2015-2016
ANNUAL REPORT

CanFASD
CANADA FASD RESEARCH NETWORK

CanFASD
WHO WE ARE

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is Canada's first comprehensive research organization dedicated to addressing the extraordinary complexities of FASD. CanFASD is a national, charitable organization whose focus is on supporting research and knowledge exchange activities for evidence-based decision-making in policy and practice. We support research teams that are focused on the areas of diagnosis, intervention and prevention. Our researchers currently lead over 50 major projects, connecting researchers, students, practitioners, policymakers, families and communities across Canada and internationally.

Together. Finding answers.

Improving outcomes.

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TODAY & TOMORROW

VISION

All Canadians are engaged and united with awareness, evidence and knowledge and are effectively addressing the complexities of FASD.

MISSION

CanFASD supports Canada's leadership, across all sectors and at all levels, in addressing the extraordinary complexities of FASD.

The Network does this through producing and sustaining national collaborative research, shared with all Canadians, focusing primarily on the critical areas of prevention, intervention and diagnosis.

The work of the Network leads to increasingly effective prevention strategies and practice and improved support for people affected by FASD.

CanFASD
RESEARCH

Why is research on FASD important?

FASD is the leading known cause of developmental disability in Canada. At least one in every one hundred Canadians, or more than 380, 000 people, currently live with this disability. Despite 40 years of public health campaigns warning against the risks associated with alcohol use in pregnancy, prevalence does not appear to be decreasing. With an estimated cost of $4 billion dollars per year, governments are paying attention to the social, economic, and public health consequences of this devastating and lifelong disability, and are investing in much needed community-based programs to assist pregnant women and their families. However, there is presently insufficient evidence available to provide policymakers, service providers, or families with a clear understanding of how best to deliver this assistance. The capacity required to deliver cost-effective, accessible and sustainable prevention, intervention and diagnostic services is limited.

CanFASD is working to bridge this gap. By bringing together all stakeholders – including researchers, parents and caregivers, clinicians, front line service providers, community advocates, program planners, civil servants, political leaders, and people living with FASD – CanFASD is fostering the development of the high impact research initiatives needed to help answer today's most pressing questions about the prevention, diagnosis and treatment of FASD. We also help set the foundation for the development of increasingly effective programs and policy development.

Message form the
BOARD CHAIR

Tim Moorhouse

This has been another exceptional year for the Canada FASD Research Network. I am delighted with the Network's accomplishments and remain absolutely convinced of the potential for real and profound impact on the prevention, diagnosis and intervention of FASD over the next few years. The capacity of the Network to work comprehensively within our mission and take steps in achieving our vision for FASD in Canada continues to improve year over year.

I would like to thank Dr. Amy Salmon for her work as we transitioned as an organization over the last year and also say how pleased I am that Audrey McFarlane has stepped into the Executive Director role on an interim basis upon Dr. Salmon's departure. Audrey's long history with the organization has allowed her to quickly come up to speed in the role and she has spent a great deal of time working with the Network staff team, our Research Leads, the Family Advisory Committee and our other key partners to ensure the goals and strategies of CanFASD have been met and in many cases exceeded over the past year.

The Network has spent a good part of the past year working with the Research Leads to ensure we are working together as effectively as possible and finding additional ways to support the work they are doing in relation to FASD Research. We also had a tremendous opportunity this year to bring the Network Research Leads and the founding Canada Northwest FASD Partnership members together to build a stronger working relationship and look at additional ways that the Network can support the Partnership's four new priorities for FASD across the seven regions.

From my perspective, some of the highlights of the past year include the launch of the Diagnostic Guidelines, the initial discussions on how we may be able to support the various recommendations of the Truth and Reconciliation Commission and the Diagnosis Education On Line Curriculum. Each of these initiatives has required excellent work by some remarkable people and collectively represent major milestones for FASD.

We have appreciated the continued commitment and support of the Network by the Canada Northwest FASD Partnership, the Government of New Brunswick and the Government of Canada through the Public Health Agency and First Nations Inuit Health Branch and anticipate other provincial jurisdictions joining CanFASD in the next year. We are much more effective in preventing FASD and in providing research and evidence-based knowledge to support those persons with FASD, their families, caregivers and communities across Canada when we work collectively and collaboratively.

I would like to thank our exceptional staff and Research Leads, the members of the Family Advisory Committee, our provincial, territorial and federal government partners, our key program partners and the members of the CanFASD Board of Directors that I have the privilege to work with. Together we are making a difference.

