

2018–2019
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.



Improving outcomes.

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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.

DEFINITION

of FASD

At CanFASD, we have been working to create a common definition of FASD for use in a Canadian context.

We believe that if all governments, service agencies, and researchers use a common definition of FASD, it will:

- Reduce stigma, given that many existing definitions are quite harsh and use incorrect or outdated information
- Increase understanding of the disability
- Increase consistency in our messaging
- Reduce confusion

When talking about FASD, we recommend that individuals avoid:

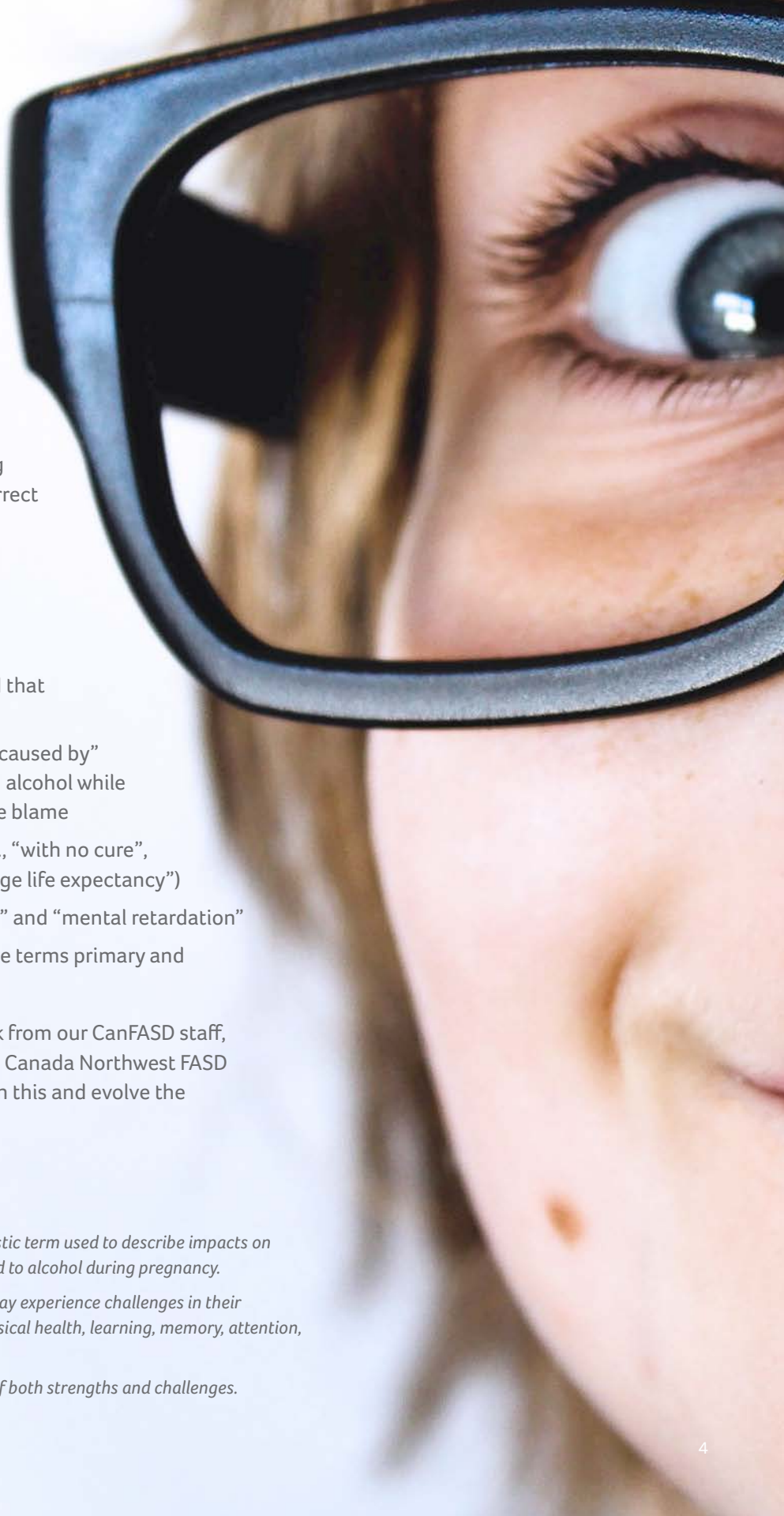
- Referring to FASD as something that is “caused by” or is “the result of” a mother consuming alcohol while pregnant, as this can inadvertently place blame
- Fatalistic terminology and phrasing (e.g., “with no cure”, “devastation”, “preventable” and “average life expectancy”)
- Outdated terms, like “mental deficiency” and “mental retardation”
- In line with our language guide, avoid the terms primary and secondary disabilities

