



MICYRN

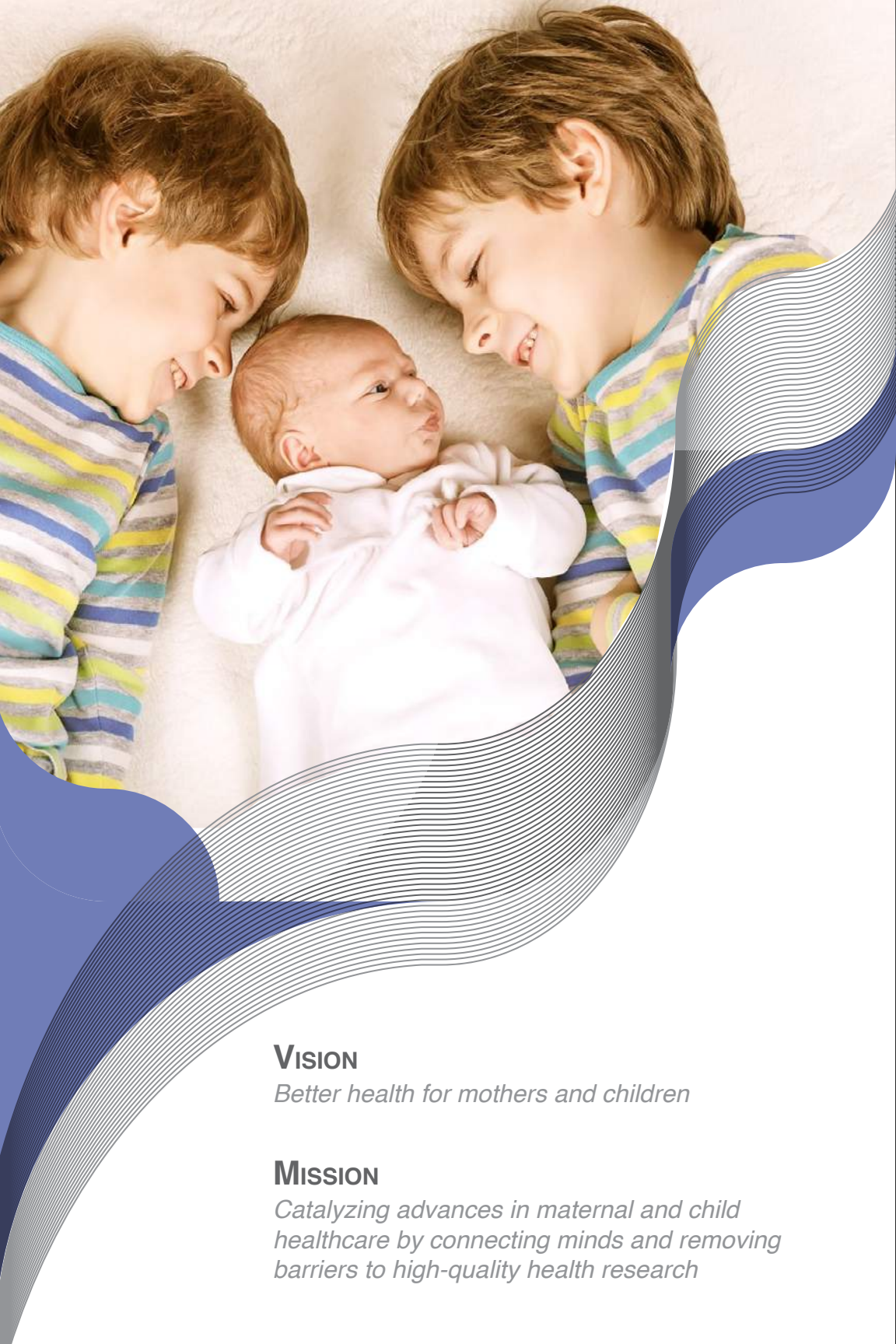
better health for mothers and children



Annual Report

2017





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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

From the chair of the board of directors

It is a pleasure to be taking over the position of board chair from Dr. Stephanie Atkinson. During her three-year term MICYRN has continued to evolve, this year merging with the Council of Canadian Child Health Research (CCCHR) to better facilitate our already aligned priorities and reduce the duplication of energies and resources. We look forward to the research advancements that the harmonized network will make in the coming years.

