

2016-2017  
ANNUAL REPORT





CanFASD

## WHO WE ARE

The Canada Fetal Alcohol Spectrum Disorder Research Network (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. CanFASD's unique partnership brings together many scientific viewpoints to address complexities of FASD, supporting research teams that are focused on the areas of diagnosis, intervention and prevention.

## Together. Finding answers.

Our researchers currently lead over 50 major projects, connecting students, practitioners, policymakers, families and communities across Canada and internationally.

Our vision is that all Canadians are engaged and united with awareness, evidence and knowledge and are effectively addressing the complexities of FASD.





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## CanFASD 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.

## RESEARCH

### **Why is research on FASD important?**

FASD is the leading known cause of developmental disability in Canada. At least 4% of the population 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. In fact, binge drinking among women of child-bearing age is on the rise. 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. Consequently, governments are now 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 high impact research initiatives needed to help answer today's most pressing questions about the prevention, diagnosis and management of FASD. We also help set the foundation for the development of increasingly effective programs and policy development.





## GOALS

As the centre of expertise in Canada:

- Inform policy, practice and decision making at the local, regional, provincial, national and international levels.
- Develop and foster relationships, research programs, and initiatives across the spectrum of FASD activity.
- Facilitate and enhance productive linkages across jurisdictions, communities, cultures and disciplines related to FASD.
- Answer high priority questions that are meaningful about the prevention, diagnosis and intervention of FASD.
- Disseminate research and evidence based knowledge about the prevention, prevalence, surveillance, diagnosis and treatment of FASD.
- Build research capacity and knowledge across and within all communities.
- Ensure that the voices of individuals with FASD and their families living with FASD are incorporated into research development.



## Message from the BOARD CHAIR

**Tim Moorhouse**

It has been a privilege and pleasure to chair the CanFASD Board of Directors over the past year. There is so much excellent work that has been undertaken, or supported by, the Network that it is hard to single out specific highlights. Hopefully through the various contributors to the Annual Report we will manage to cover most of them.

First up I would like to note the Learning Together Workshop that took place in August and the Research Priority Setting Day that followed immediately after. The Workshop was co-chaired by Dorothy Reid, Family Advisory Committee Co-Chair and Michelle Stewart, CanFASD Research Lead – Justice. The workshop itself was an amazing opportunity to bring researchers together with families, caregivers, individuals, organizations and agencies and governments to look together at what research and information is needed, at all levels, to support all of our collective efforts to “move forward” the science, practice and quality of life elements of FASD. The Workshop and Research Priorities Day also served to define and confirm the “way of doing business” for

CanFASD in relation to how research directions and priorities will be determined. The collaborative and interdependent approach effectively modelled the way this organization will engage individuals, communities, organizations, agencies and government to help us continue to be strategic and effective in meeting and resolving the challenges of FASD from a research perspective. We appreciate the funding that was provided by the Canadian Institutes of Health Research that supported the Workshop.

CanFASD has continued to review the recommendations from the Truth and Reconciliation Commission and will continue to actively look for opportunities to contribute to the recommendations from the Commission’s Report.

This past year has seen both the CanFASD Ambassador Committee and the Alumni Committee move from concept to reality. We are pleased to have June Draude and Stacey Taylor respectively agree to lead these two initiatives. The members of the Ambassador Committee will be a significant resource in making appropriate and effective connections in areas that are of importance and need to the Network, as we work to attain the vision and goals that we have set for the organization. The Alumni Committee provides a means to stay connected to those persons who have made a significant contribution to the Network as board and committee members, researchers, staff, etc., and who have left their direct roles but have an interest in staying informed and engaged in the work of CanFASD.

We are blessed as an organization to have an incredible staff team. None of the accomplishments of the Network



would happen without these people and their deep dedication to the individuals, families, caregivers and communities impacted by FASD and to the Network itself. Our staff compliment is identified later in this report and I would also like to mention that our formerly interim Executive Director, Audrey McFarlane, is now the permanent E.D. for the organization.

Our Research Leads do incredible work for the Network and in the field of FASD as a whole. The Family Advisory Committee continues to go above and beyond in helping to engage and connect with families and caregivers and guide the Network in ensuring that the work we do is relevant to their needs. I would like to thank Ray Marnoch, previous Co-Chair of the Family Advisory Committee for his years of leadership and contribution and welcome Simon LaPlante who will join Dorothy Reid as Co-Chair of the Committee.

We deeply appreciate 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.