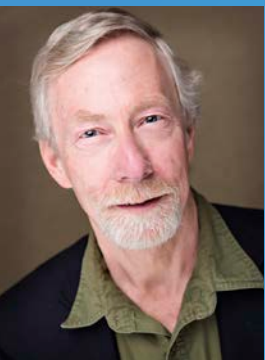
Our draft definition has received feedback from our CanFASD staff, our team of Research Leads, as well as the Canada Northwest FASD Partnership. We will continue to consult on this and evolve the definition as required.

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol during pregnancy.

FASD is a lifelong disability. Individuals with FASD may experience challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, emotional regulation, and social skills.

Each individual with FASD is unique and has areas of both strengths and challenges.





Message from the BOARD CHAIR

Tim Moorhouse

It has been a sincere privilege to serve as Chair of the Canada FASD Research Network Board of Directors over the past year. The Network continues to stimulate exponential growth in research, engagement, support and influence for those living with FASD, their families and caregivers, policy makers and practitioners. The CanFASD Board is made up of truly committed and dedicated people who provide exceptional insight, advice and direction to the organization in our efforts to work toward attaining our vision relating to FASD in Canada.

With regret the Board accepted the resignations of two Board members this year, Michelle Dubik and Claudette Bradshaw. Both brought valuable and critical perspectives to the Board table and will be missed. I would also like to acknowledge that Dr. Al Bocking has resigned from his position as the Scientific Advisor for the Network after making a very significant contribution over the past few years, particularly in how the Research Leads team functions and interacts. Happily Dr. Bocking will be starting a new role as a Director on the Board as of June 2019.

CanFASD will soon be announcing the details of our second award program, the Claudette Bradshaw Award for

Innovation in FASD and are delighted that Claudette has agreed to be the patron of the award and for the opportunity it provides for the Network to acknowledge her lifetime of contributions to community, politics and FASD.

I would also like to draw attention to the amazing work that has been done and continues to be done developing and implementing the Network's FASD online training platforms. The uptake on the initial modules has been both encouraging and confirming that this e-learning is a valuable strategy in the work in addressing FASD in Canada and internationally.

All of the work of CanFASD is in equal measure driven by and supported by the work of our very talented Research Leads, our Family Advisory Committee, the Alumni and Ambassador Committees who continue to work, hand in hand with the Board to ensure that all of the work the Network engages in has a direct benefit to families, caregivers and individuals, practitioners and policy makers. Behind all of this, of course, are our amazing staff, led by our Executive Director Audrey McFarlane who take all of the ideas and strategies and turn them into effective action and results. Truly without the exceptional competence and commitment of the Network staff there would not be a CanFASD.

The final point I would like to reference is that 2019 kicks off the Network's next strategic planning cycle. Over the next few months many of you will be contacted as we reach out to a broad range of our stakeholders to help us shape, and remain focussed and relevant, in moving the Research Network forward. I thank you in advance for your assistance and support as we move through the strategic plan renewal process.

To close, I would like to acknowledge that we are very aware we do not do the work alone. We have many partners, agencies, organizations, institutions and individuals that enable to work of the Network to carry on and to continue to grow and develop. In particular we deeply appreciate the continued commitment and support of the Network by the Canada Northwest FASD Partnership, the Government of New Brunswick, Government of Ontario 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 to provide this brief report on the research activities of CanFASD for the 2019 Annual Report. Once again, the Research team have all been leaders in their respective fields of Prevention, Diagnosis, Interventions, Justice and Child Welfare. Some of the highlights include the release of CanFASD and the University of Regina's Truth & Reconciliation Call to Action #34: A Framework for Action which builds on the successful workshop held at the University of Regina in 2017. The Prevention Network Action Team (pNAT) continues to be very active under the leadership of Dr. Nancy Poole. A Prevention Summit was held in Toronto in November 2018 bringing together a wide sector of agencies and government to discuss opportunities for action on FASD prevention research, practice and policy. Participants identified four emergent areas for future focus including advocating for provincial/territorial and national alcohol policy that supports FASD prevention; articulating a 10-year plan for the pNAT, inclusive of plans for work with Indigenous communities to address TRC Call to Action #33 and work with organizations reaching girls; bringing more experiential women in to the pNAT; and engaging with child welfare and substance use systems of care to

increase understanding and collaborative action that serves to wrap support around mothers and children where mothers have alcohol problems and related health/social concerns.

