

The Picture in 2015

Annual Report

maternal infant
child & youth
research network



réseau de recherche
en santé des
enfants et des mères



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Letter from the Chair and Scientific Director

When putting together this year's annual report we stopped to reflect on how far MICYRN has come since first founded in 2006. At that time, the directors of the child health research organizations across Canada came together to respond to new opportunities in clinical research, with the view that only through coordinated efforts can we achieve the greatest results. Now, ten years later, the network is still unique in the world for this type of collaborative engagement. Commencing as CYRN (the Child & Youth Research Network), acknowledgement of the critical role of maternal health, the gestational environment, and early infant experiences on lifelong health and wellbeing quickly led to the expanded scope and inclusion of maternal and infant health research. Early reviews revealed national-scale studies were being conducted by more than 100 research teams and specialty networks, each working in silos to address barriers to multi-jurisdictional research. One of MICYRN's leading priorities has been to address these barriers. As of 2015, 83% of the research teams that sought the support of MICYRN were funded.

MICYRN provides teams with connections to a broad range of stakeholders and multiple avenues to help shape proposals, carry out studies, and relay the results of research. The network's working groups in ethics, informatics, and clinical trials can provide assistance in these key areas. In addition, the MICYRN coordinating centre staff can provide a very cost-effective suite of complementary skills for project management, communications, and meeting organization – meaning more grant funds can be spent doing research.

Early work by MICYRN also countered demand to create a national birth cohort in finding that upwards of 45 Canadian pregnancy and birth cohort studies had already been funded. A seed grant supported a small workshop to bring cohort leaders together and begin collegial interactions, including establishment of a cohort inventory hosted these past years on the MICYRN

website. This year, MICYRN's birth cohort working group provided the critical foundation in a successful application to CIHR to create a national registry of cohort metadata, which will support research on the developmental origins of health and disease (DOHaD). New connections were established with basic science DOHaD researchers and environment investigators.

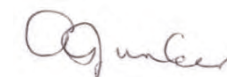
In this report to our communities and members we also highlight progress made on some of our newer initiatives, including rare diseases, stakeholder engagement, and clinical trials. MICYRN is actively engaged on both the national and international stages, and through its strong, effective membership is helping to catalyze research and champion causes central to maternal, infant, child and youth health and health care.

As always, we would like to take this opportunity to thank our members and partners who have generously contributed not only financially, but also through their time and expertise. We are pleased to highlight our progress and provide insight into where the network is headed. This is the picture of 2015.

Sincerely,



Stephanie Atkinson, PhD, FCAHS
Chair, Board of Directors



Anne Junker, MD
Scientific Director





Governance

We are grateful to the leadership and contributions provided by Drs. Janet Rossant (SickKids Research Institute) and Elizabeth Asztalos (Sunnybrook Research Institute), who stepped down as the representatives for their member organizations. Taking over for SickKids Research Institute is Dr. Michael Salter, the chief of research and a senior scientist in neurosciences and mental health. Sunnybrook Research Institute is now represented by Dr. Jon Barrett, a senior scientist and head of the maternal-fetal medicine program.

This year, Drs. William Avison and Patrick McGrath were elected to the board of directors. Dr. Avison, a professor emeritus at the University of Western Ontario and scientist at CHRI, brings expertise in the sociology and epidemiology of mental health to MICYRN. Dr. McGrath is the integrated vice-president of research and innovation at IWK Health Centre, and a leading researcher on pediatric pain and distance treatment to increase access to psychosocial health care.

The 2015 MICYRN Annual Report continues to highlight the network's contributions to building maternal, infant, child and youth research capacity across the country through four processes: connecting, facilitating, catalyzing and informing.