*Tim Moorhouse*





## Message from the SCIENTIFIC ADVISOR

**Dr. Alan Bocking**

It is a privilege and honor to serve as the Scientific Advisor for the CanFASD Research Network. Collectively, this team of Investigators is undoubtedly the most comprehensive group, working together to address the complexities associated with FASD. The Network through either direct support or leveraged grants has secured over \$4 million this fiscal year to fund close to 50 different projects. These are too numerous to mention individually in this report but span the areas of prevention, justice, diagnosis and interventions. The Network investigators and their research teams have published close to 50 peer review publications, technical reports and book chapters as well as presented the results of their work at 76 conferences and workshops nationally and internationally. In addition to its research mandate, CanFASD is committed to the effective and consistent transfer of this new knowledge to individuals, families, caregivers, service providers as well as policy makers. One of the tools that CanFASD uses for this purpose is social media. In the past year, the Prevention

Network Action Team (pNAT) has posted 20 blog entries on topics related to the prevention of FASD. We also host workshops and symposiums which bring together groups of families, caregivers and researchers to identify what the key, relevant research questions are to help guide the research agenda and to share firsthand research findings. This year we were fortunate to host two such workshops. The first was in August of 2016 in Regina which was led by our Family Advisory Committee and Dr. Michelle Stewart entitled FASD Research: Learning Together. I would encourage you to read more about this in this Report from the Family Advisory Committee. The second workshop was also held at the University of Regina under the leadership of Dr. Stewart and focused on justice issues – in particular, the needs and concerns of indigenous peoples as they relate to FASD and how CanFASD can best assist in addressing the Truth and Reconciliation Commission Recommendation 34.

The DataForm project is described elsewhere in this report and is a unique research platform established to collect and store, for analysis, information regarding the diagnostic features and functional attributes of individuals seen in the FASD Diagnostic Clinics across Canada. This critical project is supported jointly by CanFASD and Kids Brain Health. Dr. Nancy Poole is a Co-Investigator with colleagues in Australia to evaluate on a project to the effectiveness of an evidence-based FASD prevention intervention to reduce the rates of alcohol use in pregnancy among Aboriginal women in three



communities in the remote Pilbara region of Western Australia. This project, funded by the National Health and Medical Research Council for 5 years, uses the 4 pillar approach to FASD prevention developed by Dr. Poole and the pNAT to guide this research.

Dr. Dorothy Badry from the University of Calgary received the Alberta Premier's Award of Excellence in Education. Dr. Badry received the award for the work she has done in educating the province's social workers and in advocating for individuals and families with FASD.

We are extremely grateful to our governmental partners for their ongoing support and recognition of the need to acquire high quality evidence through research to develop and implement effective policy as it relates to FASD.

*Dr. Alan Bocking*





## Board of DIRECTORS



Tim Moorhouse – *Chair*



Olecia Walker



Michelle Dubik



Lisa Brownstone



Helen Klengenberg



Claudette Bradshaw



Wendy Bradley



## MANAGEMENT & RESEARCH Team



Audrey McFarlane  
*Executive Director*



Dr. Alan Bocking  
*Scientific Director*



Kathy Unsworth  
*Managing Director*



Dr. Katherine Flannigan  
*Research Coordinator*



Edward Swatschek  
*Manager of Corporate Services & Communications*



Dr. Jocelynn Cook  
*Data Research Lead*



Dr. Nancy Poole  
*Prevention Research Lead*



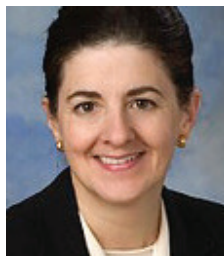
Dr. Michelle Stewart  
*Intervention (Justice) Research Co-Lead*



Dr. Mansfield Mela  
*Diagnostics Research Co-Lead*



Dr. Dorothy Badry  
*Child Welfare Research Lead*



Dr. Ana Hanlon-Dearman  
*Diagnostics Research Co-Lead*



Dr. Jacqueline Pei  
*Intervention Research Co-Lead*

# FAMILY ADVISORY Committee

CanFASD Research Network initiated a Family Advisory Committee (FAC) in 2013, with an initial meeting in January 2014. 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 more understandable and useful for families. We have nine members from British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Yukon and Northwest Territories. We are actively recruiting a representative from Nunavut. The FAC members are very active in their respective jurisdictions in promoting knowledge, support and programs available to caregivers through workshops, social networks and public speaking engagements.

