

Canada FASD Research Network Annual Report 2011 - 2012



Our Vision

To support Canada's leadership in addressing the extraordinary complexities of Fetal Alcohol Spectrum Disorder (FASD).

Our Mission

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 Fetal Alcohol Spectrum Disorder.

Our Values

- ▶ To do and/or facilitate research that is meaningful to families, governments and stakeholders
- ▶ To work collaboratively with all partners
- ▶ To use appropriate language when communicating about FASD, by recognizing the sensitivities and complexities of FASD

Our Goals

- ▶ To develop and foster relationships, research programs, and initiatives across the spectrum of FASD activity
- ▶ To facilitate and enhance productive linkages across jurisdictions, communities, and disciplines related to FASD
- ▶ To answer high priority questions that are meaningful about the prevention, diagnosis and treatment of FASD
- ▶ To disseminate empirically validated knowledge about the prevention, surveillance, diagnosis and treatment of FASD
- ▶ To inform policy, practice and decision making
- ▶ To become a centre of expertise on FASD in Canada
- ▶ To build a sustainable research network
- ▶ To build research capacity and knowledge across and within all communities

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Message from the Board Chair

As Chairman of Board for the Canada Northwest FASD Research Network I am pleased to celebrate our organization's success, growth, and transition. Since inception in 2005, the Research Network has moved into its current role as a leader in supporting collaborative, multi-disciplinary, and intersectorial research on a wide range of topics centred on Fetal Alcohol Spectrum Disorder (FASD) prevention, diagnosis, and intervention.

In the last year, with the support of our ministerial sponsors in the Canada Northwest FASD Partnership, we have become a national organization with a new name, Canada FASD Research Network (CanFASD) and a new, strong organizational structure, which offers a solid foundation for creating and sharing new knowledge needed by governments, service providers, families, and communities to improve the outcomes across the lifespan.

With this expansion, the Central Office has been reorganized. Dr. Sterling Clarren remains the Scientific Director, while Dr. Jocelynn Cook has been recruited as the Executive Director with both reporting independently to the Board of Directors. We are very pleased with the dynamic leadership that they bring together to the organization.

With our new national perspective, we have increased our capacity for FASD research. In the last year alone, members of our Network Action Teams successfully secured over \$3.4M in competitive research grants. Results of their research have been reported in peer-reviewed, scientific journals, at professional meetings, and in reports for service providers, families, and policy makers.

As we look to the future of the Canada FASD Research Network, we remain focused on both expanding and sustaining our organization, ensuring that we can remain responsive to the changing economic and social conditions in which people with FASD and their families live, and that new findings from our research be made accessible to those who can best use them to effect change.

We thank the Canada Northwest FASD Partnership for their continued leadership and commitment to seeing this important work continue and welcome future partners in our work.

Audrey McFarlane

Canada FASD Research Network, Board of Directors, Chairperson



Message from Senior Management

The past year marks the end of the Canada Northwest Fetal Alcohol Spectrum Disorder (FASD) Research Network and the beginning of the Canada FASD Research Network. FASD remains an epidemic problem of extraordinary complexity and the Network remains committed to working collaboratively with researchers, clinicians, advocates, families, communities and government systems to develop clear, fact-driven approaches to prevention and intervention while improving and expanding diagnostic availability. Now we will continue our work with colleagues across all of Canada. We are proud of the efforts in the last year that have led to new knowledge. Yet the more we know, the more urgent seems the need to prevent this condition and help those who have FASD and their families. We are eager now to expand our efforts across Canada and work with all who wish to work with us.

Thanks to solid planning and hard work by our Board of Directors, our Central Office staff, and most importantly the leaders and members of the Network Action Teams, all aspects of the Network have been active in 2011-2012. Together, members of the Network have published 38 articles, reports and book chapters, given 56 presentations, written over 120 blog posts on both intervention and prevention and distributed 8 electronic newsletters to over 400 subscribers from across Canada. Network researchers have also generated over \$3M in external research funding for their FASD-specific projects.

We believe that the work that has been accomplished positions the Network to take a leadership role in bringing a comprehensive approach to FASD prevention in Canada, to help in the development of new intervention approaches, to bringing consistency and quality improvement practices to clinics that provide FASD diagnoses using the Canadian Guidelines, and ultimately to helping the families who care for those with FASD to remain strong, hopeful and effective. We are ready to move forward in partnership and as a country to collaborate in these exciting and necessary activities.

We are pleased with our successes but challenged to do more. We thank you for your continued interest and support.

Sterling K. Clarren, MD, FAAP
Canada FASD Research Network, Scientific Director

Jocelynn Cook, MBA, PhD
Canada FASD Research Network, Executive Director

Background

Fetal Alcohol Spectrum Disorder (FASD) represents a constellation of adverse effects resulting from prenatal exposure to alcohol. It is the leading known cause of developmental disability in Canada and has life-long consequences. The prevalence, based on research studies primarily conducted in the United States and Europe in the 1980's and 1990's, is estimated to occur at a rate of 1 out of 100 live births. Recent epidemiological studies suggest prevalence rates as high as 2-5%¹, suggesting that FASD is a public health problem of epidemic proportion and translating to between 689,656 and 1,724,140 affected individuals in Canada².

A recent study that examined key cost components associated with FASD in Alberta suggests that the annual long-term economic cost from the disorder rose from \$130M to \$400M each year for the Alberta economy; the annual short-term economic cost for FASD in Alberta rose from \$48M to \$143M, and the daily cost for FASD in Alberta rose from \$105,000 to \$316,000³. It has also been estimated that the total cost of FASD in Canada is an estimated \$4 billion a year based on a rate of one FASD case in 100 pregnancies⁴, further illustrating the substantial financial burden of FASD to Canadian families and the need to make positive changes. Direct and indirect costs included use of healthcare, social services, special education, loss of income potential and judicial/penal expenses.