Tim Moorhouse

Message form the
SCIENTIFIC ADVISOR

Dr. Alan Bocking

This year marks my first full year as Scientific Advisor for the CanFASD Research Network. In this role I am privileged to work alongside many talented investigators, each of whom are nationally and internationally recognized in their area of expertise. Overall, the Network has published 43 peer-reviewed journal articles, manuscripts, technical reports and book chapters. The Network, through its direct support of research and knowledge translation has leveraged $3,327,000 in funding during the last fiscal year. Our Research Leads have contributed extensively in the dissemination of new knowledge through participation in and presentations at 37 scientific meetings in Canada and around the world.

The Prevention Network Action Team (pNAT), under the leadership of Dr. Nancy Poole, continues to set the bar high for how effective networks should function. The 4-stage approach to Prevention of FASD has been accepted internationally as the preferred template from which to address this complex problem and indeed is being applied by collaborators in other countries such as Australia. Dr. Poole has recently published a key article identifying the gaps in knowledge as it relates to the prevention of FASD which was developed through an iterative consensus approach with experts in the field.

Dr. Michelle Stewart's research focusses on community-engaged projects and partnerships for individuals with cognitive disabilities including FASD, mental health and racialized health inequities within the criminal justice system. Dr. Stewart has recently completed an environmental scan of FASD and justice practices across Canada and has contributed extensively to the development of policies across different jurisdictions through presentations, including one to the Standing Committee on Justice and Human Rights regarding Bill C-583 and is currently conducting projects in BC and Saskatchewan.

Dr. Mansfield Mela is actively engaging mental health professionals across the country in improving their understanding of the special needs of individuals with FASD and has embarked on an important project to identify the various clinical pathways in Canada for individuals with FASD as well as mental health and addiction issues. This project is supported by the Canada Northwest FASD Partnership as one of its four key priorities for the next 2 years. Dr. Mela is also collaborating on projects assessing sleep/wake behaviors and quality of life in individuals with FASD as well as the utilization of pharmacotherapy.

Dr. Jacquie Pei continues to evaluate a number of different interventions for individuals with FASD including a Math Interactive Learning Experience aimed at improving self-regulation. In addition to the CanFASD Research Network support, her work is funded by the Social Sciences and Humanities Research Council of Canada, the Alberta Centre for Child, Family and Community Research, the Women and Children's Health Research Institute and Glenrose Rehabilitation Hospital in Edmonton, the Alberta Cross-Ministry Committee on FASD, the Canadian Institutes of Health Research and NeuroDevNet, a National Network of Centres of Excellence in Neurodevelopmental Disabilities.

Dr. Ana Hanlon-Dearman continues her work on enhancing the integration of services for Children with FASD amongst primary health care providers. Dr. Hanlon-Dearman is a co-investigator on a project funded through NeuroDevNet to develop, implement and evaluate internet-based behavioural sleep interventions for children with neurodevelopmental disabilities including FASD.

Dr. Jocelynn Cook leads the Dataform Project in partnership with NeuroDevNet and aims to replicate the previous iteration where data was collected from 29 clinics across the country to further characterize the impact of FASD on the various brain domains and other associated co-morbidities. This information is vital as the new diagnostic guidelines for FASD which were recently published in the Canadian Medical Association Journal are applied across the country.

The CanFASD Research Network continues to stimulate research in each pillar of research – prevention, diagnosis and intervention. And it is through this work and partnerships and relationships at all levels that we are able to improve policies and services and ultimately the lives of those individuals and their families living with FASD.

Dr. Alan Bocking

Board of DIRECTORS

Tim Moorhouse – *Chair*

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MANAGEMENT & RESEARCH Team

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Interim Executive Director

Dr. Alan Bocking
Scientific Director

Kathy Unsworth
Director of Business & Partnership Development

Edward Swatschek
Manager of Corporate Services & Communications

Dr. Jocelynn Cook
Data Research Lead

Dr. Nancy Poole
Prevention Research Lead

Dr. Michelle Stewart
Intervention (Justice) Research Co-Lead

Dr. Mansfield Mela
Diagnostics Research Co-Lead

Dr. Ana Hanlon-Dearman
Diagnostics Research Co-Lead

Dr. Jacqueline Pei
Intervention Research Co-Lead

FAMILY ADVISORY Committee Members

Left to right:
Ray Marnock – *Co-Chair,*
Simon LaPlant
Marsha Wilson
Dorothy Reid – *Co-Chair*
Françoise Corbin-Boucher
Tammy Roberts
Wanda Belland

Not pictured:
Sonja Schmidt
Marva Smith

CanFASD KT (Knowledge Translation)

KT is a relatively new term that is used to describe a relatively old problem — the underutilization of evidence-based research in systems of care. Underutilization of evidence-based research is often described as a gap between "what is known" and "what is currently done" in practice settings.