To assist us in fulfilling our mandate, the FAC, in partnership with the Canada FASD Research Network (CanFASD), hosted a unique workshop in August 2016 entitled FASD Research: Learning Together. This work was funded by the Canadian Institutes of Health Research and Canada FASD Research Network. The event brought together caregivers of people with FASD, individuals with FASD, and FASD researchers for two days of discussion around FASD research in Canada. The goals were to share and discuss new knowledge related to FASD prevention, diagnosis, and intervention, and engage in multi-directional conversation to identify emerging issues that may guide future research directions. Prior to the workshop, a national online survey and several community discussion groups were conducted to gather information and form the basis for the workshop conversations.

Four themes emerged from the online survey and discussion groups, and were expanded in the workshop discussions. FASD as a 'Whole Body Disorder' was a discussion that builds on the need to understand FASD as more than a brain-based injury. Conversations included the following sub-themes:

- Multiple Medical Conditions
- Mental Health
- Non-Medical Interventions
- Lack of FASD Awareness
- Quality and Continuity of Care

Aging and Transitions was a focus of discussion that includes consideration about what it means to age with a disability and the impact of aging caregivers, including:

- Autonomy
- Lifespan Development
- Social Determinants of Health
- Barriers to Continuity of Supports
- Challenging Systems
- Aging Caregivers

In addition to these themes, workshop participants offered their insights on effective collaboration and next steps for advancing FASD research in Canada. Participants expressed overwhelmingly positive feedback about the workshop, and 97% confirmed that the themes presented were consistent with their lived experiences.

During the workshop, participants had questions in areas that have some research evidence. This demonstrated to us the continuing need to make research data available to caregivers, service providers and individuals with FASD. To assist in disseminating

this research, we completed a final report on the workshop and included references and links to the pertinent research in each area. The report was sent to all participants and is available on the CanFASD website at <https://canfasd.ca/wp-content/uploads/sites/35/2016/10/FASD-Learning-Together-Final.pdf>. In addition, CanFASD prepared a series of issue papers on areas of interest and have posted those on the webpage as well. These can be found at

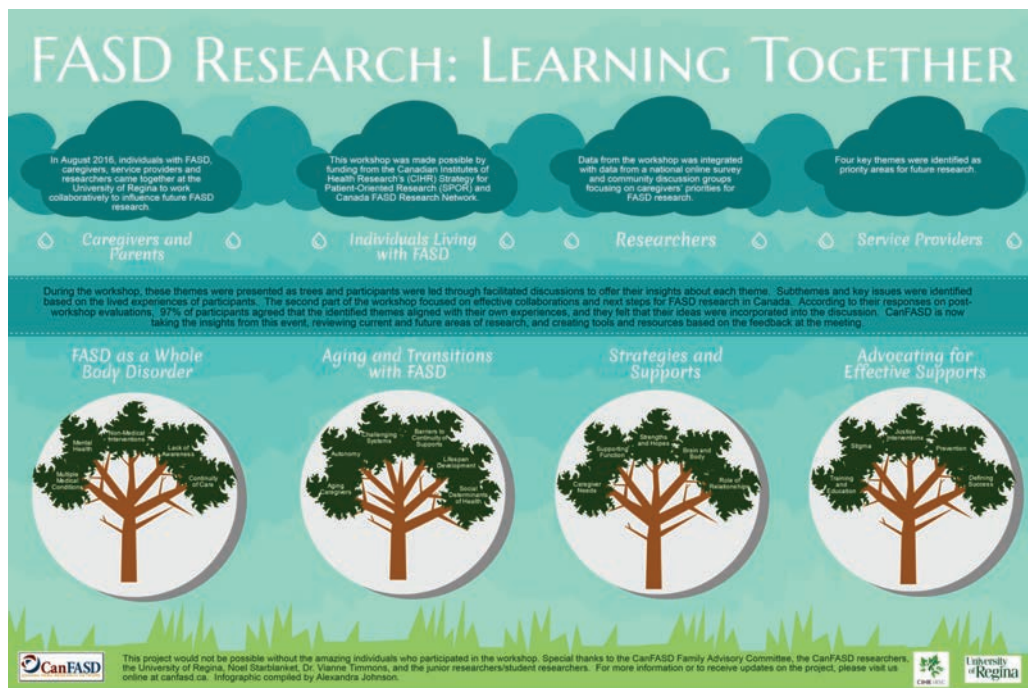


Strategies and Supports that are appropriate for those living with FASD can be very challenging to access and maintain. Discussion included the following subthemes:

- Caregiver Needs
- Supporting Function
- Brain and Body
- The Role of Relationships
- Strengths and Hope

Advocating for Supports is key to not only accessing appropriate supports and services but also enhancing and expanding those supports. As an emerging discussion, the subthemes included:

- Training and Education
- Stigma
- Justice Interventions
- Prevention
- Defining Success for FASD



<https://canfasd.ca/policy-service-providers/policy-papers/>. CanFASD also produced two documents to assist caregivers and individuals with FASD in applying for the Disability Tax Credit, one for the individual and one for pediatricians completing the supporting documentation.