2015 Board of Directors

| | |
|--------------------------------------|---|
| Stephanie Atkinson (chair) | McMaster University |
| William Avison | Children's Health Research Institute (CHRI) |
| Alan Bocking (vice-chair) | Lunenfeld-Tanenbaum Research Institute, Mount Sinai Hospital |
| Sandra Davidge | Women and Children's Health Research Institute (WCHRI) |
| Katie Lafferty | Canadian Partnership for Stroke Recovery |
| Patrick McGrath | IWK Health Centre |
| Alain Moreau | Centre hospitalier universitaire Sainte-Justine |
| Martin Osmond | Children's Hospital of Eastern Ontario (CHEO) Research Institute |
| Brent Scott | Alberta Children's Hospital Research Institute (ACHRI) |
| Aubrey Tingle | Professor Emeritus (Pediatrics) University of British Columbia |

Global contributions made by representing Canada

MICYRN has been invited to play a role in a number of ventures due to its strong international connections in the child and maternal health research community. These contributions ensure a strong voice is representing Canada on global initiatives.

1. Critical Path Institute – Global trials (page 17)
2. Youth Advisory Group – iCAN Research
3. CIHR ethics review of innovative clinical trials (page 13)
4. GA4GH – Ethics review equivalency (page 13)

4

Collaborations leading to new funding for research opportunities

Many discoveries that change the course of medical care for the better come out of collaborations. MICYRN is working to initiate these collaborations in maternal and child health research.

1. Rare Diseases: Models & Mechanisms Network (page 15)
2. Clinical Trials via KIDSCAN and PTN (page 17)
3. DOHaD research via REACH Registry and birth cohort inventory
4. Can-SHARE – (page 13)
5. Networking in Pediatric Chronic Disease

5

By the Numbers

23

Specialty research networks affiliated with MICYRN

Two new networks, the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) and Pediatric Investigators Collaborative Network on Infections in Canada (PICNIC) affiliated with MICYRN in 2015. Our rich diversity of networks captures virtually all the neonatal and pediatric intensive care beds, all of the academic pediatric emergency, surgical and anesthesia services, most subspecialty pediatric practices, and 70% of the high-risk maternity beds in the country.

Success rate for research teams applying for funding

Overall, there is a high rate of success for research teams who seek the support of MICYRN's connections and infrastructure in their funding applications. (page 20)

83%

At a Glance

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

Four-pillar approach to improving research effectiveness and uptake

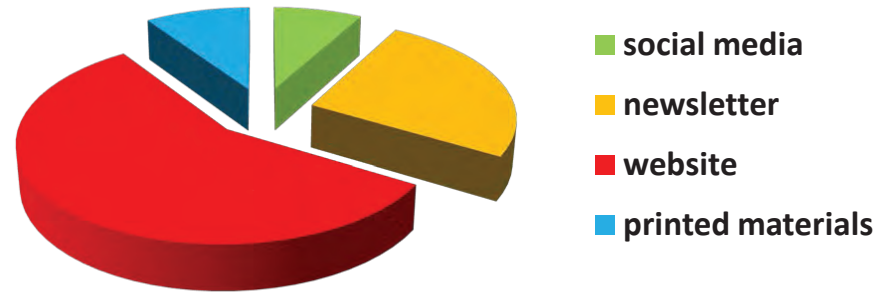
1. Connecting
2. Facilitating
3. Catalyzing
4. Informing

Reach across Canada



Engagement

- social media:** 253 Twitter followers and Facebook visits (Oct-Dec)
- newsletter:** 808 addresses on MICYRN and RDMM distribution lists
- website:** 1800 average number of unique visitors (2442 total)
- print materials:** 275 copies of reports and pamphlets distributed



Authorization for Consent to Medical Treatment of Minor Child

If your child needs emergency medical care and you aren't available to give formal consent to medical authorities, care may be unnecessarily delayed. To protect your child, leave a completed **EMERGENCY CONSENT FORM** with your baby-sitter, day care center or temporary guardian. In the event of a medical emergency, the form should accompany your child to the hospital.

I/we hereby authorize _____ to give consent for all medical and/or surgical treatment that may be required for our child during our absence.