On behalf of all our members, I must take this opportunity to recognize Dr. Anne Junker, who will be stepping down as scientific director after ten highly effective years. Her vision and dedication to MICYRN and its partner institutions and programs have been transformative. Under her leadership, MICYRN evolved from working groups that performed environmental scans to a federally incorporated non-profit society that has formal affiliation agreements with over 20 Canadian pediatric specialty networks; partnerships with national organizations advancing maternal and child health; and international relationships. Anne has given Canada a global voice in rare diseases and pediatric clinical trials research; supported the Rare Diseases: Models and Mechanisms Network; and brought Canada's willing collaboration to the establishment of a global pediatric clinical trials network spearheaded by groups in the EU and USA. Relationships were also established with leaders of pregnancy and birth cohorts to develop a registry supporting research into the developmental origins of health and disease.

Looking forward, MICYRN will build on the work accomplished under both Anne and Stephanie's direction.



Brent Scott, MDCM, FRCPC
Chair, Board of Directors

Message

From the scientific director

It has been an honour to serve as MICYRN's scientific director for the past ten years, and I would like to thank the board, member representatives, and coordinating centre staff. Through your hard work and dedication, MICYRN has become a truly collaborative national network able to respond quickly to arising needs of the maternal and child health research community.

Global strategies for pediatric clinical trials and rare disease research were a substantial topic in 2017, leading to the development of multi-national networks and successful funding applications in Canada, Europe and the United States. MICYRN was involved in a number of these partnerships, which we hope will continue to grow in the future. With continued need for ethics review and clinical informatics tools, MICYRN provided support to a number of investigators and input on several successful grant applications, offering in-kind services.

This work would not be possible without the generous contributions from our member organizations and partners, who consistently show their confidence in MICYRN's mission by giving their expertise, time, and financial support.



Anne Junker, MD
Scientific Director

Governance

MICYRN's leadership

In January, Dr. Alan Bocking stepped down after completing his two-year term as MICYRN's vice chair. He was extremely pivotal in directing the maternal research agenda, giving his time and expertise to ensure MICYRN was effective in addressing needs and opportunities. We are grateful for his tireless efforts in supporting the network's mission and objectives.

Drs. Jon Barrett (Sunnybrook Health Sciences Centre) and Patrick McGrath (IWK Health Centre) completed their terms on the board, and we would like to thank them for their service. With the harmonization of MICYRN and CCCHR, Dr. Terry Klassen (CHRIM), formerly on the CCCHR executive, joined the board of directors. Under the new model, the network will take on an additional objective—advocacy and training.

Dr. Brent Scott (ACHRI) assumed the position of chair, while Dr. Stephanie Atkinson (McMaster University) remained on the board after completing her term as chair.

2017 BOARD OF DIRECTORS



Brent Scott, MDCM, FRCPC
Alberta Children's Hospital Research Institute



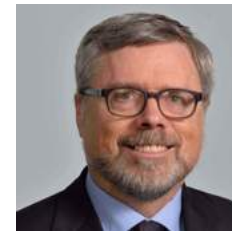
Stephanie Atkinson, PhD, DSc (Hon), FCAHS
McMaster University, Department of Pediatrics



William Avison, PhD, FCAHS
University of Western Ontario
(Professor Emeritus)



Sandra T. Davidge, PhD, FCAHS
Women and Children's Health Research Institute



Terry Klassen, MD, MSc, FRCPC
Children's Health Research Institute of Manitoba



Katie Lafferty, MS
Canadian Partnership for Stroke Recovery



Suzanne Tough, PhD
University of Calgary

Notes and Noteworthy

RECOGNITION

MICYRN executive members, affiliated teams, and supported investigators were recognized for research excellence.