The FAC is committed to continue to collect information on the research priorities of caregivers and individuals with FASD through a variety of methods. We are fortunate to have an excellent relationship with a number of passionate and

compassionate FASD researchers who are extremely receptive to the needs of those living with FASD. Our experience with the FASD Research Workshop has convinced us that we need to work together – individuals, service providers, caregivers, researchers and policy makers – to ensure FASD research focuses on the needs of those living with the disorder and is effective in enhancing positive outcomes.

## The DataForm PROJECT

The purpose of the DataForm project is to analyze different diagnoses made within the FASD spectrum and the frequency of each functional deficit. All FASD Diagnostic Clinics have been invited to participate. This database represents an integrated and coordinated approach to identifying functional disabilities and recommendations within the FASD population. These data reflect the pan-Canadian FASD diagnostic clinical experience and can be used to inform best practices and policies that address gaps in service delivery.

The information made available through this core resource will assist researchers from many different disciplines to address specific questions as they relate to the diagnosis of FASD as well as identifying and testing new interventions to improve the lives of individuals with FASD as well as their families and caregivers.

The benefit of collecting and analyzing the data, as well as understanding the needs of those with FASD based on their diagnostic assessment and recommendations for treatment, will improve public policy and resource allocation around service provision and ultimately improve the quality of life for individuals with FASD and their families.

*This project is funded by Kids Brain Health.*

A young child is standing on a light-colored couch, wearing a white t-shirt and blue jeans. They are wearing a large cardboard box on their head, which has a rectangular cutout for eyes and a wide, toothy smile drawn on it. The child is holding a large, flat cardboard sword with both hands. The background is a bright, out-of-focus indoor setting with light-colored walls and a window.

Without data you're just another



## Dr. Sterling Clarren RESEARCH AWARD

The Dr. Sterling Clarren Research Award is named in honour 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 of FASD.

This year's recipient is Dr. Kelly Coons. Dr. Coons is completing her PhD in Interdisciplinary Rural and Northern Health at Laurentian University under the supervision of Dr. Shelley Watson. Kelly's doctoral work focused on health care students practicing in rural and Northern Ontario and their knowledge, attitudes, and self-efficacy regarding FASD and alcohol consumption during pregnancy. The results of this study will improve future health care professionals' confidence and knowledge about FASD and their ability to appropriately counsel pregnant women about the potential risks of drinking alcohol during pregnancy.



person with an opinion.

*W. Edwards Deming*



## GOVERNMENT Relations

At a national level, CanFASD has a long-standing working relationship with the Public Health Agency of Canada and together we have implemented a number of important FASD initiatives that are shaping programs and policies, including the updated Diagnostic Guidelines (Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan), screening tools, data collection and education for clinicians and front-line service providers.

Provincially, CanFASD works with its provincial members to provide evidence and support to improve regional and national efforts to address the extraordinary complexities of FASD.

The mission of CanFASD is to produce and maintain national, collaborative research designed for sharing with all Canadians, leading to prevention strategies and improved support services for people affected by FASD. Over the past year, CanFASD has undergone a period of significant activity, and has been very successful at leveraging resources, creating research capacity and translating knowledge into practice.



# FINANCIAL Snapshot

## CANADA FETAL ALCOHOL SPECTRUM DISORDER RESEARCH NETWORK

### Balance Sheet

March 31, 2017 with comparative figures for March 31, 2016.

	2017	2016
<b>Assets:</b>		
Current assets:		
Cash	\$ 390,233	\$ 331,194
Investments	10,039	10,035
Accounts receivable	—	35,194
HST receivable	29,925	27,955
Source deductions receivable	8,897	3,986
Prepaid expenses	38,471	78,563
	477,566	486,931
Capital assets	9,979	9,980
	496,911	496,911
<b>Liabilities and Net Assets:</b>		
Current liabilities:		
Accounts payable and accrued liabilities	\$ 94,753	\$ 29,232
Deferred capital contributions	4,643	4,643
Deferred contributions	18,908	152,235
	118,304	186,110
Net assets:		
Unrestricted net assets	363,241	310,801
	487,545	496,911

# 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



Canada  
Northwest  
FASD  
Partnership



Public Health  
Agency of Canada

Agence de santé  
publique du Canada



# 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





[www.canfasd.ca](http://www.canfasd.ca)