

2017–2018  
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 the 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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# STRATEGIC PLAN

## 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 FASD 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.

## NETWORK GOALS

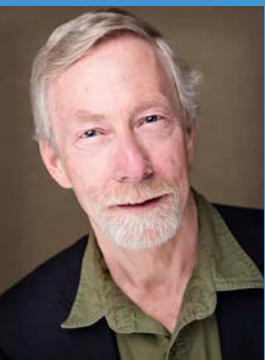
As the centre of expertise on FASD in Canada, our goal is to inform policy, practice and decision-making at the local, regional, provincial, national and international levels to:

- Develop and foster relationships, research programs, and initiatives across the spectrum of FASD activity.
- Facilitate and enhance productive linkages across jurisdictions, communities, and disciplines related to FASD.
- Answer high priority questions that are meaningful about the prevention, diagnosis and treatment of FASD to disseminate empirically validated 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 and families affected by FASD are incorporated into research development.

## OUTCOMES

- Systems engaged with FASD are stimulated to respond and take action.
- A synergy of information that is accessible and usable, leading to increased knowledge.
- FASD knowledge is available to and used by policy decision makers at all levels.
- FASD related policy, practice and research advances to the benefit of those dealing with and preventing FASD.
- Statistical reduction in the incidence and prevalence of FASD over time.





## Message from the BOARD CHAIR

**Tim Moorhouse**

The CanFASD Research Network has successfully completed another year of working to achieve our vision and goals related to FASD across Canada and with our partners and stakeholders. CanFASD continues to stimulate exponential growth in research, engagement, support and influence for individuals with FASD, their families and caregivers, policy makers and practitioners. The Board of Directors is a group of remarkable people who are committed to furthering the work of the Network and ensuring that it remains relevant and central to the challenges and opportunities that we face. I would like to thank each of the members of the Board for their contributions this past year.

CanFASD continues to evolve into a truly effective research network and has, in my opinion, surpassed the original vision that led to the creation of the Network. Our Research Leads, Family Advisory Committee, Alumni Committee, and Ambassador Committee collectively take the original

vision of stimulating and coordinating FASD research far beyond what was imagined. The results in terms of knowledge and application is often close to overwhelming. Of course the glue that holds all of this together is our staff team who really are the force which moves the organization to attain the goals that we set as a CanFASD collective.

We had an opportunity to meet with the Canada Northwest FASD Partnership Ministers in Calgary and had a very productive conversation at the table. There are many great things going on in each jurisdiction and we are privileged to be able to be part of the strategies and actions being undertaken. New Brunswick continues to be an active partner and we are delighted to acknowledge that Ontario has also joined the Network. We are currently identifying the ways in which the Network can best support their provincial FASD Strategy.

The Annual Report provides highlights of some of the great work that is going on across the country. I would like to point out just a couple that from my perspective are truly laying the groundwork for the future. The danger in doing this of course is to suggest that these are somehow a priority over other good work going on and I assure you that is not the case. The DataForm project, also known as the National FASD Database, continues to engage FASD clinics across Canada in providing file data based on a common format. The analysis and dissemination of that

information is helping to increase our understanding of FASD, from a clinical perspective in ways that we simply have not been able to do before. A second project is the research that is going on based on Canadian and international data on FASD prevalence. This is an area that has provided challenges to policy and resource development as we have not had as much Canadian research as we need to accurately portray the extent of FASD in our communities. These are just two examples of a wide range of excellent work that is helping us to continue to improve our knowledge and understanding of FASD.

It has been a pleasure to serve as Chair of the CanFASD Board of Directors for the past year. I invite you to continue to read through the Annual Report and visit the CanFASD web site for additional information on the organization and our achievements.