Awards

Stephanie Atkinson

*Khursheed Jeejeebhoy Award:
Best Application of Clinical
Nutrition Research Findings to
Clinical Practice*



1



Anne Junker

*CORD Rarity Award:
Scientific Leadership Award*



2



BCCHR REDCap Team

REDCap Conference Awards:

- 1st place: Best Training Materials Competition
- 3rd place: Best Poster Competition



3



Successful Grant Applications with MICYRN's Support:

- *Global Pediatric Clinical Trials Network and i-ACT for Children*
- *Innovative Pediatric Clinical Trials (Terry Klassen, PI)*



4



AIDING AND ASSISTING IN RESEARCH ENDEAVORS

MICYRN responded to requests for assistance through direct support and by connecting groups to further their research.

RDMM and MICYRN's coordinating centre were consulted as a model to emulate in similar networks to be launched in Japan, Australia, and Europe.

1

KidsCAN Trials website and Twitter account developed and managed by MICYRN coordinating centre:
website: averaged 120 visitors/month
Twitter: averaged 60 new followers/month

2

Research Engagement: Vancouver-based Young Persons' Advisory Group contributed feedback on studies at BCCHR, RI-MUHC, SickKids-RI, McMaster University, and ACHRI.

3

MICYRN and Paediatric Chairs of Canada establish joint priorities:

- develop best practices for clinician scientists
- advocacy for coordinated child health research

4

Engagement

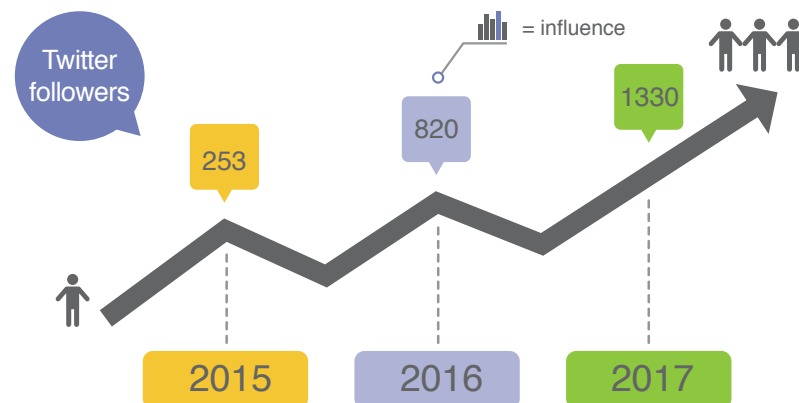


MICYRN is working to reach the thousands of Canadians engaged in maternal and pediatric health research.

COMMUNICATION CHANNELS

Through engagement activities, MICYRN continued to connect and inform in order to further research achievements by fostering collaboration, partnerships, and the implementation of resulting evidence.

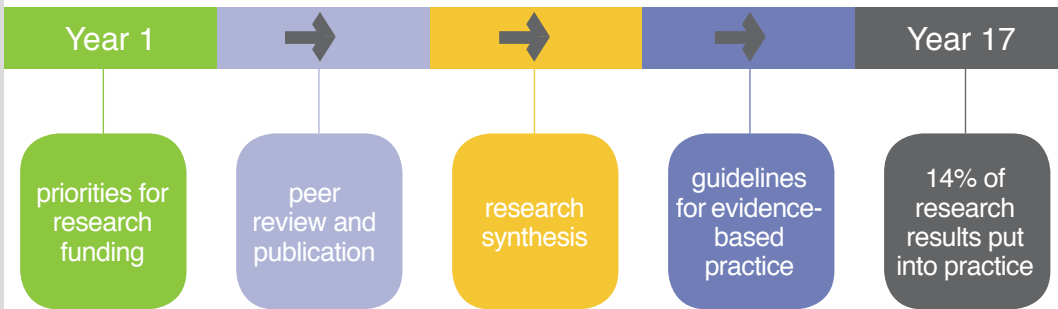
Developing communication channels that can be tapped into when needed for broad dissemination of information can improve the overall impact of research.



