dosing, comparative effectiveness, and the long-term safety of medicinal cannabinoids in children. MICYRN started the groundwork with Dr. Lauren Kelly (CHRIM) to bring together clinicians and researchers, methodologists, regulators (including Health Canada), industry stakeholders, funders, and family representatives for a workshop in 2019—the first ever in Canada.



CANADIAN  
CHILDHOOD  
CANNABINOID  
CLINICAL TRIALS

## Innovations and Challenges in NDD Research

In February, Anne Junker shared the experience of MICYRN's national ethics working group to an invitational workshop – *Innovations and challenges in recruiting children with neurodevelopmental disorders in research*. Sponsored by Neuroethics Canada, Kids Brain Health Network, and Technical Safety BC, the workshop brought together individuals from across Canada to discuss cases that had been developed to highlight issues for further deliberation, such as undertaking research on personal information posted by neurologically compromised young people to community websites.

## Research Canada Meeting



from left: Martin Osmond (CHEO), Lawrence Richer (WCHRI), Rulan Parekh (SickKids), Thierry Lacaze (MICYRN) Cheryl Rockman-Greenberg (CHRIM)

On December 4th, Thierry Lacaze presented on behalf of MICYRN at the Parliamentary Health Research Caucus Luncheon, where he discussed pediatric clinical trial successes

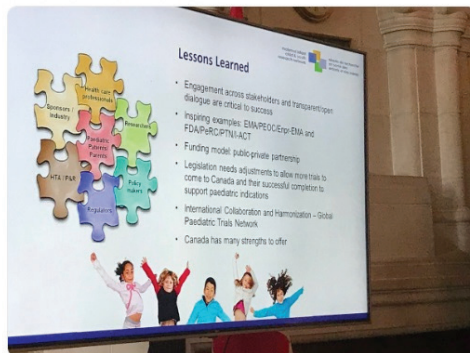
in the United States and Europe. Lessons learned from these other jurisdictions can be applied to the development of a national pediatric medicines and clinical trials systems. Dr. Cheryl Rockman-Greenberg (CHRIM) spoke on the *Current State of Canadian and International Paediatric Medicine and Clinical Trials*, and Dr. Rulan Parekh (SickKids) presented *How do we Build a Made in Canada Paediatric Medicine and Clinical Trials System?* The meeting was co-hosted by Children's Healthcare Canada and the Paediatric Chairs of Canada.

Emily Gruenwoldt Carkner  
@EGruenwoldt

Following

Engagement across stakeholders and transparent / open dialogue are critical to success and reform of peds clinical trials in Canada, says Dr Lacaze.

#HealthResearch4Kids  
#HealthResearchCaucus



10:00 AM - 4 Dec 2018 from Parliament of Canada - Centre Block

2 Retweets 3 Likes



## Financial Statements

STATEMENT OF OPERATIONS	2018/2019* (CAD\$)	2017/2018 (CAD\$)	2016/2017 (CAD\$)
<b>REVENUE</b>			
Member contributions	\$ 313,500	\$ 261,000	\$ 186,000
Other sources	\$ 155,927	\$ 77,225	\$ 34,000
<b>Total Revenue</b>	<b>\$ 469,427</b>	<b>\$ 338,225</b>	<b>\$ 220,000</b>

STATEMENT OF RESULTS	2018/2019* (CAD\$)	2017/2018 (CAD\$)	2016/2017 (CAD\$)
<b>EXPENSES</b>			
Coordinating centre operations	\$ 20,543	\$ 23,377	\$ 21,968
Salaries and benefits	\$ 273,023	\$ 266,228	\$ 243,932
Conferences and workshops	\$ 80,017	\$ 12,936	\$ 9,093
Platform salary support	\$ 24,000	\$ 3,000	\$ 32,882
<b>Total Expenses</b>	<b>\$ 397,583</b>	<b>\$ 305,541</b>	<b>\$ 307,875</b>

\* Unaudited

MICYRN is:



BC Children's Hospital Research Institute The 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
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



### Executive Staff

**Thierry Lacaze, Scientific Director**

Stephen Barbazuk, Executive Director

Christine Oriel, Administrator

Andrea Rudy, Engagement Associate

Breanne Stewart, Associate Director, Clinical Trials

The vision and support of MICYRN members who contributed financially to the network in 2018 has enabled our collective growth and transition. More than ever, we are positioned to address significant national issues and initiatives.

Thank you!



## Contact

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# MICYRN

maternal infant  
child & youth  
research network



réseau de recherche  
en santé des enfants  
et des mères

# RRSEM