*Tim Moorhouse*







## Message from the SCIENTIFIC ADVISOR

**Dr. Alan Bocking**

It is my privilege and pleasure to include a message on behalf of the CanFASD Research Leads to this year's Annual Report. This has been another very successful year in both research and knowledge translation/mobilization. Collectively, our Research Leads and Teams have led or co-led over 50 projects focused on FASD and published 57 peer-reviewed manuscripts, technical reports and book chapters and have presented their research findings at over 90 national and international meetings. They have been successful in leveraging over \$2 million in research funds as either Principal Investigators or Co-Investigators from agencies such as CIHR, SSHRC, Ontario Ministry of Children and Youth Services, Australian National Health and Medical Research Council, Saskatchewan Health Research

Fund, Government of Alberta PolicyWise, Alberta Women's and Children's Health Research Institute, Laurentian University Research Fund, Public Health Agency of Canada, and Kids Brain Health Network.

We were delighted to have Dr. Kaitlyn McLachlan from the University of Guelph join CanFASD as a Co-lead for Justice with Dr. Michelle Stewart from the University of Regina. Dr. McLachlan is a Clinical Psychologist and brings additional expertise in the area of Corrections to the Network.

Research Leads, as well as Dorothy Reid and Simon Laplante from the Family Advisory Committee, presented both plenary and concurrent sessions at both the National FASD International Conference in Calgary in October and the Adult and Adolescent FASD Conference in Vancouver in April 2018. CanFASD is relatively unique in

the research world with many of these plenary presentations being co-presented by researchers and members of the Family Advisory Committee. These were all very well received by the participants.

CanFASD awarded two Sterling Clarren Awards this year due to the unique and substantial contributions that both individuals have made to the field. Dr. Sarah Treit from the University of Alberta is a Postdoctoral Fellow who is using Magnetic Resonance Imaging to study brain development in children with FASD. Dr. Deepa Singal is also a Postdoctoral Fellow based at the University of Manitoba and the Manitoba Centre for Health Policy. Dr. Singal is using population-based administrative data for the province of Manitoba to guide program development and policy. Both

Dr.'s Treit and Singal presented the results of their work at the Vancouver Conference in April.

Members of the Network continue to collaborate closely with a number of National Centres of Excellence (NCE) including TREKK which focuses on Hospital Emergency Department Services across Canada. The National FASD Database was one of 10 projects renewed through a competitive peer-review process by Kids Brain Health Network which is also a NCE focused on brain-based developmental disorders in children. The CanFASD has been identified by the KBHN Leadership and Board as a key partner given our focus on translating evidence to inform policy and practice within our jurisdictions. Members are also collaborating with the CIHR-funded National Strategy on Patient-Oriented Research (SPOR) network on children's brain-based disabilities (ChildBright). Our research programs as well as knowledge translation initiatives are supported by our two Research Associates – Dr. Kelly Coons-Harding based in Sudbury and Dr. Katy Flannigan based in Vancouver. We were delighted to

*Dr. Alan Bocking*





# Board of DIRECTORS



Tim Moorhouse – Chair



Olecia Walker



Michelle Dubik



Lisa Brownstone



Carol Ann Cheechoo



Claudette Bradshaw



Wendy Bradley

# MANAGEMENT & RESEARCH Team



Audrey McFarlane  
Executive Director



Dr. Alan Bocking  
Scientific Advisor



Kathy Unsworth  
Managing Director



Dr. Katherine Flannigan  
Research Associate



Dr. Kelly Coons-Harding  
Research Associate



Edward Swatschek  
Manager of Corporate  
Services & Communications



Dr. Jocelynn Cook  
Data Research Lead



Dr. Nancy Poole  
Prevention  
Research Lead



Dr. Michelle Stewart  
Justice/Intervention  
Research Co-Lead



Dr. Kaitlyn McLachlan  
Justice Research  
Co-Lead



Dr. Mansfield Mela  
Diagnostics Research  
Co-Lead



Dr. Dorothy Badry  
Child Welfare  
Research Lead



Dr. Jacqueline Pei  
Intervention  
Research Co-Lead



Dr. Ana Hanlon-Dearman  
Diagnostics Research  
Co-Lead





## FAMILY ADVISORY Committee

The CanFASD FAC has a dual role on advising CanFASD researchers on the research priorities for families impacted by FASD and to assist in translating results of research to ensure they are accessible to families.