Child's Full Name _____
Date of birth _____
Child's Physical history: _____
Child's Allergies: _____
Medical Immunization _____
Parent/guardian Telephone #: _____
Emergency contact (other than _____): _____

MICYRN's Response

The network is tackling these challenges on a number of fronts and in 2015 made advances in the following areas:

- Collaborating in research to improve ethics review equivalency
- Building partnerships to improve the information and suite of tools available to investigators and ethics committee members
- Participating in the Global Alliance for Genomics and Health (GA4GH) to establish a common framework of harmonized approaches to enable effective and responsible sharing of genomic and clinical data
- Working to define issues related to data sharing and develop consensus on approaches, ultimately providing important input into policy and practices

The Issue Today

Multijurisdictional research is common in the Canadian reproductive and child health research community, but the ethics approval process is inefficient, resource intensive, and can take upwards of two years for a study to be approved at all sites. Ethics issues challenge the capacity of REB members at multiple institutions to stay up-to-date and retain expertise needed to perform high-quality reviews.

At a Brocher Foundation workshop in Geneva, Dr. Anne Junker presented the MICYRN ethics working group's model of federated review of research proposals involving multiple sites in Canada. Through a new grant, Can-SHARE (PI Bartha M. Knoppers), MICYRN is receiving funding to support the informatics, ethics, birth cohort and rare diseases work. Stress testing models of ethics review equivalency, which produced a policy paper in *Science*, will be a key activity in the year ahead.

Based on her experience with MICYRN, Dr. Junker was also invited to join an advisory panel called by CIHR to revise approaches to ethics review on innovative clinical trials.

Rare Diseases

Rare Diseases

MICYRN's Response

In 2015, the network addressed these issues on a number of fronts, including:

- Providing the key logistical and administrative support to the Rare Diseases: Models & Mechanisms Network (RDMM)
- Participating in Can-SHARE, the CIHR-Genome Canada funded Canadian arm of the Global Alliance for Genomics and Health, which aims to establish harmonized approaches to enable international sharing of genomic and clinical data

The Issue Today

There are an estimated 8,000 rare diseases, the majority of which present in childhood with serious complex conditions. About one-third of those admitted to children's hospitals have rare genetic diseases, and account for almost 50% of the hospital's spending. Validating new discoveries and sharing information is essential to investigating the genetic causes of rare diseases.

The RDMM, which is funded by the CIHR Institute of Genetics and Genome Canada, was established to expedite collaborations between clinicians identifying rare disease gene mutations in patients and researchers who can use model organisms to study these genes.

From 2014-2017, the RDMM will award approximately 100 catalyst grants for projects that will validate putative disease genes and potentially identify therapeutic and disease management strategies to help patients and their families. This was the first full year of the network's invaluable work, and 29 grants were awarded.





Clinical Trials

Clinical Trials

MICYRN's Response

The network is collaborating to:

- Catalyze the development of a Canadian coordinating and advisory network and infrastructure for pediatric and perinatal clinical trials (KIDSCAN)
- Serve as a national portal to coordinate opening Canadian sites for the NIH-sponsored Pediatric Trials Network (PTN)
- Contribute to development of a multi-national infrastructure to support global pediatric trials with the European Network for Pediatric Research at the European Medicines Agency (Enpr-EMA) and the Critical Path Institute (C-Path)

The Issue Today

Clinical trials in maternal and pediatric populations are difficult to carry out, so most medications used to treat them are not adequately studied. Demand for rare disease therapeutics and the grouping of clinical conditions into small populations with specific genetic causes means clinical trials for new therapies must involve multiple sites.

Progress was made on the KIDSCAN business case development under the leadership of Dr. Thierry Lacaze (CHEO-RI). The proposed network of clinical trial sites would facilitate multi-centre drug, device and non-drug trials through a national coordinating centre and platforms of trial expertise. The primary purpose is to provide support to design, conduct and report trials from either rare or common disease studies and subspecialty networks or industry.

With the NIH expanding activities in Canada, POPS (Pediatric opportunistic PK study) continued active recruitment at the inaugural sites CHU Ste Justine, CHEO, SickKids, and CHRIM. A second PTN study, SCAMP (neonatal abdominal infections) encouraged the opening of sites at CFRI and WCHRI.

Anne Junker was invited to join international discussions to create a global pediatric trials network. Hosted by C-Path, planning is underway to create iACT, the Institute for Advanced Clinical Trials in Children where Dr. Junker sits on the Global Interoperability and Publications/Academic Affairs subcommittees. Input was also provided to colleagues in Enpr-EMA, who are responding to European research infrastructure funding opportunities.