BUILDING CAPACITY FOR HIGH-QUALITY APPLIED HEALTH RESEARCH



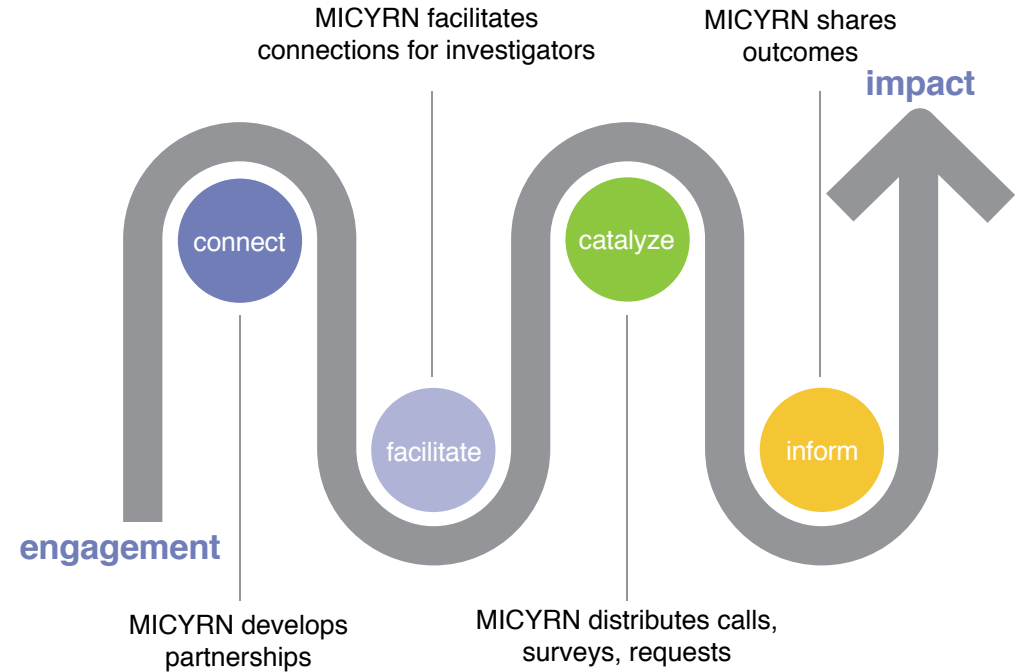
ESTIMATES SHOW RESEARCH OUTCOMES THAT WILL IMPROVE TREATMENT TAKE 17 YEARS TO MAKE IT TO PRACTICE.*



MICYRN is looking to engage investigators, knowledge mobilizers and hospital administration to reduce barriers to uptake of evidence in clinical practice.

* Dr. Christine Chambers, "Moving Child Health Research from Knowledge to Action." Celebrate Research Day, BCCHR

WORKING TO INCREASE RESEARCH ENGAGEMENT AND IMPACT OPPORTUNITIES



A photograph of two young children sitting on stone steps outdoors. The child on the left is a toddler with dark hair, wearing a white t-shirt and plaid pants. The child on the right is a young girl with blonde hair, wearing a denim jacket over a white t-shirt and blue jeans. She is holding a red apple and appears to be about to take a bite. The background is a soft-focus outdoor setting. The image is framed by a green and blue abstract graphic design.

Partnerships

The past decade has seen an explosion in the number of global health research partnerships. Collaborations can maximize return on investment and improve opportunities for discovery.

MICYRN recognizes the need for greater inter-institutional collaboration at the national and international levels. Connecting investigators, networks and research teams helps ensure strong proposals are developed and ultimately successful.