CanFASD staff and researchers are committed to producing national, multidisciplinary and collaborative research that can be shared with all Canadians. This research leads to prevention strategies and improved outcomes for people affected by FASD, in addition to supporting the research and knowledge exchange activities that are needed to support evidence-based decision-making in policy and practice. This is accomplished through conference and community presentations, publications, technical reports and online communications.

In 2015 CanFASD developed an online education curriculum based on the updated diagnostic guidelines, published in December 2015 in the Canadian Medical Association Journal. The evidence-based guidelines and recommendations are based on widespread consultation with expert practitioners as well as research and community partners in the field.

Multidisciplinary Team Training for Diagnosis of FASD: An Accredited Online Curriculum

This online FASD curriculum was developed by CanFASD to assist professionals in learning the processes and procedures, and in developing the skill set needed to be effective members of a multidisciplinary diagnostic team.

The curriculum is designed for clinical and allied health professionals who are either currently working in FASD clinics or for those who will soon become members of a multidisciplinary diagnostic clinic in Canada.

This course is MOC-3 accredited and provides standardized training based on current evidence and the new Canadian guidelines. Diagnostic teams are encouraged to take this course together and there are places for discussion and deliberation among the team within the curriculum as well as a learning community to share ideas and enhance learning.

To learn more about the Education Program, or to register yourself or the members of your Diagnostic Centre, please contact info@CanFASD.ca or visit www.CanFASD.ca.

This work was funded by the Canada FASD Research Network, the Public Health Agency of Canada and The Lakeland Centre for FASD.

About KNOWFASD.ca

KNOWFASD.ca is an interactive website that provides information across the spectrum and lifespan of individuals who have FASD. It summarizes some of the common neurobehavioural features from current research and explains some of the neurobehavioural difficulties. Not all individuals with FASD will experience all of the issues presented.

Because FASD is a spectrum disorder, life can be very different for each person affected. The site has an ages and stages interactive feature, as well as a wiki environment, that provides information on many of the life challenges individuals may face in areas such as health, education, life skills, housing, social relationships, employment, and mental health. Within the wiki environment, intervention options include: tips, resources, and links specific to each area of neurobehavioural challenge.

KNOWFASD.ca is a KT project created by the Intervention on FASD Network Action Team (iNAT) of the Canada FASD Research Network. Find out more at **www.canfasd.ca.**

SMALL STEPS *Matter*

Small Steps Matter is a Knowledge Translation project from the Prevention Group of CanFASD and was done in partnership with the Education Training Council, Alberta FASD Cross Ministry Committee (http://fasd.alberta.ca).

Go to the website to learn what harm reduction is, why some women use alcohol and drugs during pregnancy and how service providers can help.

Learn more at http://bccewh.bc.ca/wp-content/uploads/ 2015/09/Harm-Reduction-Poster-Aug-18-2015.pdf.

FINANCIAL *Snapshot*

CANADA FETAL ALCOHOL SPECTRUM DISORDER RESEARCH NETWORK
Balance Sheet
March 31, 2016 with comparative figures for March 31, 2015.

	2016	2015
Assets:		
Current assets:		
Cash	$ 331,194	$ 310,634
Investments	10,039	10,056
Accounts receivable	35,194	77,804
HST receivable	27,955	29,124
Source deductions receivable	3,986	—
Prepaid expenses	78,563	9,112
	486,931	432,730
Capital assets	9,980	6,500
	496,911	443,230
Liabilities and Net Assets:		
Current liabilities:		
Accounts payable and accured liabilities	$ 29,232	$ 12,529
Deferred capital contributions	4,643	6,500
Defered contributions	152,235	101,432
	186,110	120,461
Net assets:		
Unrestricted net assets	310,801	322,769
	496,911	443,230

FAMILY ADVISORY *Committee*

CanFASD Research Network initiated a Family Advisory Committee in 2013, with an initial meeting in January 2014. The committee consists of representatives from British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Northwest Territories and Yukon. The purpose of the FAC is to advise on research priorities for families impacted by FASD and to assist in translating results of research to ensure they are accessible to families. The goals of the Family Advisory Committee are to:

- Identify and inform emerging research priorities as they relate to those who provide support to individuals with FASD
- Provide guidance on research design and desired outcomes so that the research is sensitive to and is useful to individuals and families
- Help to raise broad-based public and systems awareness about research needs and priorities for individuals and families
- Advise and aid in the development of communication processes to actively engage researchers with individuals and families
- Raise community and systems understanding of the importance of increasing investments in research that is relevant to supporting people with FASD and their caregivers
- Develop and foster relationships to guide FASD research in ways that are meaningful, accessible and respectful to those who provide support to individuals with FASD
- Provide input into the communication of research findings (and other related publications) and the development of practical documents that will inform families, support systems, and the community at-large
- Facilitate and enhance productive linkages across jurisdictions, communities and disciplines

The Family Advisory Committee has been meeting regularly and has focused on dialoguing with FASD researchers and building relationships with the research community. The committee has met with CanFASD research leads and has provided input into the development of the Can FASD research plan. We consulted with researchers in the development of the FASD Caregiver Survey recently completed and have hosted Parent/Caregiver networking sessions during two major FASD research conferences.

As individuals, Family Advisory Committee members have been very active in connecting with the larger community and have participated in a variety of webinars, conferences and meetings promoting the research network activities and emphasising the need to involve parents and caregivers in all aspects of research into, and services for, individuals with FASD.

Dr. Sterling Clarren RESEARCH AWARD

The Canada FASD Research Network is pleased to announce the selection of the recipient of the 2015/16 Dr. Sterling Clarren Research Award. The Award has been named in honor of Dr. Sterling Clarren to recognize his pioneering contribution and leadership in the field of FASD. The award is presented annually to an individual in recognition of a completed study that has made a substantial contribution to understanding the human dimensions FASD.

This year's recipient is Dr. Angelina Paolozza. Dr. Paolozza completed her PhD at Queen's University under the supervision of Dr. James Reynolds. She worked on a pan-Canadian, multi-site study funded by NeuroDevNet which investigated multiple research techniques to further the development of objective, low-cost, and high-throughput tools for large scale screening of clinical populations which may help streamline the diagnostic process for FASD. She is currently a postdoctoral fellow at the University of Toronto researching typical motor and visual development in infants.

Support OUR WORK

CanFASD is a registered charity, funded by leading health and policy organizations across Canada. Your financial support helps to develop and share the evidence needed to inform the policies and programs that pregnant women, families, and people impacted by FASD need.

Decision-makers in governments, communities, and families need to know which initiatives will have the most impact and which are most cost-effective. Sound data provides a compass to guide those decisions. CanFASD is Canada's only national network focused on FASD. We bring a multi-disciplinary approach to the study of the disability, pooling together the findings of researchers, parents and caregivers, clinicians,

service providers, community advocates, program planners, government officials, and people living with FASD.

Our goal is to ensure that the scope of our approach is reflected in the breadth of our funding base so that we can continue to have a national reach. You have an important role to play in making sure the knowledge developed at CanFASD reaches the stakeholders who need it to make effective policy decisions, provide the best supports, and make the healthiest choices possible.

Partners and Stakeholders

Member BENEFITS

Membership in CanFASD benefits governments by increasing capacity for meaningful FASD research in their jurisdictions, as well as offering the potential to reduce longer-term costs associated with diagnosis, prevention and intervention. Canadians, especially those affected by FASD, benefit from better, more meaningful information, and more effective policies and programs that can lead to improved outcomes.

Provinces who become members of CanFASD benefit from increased research capacity, advice and assistance in moving forward with evidence-based policy-making and program planning, and learning from the work and experiences of other member jurisdictions. They receive policy-relevant information and recommendations on topics and issues related to FASD tailored to the needs and priorities of their jurisdiction, and gain access to researchers across the country who can assist them in meeting those needs. Better, more meaningful information that matters to families and service providers is made available to guide evidence-based decision making that will lead to new, and more cost-effective programs and services.

Members: Alberta, British Columbia, Manitoba, Northwest Territories, Nunavut, Saskatchewan and the Yukon and New Brunswick.

Non-members

As members, contributing Provinces and Territories receive benefits such as:

- Access to a trusted agency to turn to for answers to important policy questions
- Responses to direct requests for information (i.e., Policy/position papers on FASD to highlight policy implications for governments)
- Opportunities to have input into CanFASD's research direction/agenda
- Annual reports
- Invitation to CanFASD symposia, workshops and learning events
- Annual visits and presentations by CanFASD staff
- Opportunities to stimulate, collaborate and participate in CanFASD research and evaluation projects
- Travel awards for researchers and trainees
- Access to member researchers and governments
- Access to platforms and tools developed by the Network
- Representation on CanFASD's Family Advisory Committee
- Mentoring from other member jurisdictions, with venues for sharing information and experiences and learning from those of others