MICYRN's Response

MICYRN's clinical research informatics (CRI) working group continued to provide support to its members by:

- Creating a consistent, comprehensive informatics infrastructure with a focus on integrated tools that meet diverse needs, including capture of patient-reported outcomes and ability to harmonize, link or integrate data across different platforms
- Launching initiatives to improve guidance for the access, transmission, storage, analysis, linking and sharing of research data
- Establishing a common framework of harmonized approaches to enable effective and responsible sharing of genomic and clinical data

The CRI team embarked on a test of 2-factor authentication security level for REDCap access, with an aim to develop recommendations and best practices. They also initiated a demonstration project to acquire and test Integrating Biology & the Bedside (i2b2), a scalable open-source informatics framework to enable secondary usage and sharing of clinical data for discovery research.

The network is building partnerships with the Public Population Project in Genomics and Society (P3G), Maelstrom Research, and the Public Health Agency of Canada (PHAC) to improve the suite of tools available to investigators. In 2015, Dr. Elodie Portales-Casamar (CFRI) was welcomed as the new CRI lead, taking over for Dr. Lawrence Richer (WCHRI).

The Issue Today

As data becomes increasingly electronic, requirements for data security and consensus on standards are paramount. However, support tools, processes, personnel and training often pose a high cost to research studies. In addition, there is an ever-evolving need to integrate research study data with clinical care data and to share it across sites and internationally, requiring uniform quality.

Assisting Research Teams

MICYRN is unique in the world for the collaborative engagement of multiple stakeholders and provision of research support. A sizable number of new investigator teams that were provided letters of support documenting the value MICYRN can bring them through in-kind services and access to expertise have been successful in grant competitions.

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 executive management. The obvious benefit of this is a savings of time and resources to the teams, leaving more capacity for research. Of the eleven teams that sought MICYRN's support in 2015, nine results came in with eight of those being funded.

MICYRN also provides valuable connections for research teams through our members, partners and key stakeholders to help develop the best research studies possible, and ensure broad dissemination of research results. We are also building international partnerships with other network coalitions to foster collaboration.



Letters of support

The following table lists the teams with successful grant applications that were provided a letter of support illustrating how MICYRN can offer services to assist in their research or support their work.

| Study | Home Institute | Lead PI | Funding Agency |
|--|--|--|---------------------------------------|
| Maximizing mothers' milk for preterm infants (MaxiMoM) | Hospital for Sick Children | S Unger D. O'Conner | CIHR - Foundation Scheme - Live Pilot |
| PARTNERS – Patient assisted research transforming national effectiveness in rare diseases | University of Calgary | L. Korngut J. Campbell K. Boycott L. Zinman | SPOR Networks in Chronic Disease LOI |
| POPEYE: Prevention of ongoing psychosocial comorbidities through early intervention in youth living with epilepsy | Hôpital Sainte-Justine | L. Caramant F. Brunet P. Conrod J. Michaud J. Rho | SPOR Networks in Chronic Disease LOI |
| CHILD-BRIGHT: Child health initiatives limiting disability – Brain research improving growth and health trajectories | Institute of the McGill University Health Centre | T. Kitch A. Majnemer S. Miller M. O' Donnell P. Szatmari | SPOR Networks in Chronic Disease LOI |
| Improving Lives of Children and Youth with Neurodevelopmental Disabilities | University of British Columbia | D. Goldowitz C. Fuller J. Gorter P. McGrath M. Shevell | SPOR Networks in Chronic Disease LOI |
| HUGS for health – healthy bugs for healthy babies | McMaster University | D. Sloboda | CIHR-IHDCYH Team Grant LOI |
| Teacher help: Novel technologies for meeting the immediate needs of youth with mental health disorders in Canada | Dalhousie University | P. Corkum | CIHR (eHIPP) |
| Can-SHARE with Global Alliance for Genomics & Health | McGill University Health Centre | B. Knoppers | Genome Canada, CIHR |

Engagement

Identify channels, communicate, consult, and collaborate

Whether through traditional end-of-grant KT methods of translating research into practice and policy, or by engaging with the public in real time for immediate education and uptake, effectively communicating study results and activities is a critical element of work in health care research. In 2015, MICYRN's engagement associate began to develop the network's engagement process framework, implement strategies to identify and connect with new audiences and produce relevant and timely communications. Effective engagement also increases opportunities for new partnerships and funding, fosters connections between researchers, and influences national discussion.