INTERNATIONAL

In 2017, the U.S. FDA awarded grants to two proposals aiming to improve the conduct of global clinical trials of new drugs and devices for children, both of which had letters of support from MICYRN indicating what Canada could bring to a global network. The Institute for Advanced Clinical Trials for Children was awarded a US \$1M per year grant for up to four years; Anne Junker represented Canada on the External Advisory Committee, which provides advice on global interoperability. Duke University hosts the Pediatric Trials Network (PTN)—for which MICYRN facilitates the Canadian sites—and was a grant recipient under the same competition. The KidsCAN Trials team (Dr. Thierry Lacaze, lead) visited Duke to discuss continued expansion of PTN work in Canada and future knowledge and resource sharing.

MICYRN continued to represent Canada at the European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA), out of which the European Paediatric Clinical Trial Research Infrastructure (EPCT-RI) originated. EPCT-RI and the European Clinical Research Infrastructure Network (ECRIN) came together to form the Paediatric Clinical Research Infrastructure Network (PedCRIN), which was awarded €3.3M in funding over four years from the European Union's Horizon 2020 program. This funding will help connect pediatricians and other European and international partners to combine resources and expertise for conducting robust studies, while minimizing risk and protecting child participants.

In September, Thierry Lacaze visited ECRIN and PedCRIN to discuss opportunities for collaboration between Canada and the EU. The productive meeting resulted in an agreement to

initiate work on various training and educational items, as well as sharing material and experience as the organizations evolve.



(from left: Michiko Takakura, Noriaki Imanishi, Yoshihiko Izumida (Japan Agency for Medical Research and Development), Anne Junker (RDMM, MICYRN), Stuart Turvey (BCCHR), Michel Leroux (RDMM), Ituro Inoue (National Institute of Genetics))

Japanese scientists from the Initiative on Rare and Undiagnosed Diseases—a program of the Japan Agency for Medical Research and Development—visited Vancouver in late 2017 to meet with the Vancouver-based members of the Rare Diseases: Models & Mechanisms (RDMM) Network. They spent an afternoon with the MICYRN coordinating centre staff to hear about activities that support the RDMM. The team came to learn how the Canadian RDMM operates as they look to establish a Japanese rare diseases network.

NETWORKS

MICYRN has increasingly become a first point of contact for national and international bodies looking to connect with Canadian pediatric subspecialists with expertise in niche areas. In 2017, some of these contacts included Health Canada looking

for individuals to contribute to focus group sessions on new therapies for pulmonary arterial hypertension; SynteractHCR—a CRO wanting to conduct a feasibility survey for a metabolic disease; and on several occasions by the European Medicines Agency.

In March, the EU created 23 rare disease European Reference Networks (ERNs) as legal entities to serve as research and knowledge centres and, for the first time, provide the unique opportunity for clinicians to work across borders in Europe. Several of MICYRN's affiliated networks align with the ERNs; leaders of those presented at the 2017 Canadian Organization for Rare Disorders (CORD) conference, raising awareness of the considerable impact our networks have made. The Canadian Health Standards Organization has been contracted to implement the ERNs and continue to work on training, standards development, and evaluation.



Dr. Phil Hieter (RDMM), second from right
CORD 2017 conference rare disease network panel

CONFERENCES

In today's era of online information exchange (webinars, blogs, social media), coupled with the narrowing of research sub-specialties, attending conferences may seem like an unnecessary use of time and resources. Face-to-face meetings at conferences, workshops, and symposiums, however, are still a very important process in research communication. It can significantly improve opportunities to generate immediate feedback and debate, make international connections, reach policymakers, meet other investigators who may not be visibly active online,

and establish research cooperation. Importantly, it can also cut through the overwhelming amount of online content and deliver the best—and most targeted—material to researchers. MICYRN is committed to providing support to face-to-face meetings and conferences, and in 2017 assisted in developing the judging process for the annual Canadian National Perinatal Research Meeting, which showcases Canada’s immense contribution to perinatal research and its role in the global effort of supporting and maintaining maternal and child health and policy. As a conference gold sponsor, MICYRN developed a tool that enabled real-time tallying of presentation scores, with expert advice from the BCCHR Research Informatics team.