We consist of representatives from British Columbia, Yukon, Alberta, Saskatchewan, Northwest Territories, Manitoba, New Brunswick, Nunavut and are welcoming a member from Ontario this year. The committee is co-chaired by Simon Laplante and Dorothy Reid.

We have been busy this year representing the voice of caregivers in a variety of venues including the National FASD Conference in Calgary, the Housing Conference in Edmonton, on the Yukon Interagency Committee and at the International Adolescent and Adult FASD conference in Vancouver. We have collaborated in the development of a number of research projects with CanFASD Research Leads, specifically Dr. Mansfield Mela and Dr. Michelle Stewart. At the National FASD conference in Calgary last October, the FAC participated in various presentations and worked in conjunction with the Alberta Family Advisory Council to staff a caregiver's room during the conference. We held a half day joint meeting with the Alberta Council following the conference.

We took the opportunity at the International FASD Adult and Adolescent Vancouver Conference to participate in a plenary session and a workshop on the importance of engaging in

truly collaborative research by including the voice of individuals with FASD and caregivers in all components of research: the development of the research question; determination of methodology; and dissemination of research results to ensure that the research has the potential to improve outcomes for individuals with FASD and their families. In order to “walk the talk”, the panel consisted of an adult with FASD, a caregiver, a service provider who is also a caregiver and a researcher. The plenary was followed by a workshop designed to create a checklist of things to consider when doing collaborative, community-based research to ensure that the work is truly collaborative.

We also had the opportunity to meet with a group of over 30 adults with FASD to discuss their priorities for FASD research. The results of these sessions will soon be available on the CanFASD website.

CanFASD and the FAC hosted a caregivers “meet the researchers” event at the International conference. This event allowed the opportunity for caregivers to receive information and ask questions of the

researchers as well as allowed the researchers to hear more of the research priorities of caregivers of individuals with FASD. We believe this to have been a very positive event and plan to continue such events in the future.

The FAC worked on two video projects this year. One video included members of the FAC discussing the benefits of being involved with the committee and has been used in committee recruitment. The second video was designed for general awareness and discusses the importance of being involved in research for caregivers. As a key goal of the FAC is incorporating the voice of individuals living with FASD in FASD research, we are in the process of establishing an ad hoc virtual committee that would bring together adults with FASD.

We have continued to enjoy the support of the CanFASD Research Network and the CanFASD Research Leads throughout the year and look forward to working collaboratively with them to ensure that FASD research is not only of the highest quality but also focuses on improving the lives of individuals with FASD and, just as importantly, is communicated to those who need the information the most – individuals with FASD and those who love and support them.





# The Truth and Reconciliation Commission TRC OF CANADA

The Truth and Reconciliation Commission (TRC) of Canada released 94 Calls to Action on June 2, 2015 including Calls to Action #33 and #34, which focused on FASD. CanFASD is committed to working with stakeholders and partners to address these calls and support First Nations, Inuit and Metis peoples in implementing evidence-based, culturally appropriate and community-driven responses to FASD.

“We call upon the federal, provincial and territorial governments to recognize as a high priority the need to address and prevent FASD, and to develop, in collaboration with Aboriginal people, FASD preventative programs that can be delivered in a culturally appropriate manner.”

Highlights of a few of CanFASD’s most recent initiatives include partnering with the Centre of Excellence for Women’s Health and Thunderbird Partnership Foundation to organize a dialogue event where experts in FASD and Indigenous health and wellness from across Canada met to discuss *Call to Action #33* and how it could be met.