Engagement Numbers

- 67%** – increase in traffic for new website in first month
- 232** – Twitter followers gained in first three months of launch
- 75%** – increase in number of newsletter recipients
- 58** – number of countries from which website visitors originated

Website: *establishing a presence and finding new audiences*



A revamped website was launched in December that examines a number of significant issues facing maternal and child health researchers today, and how MICYRN is working to address these challenges. There was a tremendously positive response from funders and foundations on the new recognition format of their support, with current

funders highlighted on the front page and all supporters, past and present, recognized on the funders' page.

Newsletters: *communicating directly with established audience and partners*

A new feature on the website allows visitors to sign up automatically for the quarterly newsletter, leading to a wider audience that now includes communication professionals, other networks, and foundations, in addition to member representatives and researchers.



Social Media: *bringing information and dialogue to places where conversations are already happening*

Recognizing the importance of social media in health care, MICYRN developed its presence on several platforms in the latter part of the year. The network is making a number of connections online, using Twitter and Facebook to promote the work of our members, share news and research, and remain abreast of current conversations and discoveries.

Annual General Meeting

The 2015 AGM took place in Halifax with strong member attendance. Member of the board of directors, Katie Lafferty, led discussions on knowledge translation – the current state of best practices in maternal, infant, child and youth health care, including gaps, barriers and opportunities.

Chair Dr. Stephanie Atkinson led a talk on MICYRN's role in supporting emerging research partnerships and special grant opportunities, particularly those related to her field of expertise in birth cohorts. Other opportunities discussed included "A proposal to develop a Canadian Coordinating and Advisory Network and Infrastructure to Ensure Best Therapies for Children" (KIDSCAN), the SPOR Chronic Diseases Network, Global Alliance for Genomics and Health, and involvement with Cyber CFI.

"Social media has transformed communication and is on its way to transforming healthcare. As its uses in clinical care grow, so must physician awareness of the implications this has on our ethics, professionalism, relationships, and profession."¹

Conferences: *harnessing the power of face-to-face meetings to advance initiatives and contribute to discussion and debate*

MICYRN's scientific director, Dr. Anne Junker, represented the network – and Canada – at several conferences including an international, invitational Ethics Review Equivalency workshop for the GA4GH held at the Brocher Foundation near Geneva. Co-led by the GA4GH Regulatory and Ethics Working Group chairs Bartha Knoppers (McGill University) and David Townsend (Maastricht University, Netherlands), workshop attendees spoke about initiatives to harmonize ethics review and how current efforts could be leveraged to support the GA4GH international data sharing agenda. Dr. Junker presented on the work of the MICYRN ethics working group, which is a model of federated review of research proposals involving multiple sites in Canada. She also attended the 7th annual Enpr-EMA meeting in London, UK and participated in discussions on pediatric pharmacovigilance, SPIRIT-C and CONSORT-C protocols, and globalization.

Other Canadian and international working groups and committees on which MICYRN had representation in 2015 includes the Canadian Child & Youth Health Coalition, International Children's Advisory Network, the Canadian Task Force on Preventive Health Care, and CIHR Ethics Advisory Panel for innovative clinical trials.

¹ Cretien, K. and T. Kind. (2013). Social Media as a Tool in Medicine. *Circulation*, 127, 1829-36.