At the 2017 REDCap conference, members of the MICYRN informatics working group organized a workshop for the Canadian User Group, and initiated conversations about bringing the 2019 conference to Canada. In addition, at the annual CORD conference MICYRN’s executive director, Stephen Barbazuk, presented during the Designing Rare Alliance Canada session, demonstrating how collaboration can generate a national focus on tackling key issues and needs common to all research



networks, and how only through national shared infrastructure can network efficiencies of a Rare Alliance Canada be realized.

ANNUAL GENERAL MEETING

The 2017 AGM was held in Montreal in conjunction with the annual CAPHC conference and the Paediatric Chairs of Canada’s meeting.



At the 2017 strategic planning retreat, member representatives and executive met to review the direction of the child and maternal health research community to help prioritize activities in the context of a harmonized network, and explore ways to meet common objectives with larger stakeholder groups.

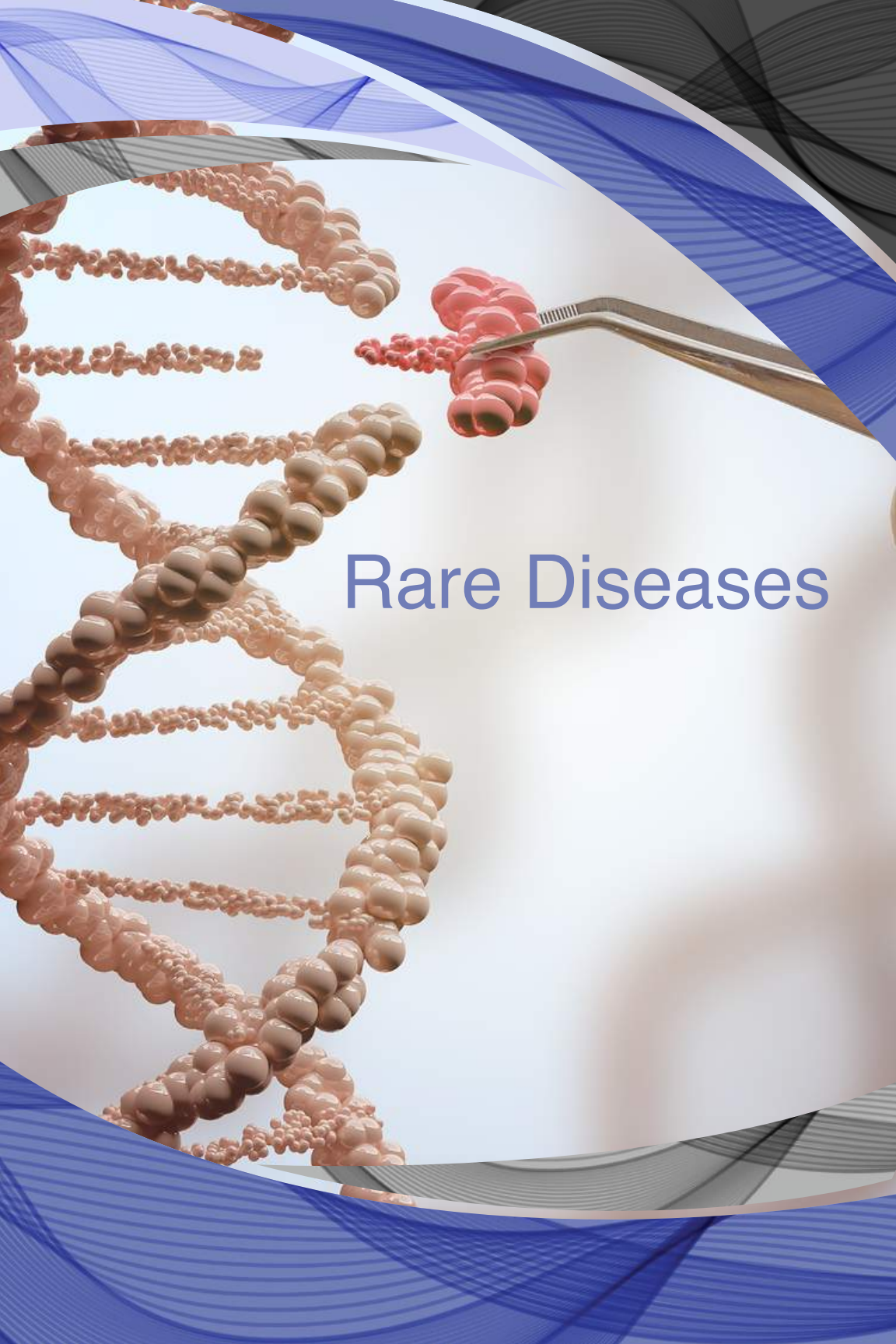
Clinical Trials

It is imperative that children are treated with medicines tested in their population—clinical trials are critical to ensuring they are given the safest and most effective treatments.

It was a pivotal year for the advancement of pediatric clinical trials in Canada. The Innovation in Pediatric Clinical Trials application (lead PI Terry Klassen, CHRIM) was awarded \$3M over four years under the SPOR operating grant program. It will respond to challenges specific to conducting clinical trials for children, including the need to coordinate studies across multiple sites because of the relative infrequency of many childhood illnesses. This grant begins the work for KidsCAN Trials, which is developing as a coordinating and advisory infrastructure platform to ensure best therapies for children with a goal to streamline clinical trial processes, enhance timeliness, and facilitate administrative and regulatory submission.