The National FASD Database has records from more than 1800 individuals making it the largest database of characteristics of individuals with FASD in the world. The research team under the leadership of Dr. Jocelynn Cook and an oversight committee is currently preparing a number of manuscripts to be submitted to the peer review literature. One of the unique and important aspects of this database is that participating clinics across the country also receive regular reports regarding key aspects of their population in comparison to the overall dataset.

CanFASD had an active presence at the 2nd Australasian FASD Conference held in Perth, Australia in November with Dr.'s Poole and Stewart presenting. In addition, a Memorandum of Understanding was signed between CanFASD and the Australian FASD Centre of Research Excellence which will build on the existing strong collaborative relationships between CanFASD and Australian Researchers. Dr. Dorothy Badry was the lead author on a publication in the journal *Dual Diagnosis*, describing the CanFASD Research Network as a successful case study for research networks. Key elements include the close relationship of the network with policy makers as well as the strong contribution of the Family Advisory Committee to the workings of the Network. CanFASD Researchers co-chaired plenary presentations at the European FASD Conference in Berlin in September 2018 and had a strong presence at the International FASD Conference held in Vancouver, BC in March 2019. Dr. Michelle Stewart and colleagues hosted a Preconference



Workshop on FASD in the justice system which was well attended and CanFASD researchers presented a total of 2 plenary presentations, 15 concurrent oral sessions and 6 posters, all of which were very well received.

Dr. Tamara Bodnar from the University of British Columbia was the recipient of the CanFASD Sterling Clarren Research

Award for her work investigating the effects of prenatal alcohol exposure on the immune system.

In conclusion, as I complete my term as Scientific Advisor, it has also been a real privilege for me to work with such a talented and committed group of staff and research leads. It has also been a pleasure to work with members of the Family Advisory Committee who in my view provide unparalleled input into the research agenda.

Dr. Alan Bocking

Board of DIRECTORS



Tim Moorhouse – *Chair*



Olecia Walker



Michelle Dubik



Lisa Brownstone

MANAGEMENT & RESEARCH Team



Audrey McFarlane
Executive Director



Dr. Alan Bocking
Scientific Advisor



Kathy Unsworth
Managing Director



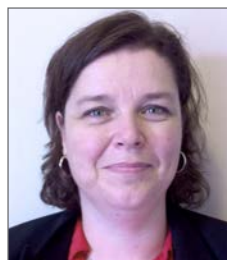
Dr. Katherine Flannigan
Research Associate



Dr. Kelly Coons-Harding
Research Associate



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*



Carol Ann Cheechoo



Claudette Bradshaw



Wenda Bradley



Dr. Vichithra
Liyanage-Zachariah
Research Assistant



Edward Swatschek
*Manager of Corporate
Services & Communications*



Dr. Jocelynn Cook
Data Research Lead



Dr. Jacqueline Pei
*Intervention
Research Co-Lead*



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



A close-up photograph of a woman with dark hair and a young child with curly hair. The woman is holding a clear glass jar filled with green leafy plants. She is pointing at the plants with her right index finger. The child is looking up at the jar with a curious expression. The background is a soft-focus green, suggesting an outdoor setting.

FAMILY ADVISORY Committee

The purpose of the Family Advisory Committee (FAC) of the CanFASD Research Network is to advise on research priorities for families impacted by FASD, and to assist in translating results of research to ensure they are accessible and meaningful to families. Within this mandate, the FAC has been engaged in a number of different activities in the 2018-2019 year.

The FAC participated in the Promoting Dignity Symposium, organized by the Canada Northwest FASD Partnership held in Winnipeg February 2019. The symposium was attended by a broad spectrum of individuals involved in the FASD world, either experientially or professionally. The symposium focused on “Changing the Conversation” about FASD and provided us with an opportunity to discuss how, albeit inadvertently, much of the FASD awareness information produced over the past two decades has increased stigma while potentially decreasing public support for assessment

and intervention. These discussions have provided a new lens with which to critically examine new FASD awareness and knowledge translation strategies and initiatives.

The FAC was involved in two separate presentations at the 8th International Conference on Fetal Alcohol Spectrum Disorder held in Vancouver in March 2019. The first presentation was a review of the progress made in 6 areas over the past 15 years. In 2004 a geographically diverse group of birth, foster, and adoptive parents/grandparents of adolescents and adults diagnosed with FASD from British Columbia came together to discuss the complexity of FASD and the needs for supports and services to improve outcomes for individuals with FASD.