A Consensus Statement was developed which includes eight tenets for enacting *Call to Action #33*:

1. Centering prevention around indigenous knowledge and wellness
2. Using a social and structural determinants of health lens
3. Highlighting relationships
4. Community based, community driven
5. Provision of wraparound support and holistic services
6. Adopting a life course approach
7. Models supporting resiliency for women, families and communities
8. Ensuring long-term sustainable funding and research

*Call to Action #34* is focused on FASD and the justice system: “We call upon the governments of Canada, the provinces, and territories to undertake reforms to the criminal justice system to better address the needs of offenders with Fetal Alcohol Spectrum Disorder (FASD), including:

- i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.
- ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.
- iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.

iv. Adoption of appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety.”

CanFASD’s Research Lead, Dr. Michelle Stewart, hosted a national symposium, which took place at the University of Regina from February 22-23, 2017 called “FASD, Justice, and Reconciliation: Tough Questions, New Collaborations.”

This event was a back drop to the development of a Framework for Action that is currently being developed to deliver an evidence-based approach to taking up *Call to Action #34*, offering guidance to different sectors that might be engaged in this work, and outlining a tangible mechanism to bring research into reconciliatory policy practices in the future.

CanFASD has also partnered with the First Nations Inuit Health Branch to look at how Jordan’s Principle funding is being used by FASD Diagnostic Clinics across Canada to improve access to FASD-related services for Indigenous families. The second phase of this project will look at recognizing that a multi-disciplinary diagnostic approach, including culturally safe and trauma-informed screening and interventions, is required. We know, based on evidence, that screening, early identification of individuals at risk of FASD, and the provision of simple interventions can improve the quality of life for individuals with FASD and their families.

## 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, the award was presented to two recipients.

Dr. Deepa Singal’s study entitled: Using Population Data to Guide FASD Program and Policy Development in Manitoba looked at the use of “big data” from the Manitoba Centre for Health Policy to conduct novel clinical and health services research in the area of FASD. This program of work ensures services and programs targeted at improving the lives of people with FASD in Manitoba are based on strong research and evaluation.