WCHRI's informatics core will provide trials data management services; the MICYRN ethics working group will provide support and collaboration to address ethics challenges facing multi-site trials; while the coordinating centre will offer its suite of services to support the program. The KidsCAN Trials website was launched and describes the services it will provide, which includes phase 2 + 3 regulatory trials and pragmatic randomized comparative effectiveness studies using innovative clinical trial designs and existing real-world data. A number of other proposals supported by MICYRN in 2017 are under review.



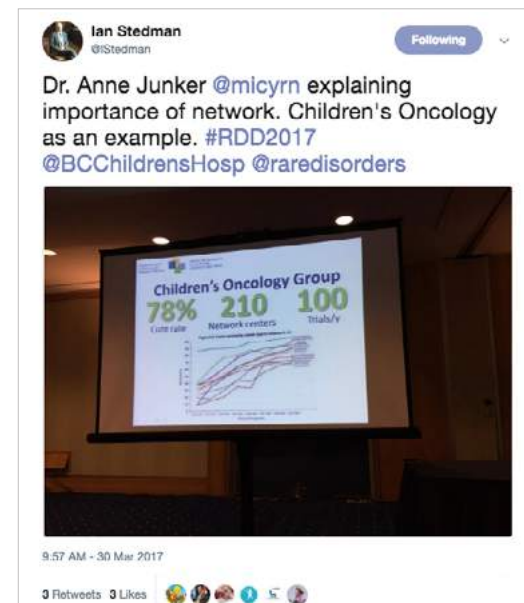


Rare Diseases

With close to a third of children’s hospital admissions due to rare diseases, research into diagnoses, therapies and possible cures is vital.

CORD continues its advocacy and development of a national plan for rare diseases, and at their fall conference Stephen Barbazuk presented on tackling key issues common to all research networks during the Designing Rare Alliance Canada session. The presentation stressed the importance of a national infrastructure to achieve the vision of Rare Alliance Canada, which would optimize clinical care and research for patients with rare diseases. He also participated on a panel for design of Rare Alliance Canada with discussions on essential features for rare disease networks; how to assure quality and sustainability; and how these networks can contribute to increasing awareness, education, and training.

At CORD’s Rare Disease Day Awards Gala, Anne Junker was presented the Scientific Leadership Award recognizing individuals making extraordinary contributions to the Canadian rare disease community. The award is given to a distinguished researcher whose career represents both scientific excellence and support of the patient community. She also presented on a panel addressing the Vision for Canadian Rare Disease Networks, explaining the importance of networks in research and clinical trials, and highlighting MICYRN’s work in bringing them together in a formal affiliation.