Member Organizations

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

Financial Statements

| Statement of Operations | 2015/2016* (CAD\$) | 2014/2015 (CAD\$) | 2013/2014 (CAD\$) |
|-------------------------|-----------------------|----------------------|----------------------|
| REVENUE | | | |
| Member contributions | \$ 205,000 | \$ 375,000 | \$ 185,000 |
| Other sources | \$ 100,000 | \$ 82,265 | \$ 50,808 |
| Total Revenue | \$ 305,000 | \$ 457,265 | \$ 235,808 |

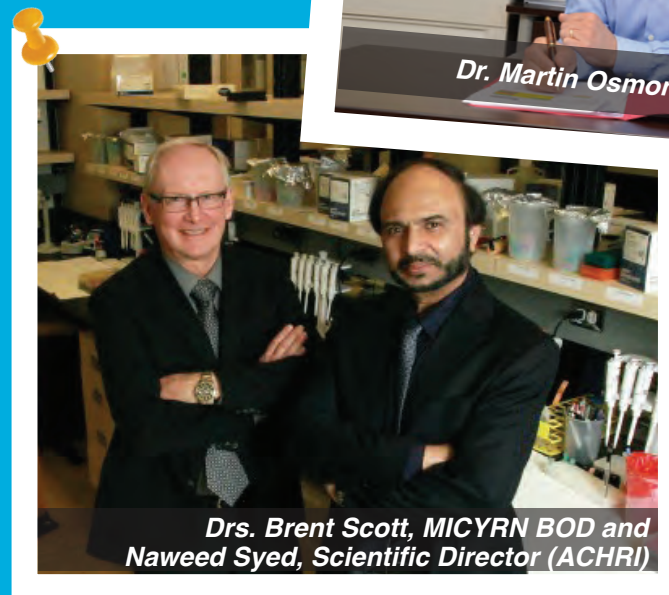
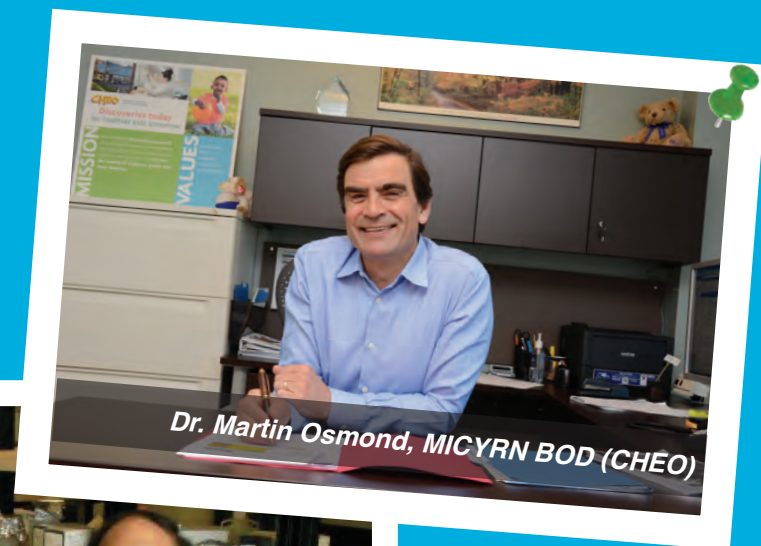
| Statement of Results | 2015/2016* (CAD\$) | 2014/2015 (CAD\$) | 2013/2014 (CAD\$) |
|--------------------------------|-----------------------|----------------------|----------------------|
| EXPENSES | | | |
| Coordinating centre operations | \$ 25,720 | \$ 32,011 | \$ 33,479 |
| Salaries and benefits | \$ 241,660 | \$ 211,732 | \$ 147,825 |
| Conferences and workshops | \$ 26,673 | \$ 21,755 | \$ 32,007 |
| Platform salary support | \$ 20,618 | \$ - | \$ - |
| Total Expenses | \$ 314,671 | \$ 265,498 | \$ 213,311 |

* Unaudited financial statements

Thank you to our 2014-15 funders!



Friends and Faces of MICYRN



A yellow brushstroke graphic with a roller handle. The brushstroke is horizontal and has a textured, painterly appearance. To the right of the stroke is a roller handle with a blue grip and a silver metal frame.

Executive Staff

Anne Junker, Scientific Director

Stephen Barbazuk, Executive Director

Christine Oriel, Administrative Assistant

Andrea Rudy, Engagement Associate



Contact

Anne Junker, MD
Scientific Director
ajunker@cw.bc.ca

Stephanie Atkinson, PhD, FCAHS
Chair, Board of Directors
satkins@mcmaster.ca

Rm V2-230, 950 West 28th Avenue Vancouver, BC V5Z 4H4 | 604-875-2581