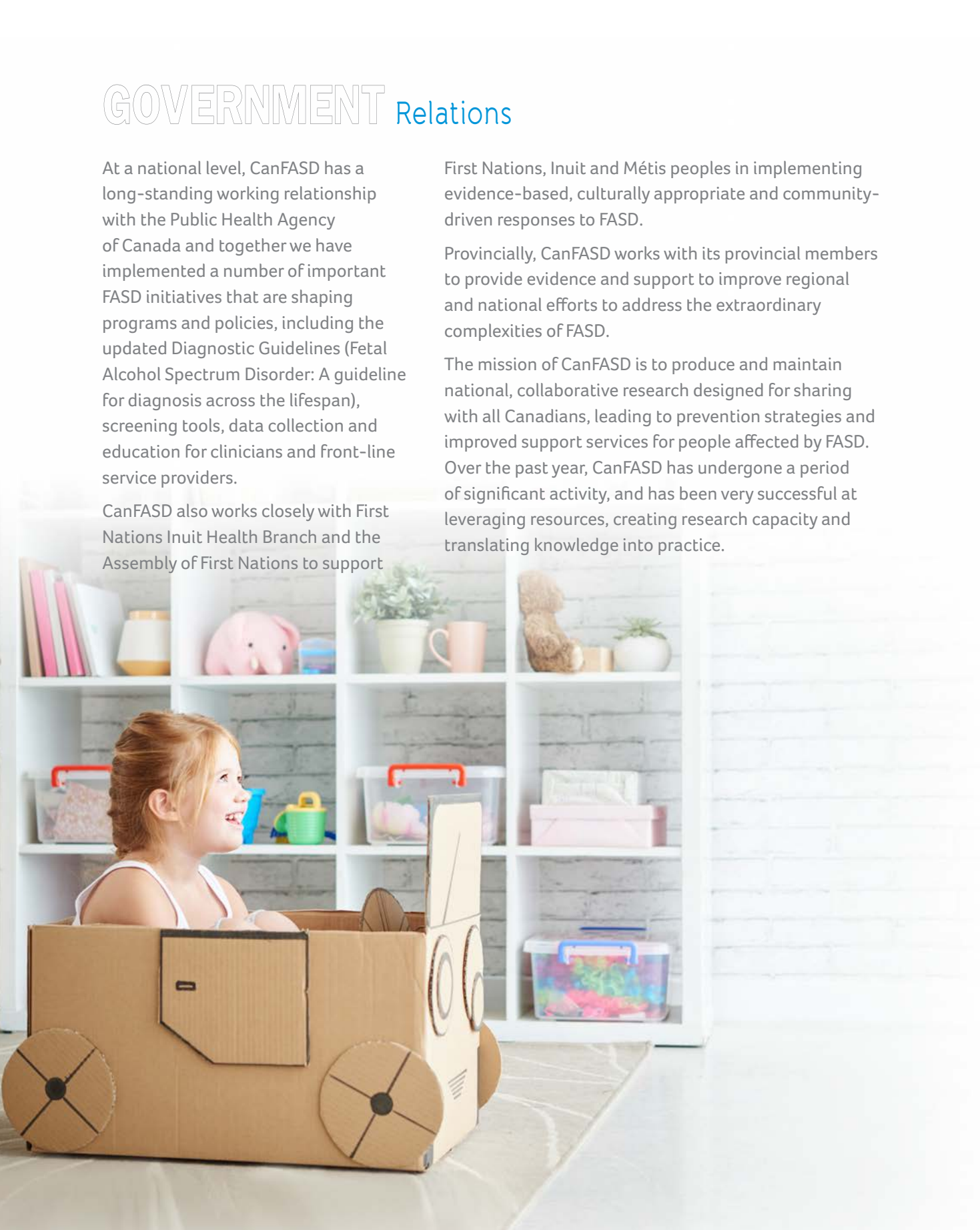
Dr. Sarah Treit’s project: Magnetic Resonance Imaging (MRI) of Brain Development in FASD was a longitudinal MRI series of studies of children and adolescents with FASD (ages 5-15 years) scanned twice each (2-3 years apart), revealing delayed development of white matter (brain ‘wiring’) and cortical grey matter maturation. This delayed structural development may partially explain worsening of behaviour commonly observed during this critical adolescent time period. In a separate study, ~70 children were scanned, including adolescents and adults with FASD, and ~70 healthy controls at a single time point, and greater reductions in brain volume were found among males than females with FASD, despite similar impairments in cognition. This suggests that prenatal alcohol exposure may affect brain structure differently in males versus females.



Drs. Sarah Treit and Deepa Singal received the 2018 Sterling Clarren FASD Research Award at the 8th International Research Conference on Adolescents and Adults with FASD in Vancouver.







# 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.

CanFASD also works closely with First Nations Inuit Health Branch and the Assembly of First Nations to support

First Nations, Inuit and Métis peoples in implementing evidence-based, culturally appropriate and community-driven responses to FASD.

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, 2018 with comparative figures for March 31, 2017.

	2018	2017
Assets:		
Current assets:		
Cash	\$ 370,493	\$ 390,233
Investments	160,039	10,039
Accounts receivable	136,340	—
HST receivable	34,020	2,925
Source deductions receivable	—	8,897
Prepaid expenses	114,768	38,471
	815,659	477,566
Capital assets	6,937	9,979
	882,596	496,911
Liabilities and Net Assets:		
Current liabilities:		
Accounts payable and accrued liabilities	\$ 46,458	\$ 94,753
Deferred capital contributions	2,786	4,643
Deferred contributions	93,908	18,908
	143,152	118,304
Net assets:		
Unrestricted net assets	691,670	363,241
	834,821	487,545



# 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 needed by 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 the 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 individuals 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 is available to provinces, territories, First Nations, Regional Health Authorities and other groups that would like to increase capacity for meaningful FASD research in their jurisdiction. Membership for governments also offers the potential to reduce longer-term costs associated with FASD diagnosis, prevention and intervention through collaboration and sharing of evidence-based best practices.

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, New Brunswick and Ontario.
- 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)