MICYRN continued to support the RDMM network, which awarded 24 grants in 2017. PIs in Europe, Australia and Japan approached RDMM to share experiences, infrastructure, and materials to assist in the development of rare disease model networks in their regions.





MICYRN continues to stress the necessity for a national ethics review board for multijurisdictional studies.

MICYRN's ethics group was tapped to provide input into plans to establish harmonious approaches for several pediatric clinical trials being developed with innovative designs that present challenging ethics issues. These approaches include cluster randomization of hospital sites, establishing outcome measures after trial commencement, and promoting participant selection of a trial arm.

Anne Junker brought the experience of MICYRN's ethics group to a national group of senior ethics officers, which formed to test a model of single ethics board review of research involving multiple sites across the provinces. A new system and processes developed by Clinical Trials Ontario now provide for a single review by either the CHEO or SickKids research ethics boards of pediatric studies being carried out in Ontario. Quebec has also introduced a program to streamline ethics review of multi-site studies in the province.



Clinical Informatics



The need for access to data is equally important as requirements for data security and consensus on standards in research.

A project exploring the utility of i2b2 (Informatics Integrating Biology & the Bedside) to harmonize large data sets in diabetes clinic registries and provincial health administrative data wrapped up in 2017. It was co-led by Drs. Lawrence Richer (WCHRI) and Elodie Portales-Casamar (BCCHR)—former and current lead of the MICYRN informatics working group, respectively—and was ultimately successful in demonstrating technical feasibility and obtaining expertise in the technology, data models, and data transformation processes. A big success was the development of a BC-Alberta harmonized data dictionary based on the European SWEET database, which will facilitate international collaborations. MICYRN supported a 0.5

FTE programmer during the first phase in 2016, with work that continued into 2017 to provide a fully functional i2b2 instance for pediatrics diabetes data in BC, drawing on ambulatory clinic and administrative health data.

At the annual REDCap conference, a workshop for the Canadian REDCap User Group was organized for attending members of MICYRN's informatics working group. During the event, the BCCHR REDCap team, headed by Dr. Portales-Casamar, won the Best REDCap Training Materials Competition for "Data Management Tips and Tricks," as well as third place in the Best Poster Competition for their entry titled "Towards a Systemic and Sustainable Validation Strategy."

DATA

The [Research Advancement through Cohort Cataloguing and Harmonization \(ReACH\)](#) initiative, which developed from MICYRN's pregnancy/birth cohort coalition, made significant advancements in its first year. The catalogue now includes 25 studies representing more than 125,000 participants. Four generic participant consent/assent forms are available to aid investigators in creating consent forms if they are developing new cohort studies or re-consenting subjects of previous studies. Pilot studies involving harmonization and co-analysis as demonstration projects of the application of the metadata catalogue are being developed within the existing Canadian cohorts. A presentation of ReACH was made at the International Developmental Origins of Health and Disease meeting in Rotterdam, Netherlands.

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	SK
Children's Hospital Research Institute 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 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	2017/2018* (CAD\$)	2016/2017 (CAD\$)	2015/2016 (CAD\$)
REVENUE			
Member contributions	\$ 261,000	\$ 186,000	\$ 225,000
Other sources	\$ 65,123	\$ 34,000	\$ 87,003
Total Revenue	\$ 326,123	\$ 220,000	\$ 312,003

STATEMENT OF RESULTS	2017/2018* (CAD\$)	2016/2017 (CAD\$)	2015/2016 (CAD\$)
EXPENSES			
Coordinating centre operations	\$ 15,074	\$ 21,968	\$ 37,569
Salaries and benefits	\$ 259,570	\$ 243,932	\$ 235,822
Conferences and workshops	\$ 13,011	\$ 9,093	\$ 29,370
Platform salary support	\$ 3,000	\$ 32,882	\$ 17,118
Total Expenses	\$ 290,655	\$ 307,875	\$ 319,879

* Unaudited

Thank you to our 2017 financial supporters!



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