The final report, entitled *Fighting For a Future*, outlines six broad areas of need with specific calls for action to change identified within each area. The six areas were: homelessness; finances; physical and mental health; education, programming and employment; legal and addictions; and family support. In the presentation at the International Conference, a panel consisting of FAC members (Marsha Wilson, Dorothy Reid and Shana Mohr), Kelly Harding, a CanFASD Research Associate and Jan Lutke, the original co-author of the *Fighting for a Future* Report, highlighted the changes that have occurred in the six areas in the past 15 years across Canada. It was apparent from our review that there has been a significant increase in FASD research in these areas, however, policy implementation and service provision have lagged behind. There are significant differences in the level and types of diagnostic and intervention services and supports across Canada thus speaking to the need for a national FASD strategy.

The second was a poster presentation of a photovoice project the committee completed last year entitled “What it takes: Supporting a loved one with FASD”. In this project, FAC members took pictures and wrote a narrative of what they believe it takes to support someone with FASD. The pictures and narratives were combined to make an 11-minute video which has been published in the first Audio-Visual Issue of the *First Peoples Child and Family Review*, Volume 13, #8. You can view the video at: www.youtube.com/watch?v=EmfKzQjGSGo.

While in Vancouver, we had the opportunity to meet with the adult Change Makers Leadership committee, a group of FASD advocates who are part of the planning for the international conferences. We collaborated with them on strategies to enhance the voice of individuals with FASD in FASD research. The FAC has developed the terms of reference for an adult advisory group to assist us in more adequately including the priorities of individuals with FASD in our discussion around FASD research. Recruitment for this advisory group, the Adult FASD Expert Collaboration Team, or AFECT for short, is a priority for our activities in the upcoming year.

FAC also completed a video on the importance of research to caregivers. This video is available for viewing from the CanFASD Research Network YouTube channel at: www.youtube.com/watch?v=wenmSKTvhAY.

The members of the FAC appreciate the support we receive from CanFASD Research Network staff and research leads. We enjoy the openness and collaborative spirit as we work together to improve outcomes.



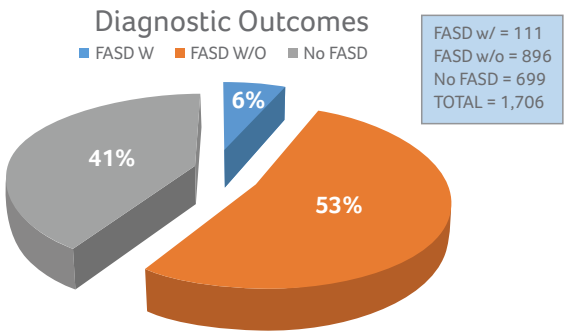
FAC members from left to right: Dorothy Reid, Simon Laplante, Wanda Beland, Mary Ann Bunkowski, Ray Marnoch, Jennifer Noah, Marsha Wilson, Tammy Roberts, Shana Mohr and Sonja Schmidt.

THE NATIONAL FASD Database

The National FASD Database, led by CanFASD's Data Research Lead, Dr. Jocelynn Cook, is the only one of its kind in the world. Currently, 26 clinics in Canada are contributing to the database, including clinics in British Columbia, Alberta, Manitoba, Ontario, New Brunswick, Yukon, and the Northwest Territories. The Database now has over 1700 records in it, 96% of whom have confirmed prenatal alcohol exposure.

The Database provides real-time information on the difficulties, challenges and needs of those who present for an FASD-related diagnosis, including type of diagnosis, recommendations for interventions, specifics of the assessment, other substance use and exposure, mental health issues, demographics and adverse outcomes such as difficulties in school and trouble with the law.

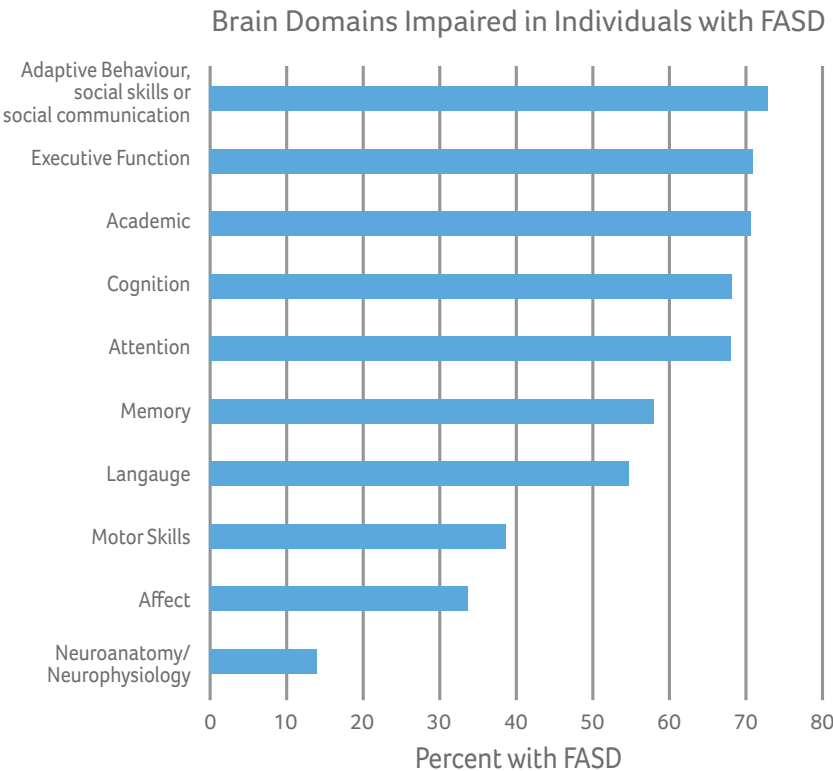
The chart below demonstrates the breakdown of diagnostic outcomes, with the majority receiving a diagnosis of FASD without sentinel facial features and only 6% of individuals having FASD with sentinel facial features.



The Canadian Guidelines for diagnosis require 3 of a possible 10 brain domains to be impaired for a diagnosis of FASD (Cook, 2016). Of the individuals diagnosed with FASD in this database, 63.9% had 5 or more domains

impaired and 5.1% had 6 or more, indicating that individuals with FASD have many challenges vs. are very impaired.

The most common areas of neurocognitive impairment in individuals with FASD were in adaptive behaviour (73.3%), executive function (70.9%), academic achievement (70.8%), cognition (68.6%), and attention (68.5%).



The information in the National FASD Database will be used to describe and better support the FASD population in Canada with longer term plans to compare data sets with other countries and across other neurocognitive disorders to enable more sophisticated and impactful analyses.

The CanFASD Research Network and its Research Leads have started submitting manuscripts for publication in the scientific literature. Join the CanFASD Blog for information and updates.

RESEARCH in Action

69
of research projects

59
of published papers

149
of presentations

12
of book chapters

69
of international presentations

1
of books

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. The 2019 recipient of the CanFASD Sterling Clarren Research Award is Dr. Tamara Bodnar. Dr. Bodnar is a Research Associate in the Department of Cellular and Physiological Sciences at The University of British Columbia (UBC), supervised by Dr. Joanne Weinberg. Her research examines the impact of prenatal alcohol exposure and other early-life environmental manipulations on immune function across development. Her research involves animal models of prenatal alcohol exposure, as well as human studies examining the impact of in utero alcohol exposure. The overall goal of her research is to identify both immune-related biomarkers and targets for possible immune-based intervention strategies for individuals with FASD.

Dr. Bodnar's project, entitled *Impact of prenatal alcohol exposure on immune function throughout the life course*, involves examining how the immune system is impacted by prenatal alcohol exposure and identifying possible consequences of altered immune function. Importantly, while the immune system protects the body against disease, it is also critically important for brain development and is involved in key processes including neurogenesis and synaptic pruning. Thus, changes in the immune system, particularly within the brain (the neuroimmune system) during the early postnatal period, will likely result in consequences for brain development.

As an extension of this work, and inspired by an informal health survey conducted by individuals with FASD, Dr. Bodnar's team initiated a new ongoing project to examine health and immune outcomes in adults with FASD. Importantly, this study funded through the Collaborative Initiative on Fetal Alcohol Spectrum Disorder (CIFASD) is designed to characterize the health status of adults with FASD, as well as to specifically probe for immune system alterations that may be predictive of altered cognitive, behavioral and adaptive function, and the risk for a range of immune/autoimmune disorders in later-life.



2019 Sterling Clarren Research Award Winner –
Dr. Tamara Bodnar

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 policy and practice.



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



Public Health
Agency of Canada

Agence de santé
publique du Canada



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