Although FASD is a permanent disability and can be overwhelming for those affected and for their families, evidence shows that with the implementation of prevention and intervention strategies and supports, there is considerable potential to reduce the development of secondary disabilities (problems that a person is not born with, but might get as a result of having an FASD) as well as the costs associated with caring for individuals with FASD. Earlier and better interventions may also result in reduced longer-term costs.

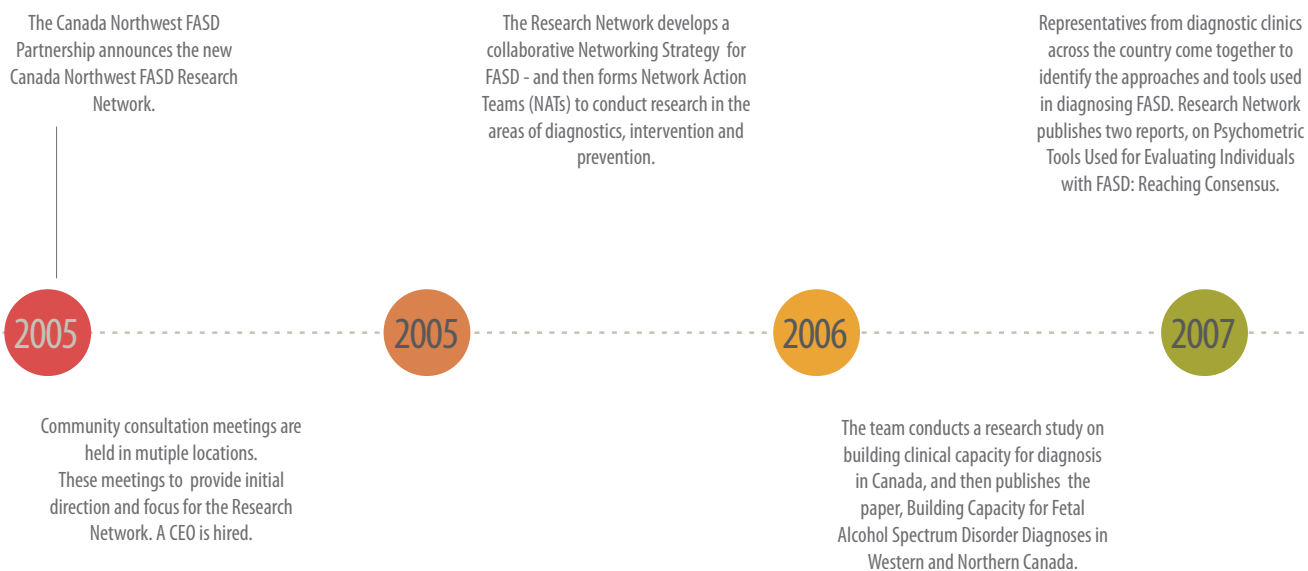
It is also recognized that supporting affected individuals and their families throughout the lifespan is critical. Millions of dollars every year are spent in an attempt to improve outcomes for affected individuals and their families, yet understanding needs and effectiveness as well as the capacity to deliver cost-effective, accessible and sustainable services remains poor. Other challenges exist with respect to ethical and sociocultural issues related to the acceptability of alcohol use. Because of this, messaging is often mixed and unclear.

1. May PA, Gossage JP, Kalberg WO, Robinson LK, Buckley D, Manning M, Hoyme HE. Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Dev Disabil Res Rev.* 2009;15(3):176-92.

2. StatsCan. Population Estimates and Projections. 2011 <http://www40.statcan.gc.ca/l01/cst01/demo02a-eng.htm>. Accessed February 28, 2012.

3. Thanh NX, Jonsson E. Costs of fetal alcohol spectrum disorder in Alberta, Canada. *Can J Clin Pharmacol.* 2009 Winter;16(1):e80-90. Epub 2009 Jan 16.

4. Stade B, Ungar WJ, Stevens B, Beyene J, Koren G. Cost of Fetal Alcohol Spectrum Disorder in Canada. *Canadian Family Physician* August 2007 vol. 53 no. 8 1303-1304.



FASD is recognized as a health, social, justice and economic problem around the world. There is ongoing research related to mechanisms underlying the developmental and neurodevelopmental impact of prenatal alcohol exposure, as well as prevention, effective intervention and diagnostics in an attempt to better understand the totality of this disorder and its lifelong implications. Research results will set the foundation for better understanding the implications of FASD and for guiding the development of effective treatment and management of affected individuals as well as to catalyze effective program and policy development. In fact, evidence from Alaska suggests that dedicated resources coupled with extensive, well-designed research is associated with a significant number of decreased births with FASD in the native population ⁵. Similar data was reported from South Africa ⁶. Other studies demonstrate several interventions that have been shown to improve the lives of individuals with FASD and their families ⁷.

Canada is a leader in the field of FASD. Canadian basic science, clinical and applied researchers contribute regularly to the literature and have a successful track record for obtaining research funding. Canada was the first country to publish guidelines for FASD diagnosis with recommendations for a multidisciplinary approach to diagnosis and follow-up.

Although there have been attempts to consolidate and to coordinate efforts, FASD-related research has often been fragmented and the translation of knowledge from the research field to policy makers, clinicians, and care givers in order to impact policy and program implementation has been inadequate. Recognizing the need for a coordinated approach, a provincial and territorial partnership formed to address these needs, and to share resources and expertise to enhance FASD prevention as well as the care and support of those living with this disability. Since 2003, the Canada Northwest FASD Partnership (CNFASDP), an alliance of seven jurisdictions (Alberta, British Columbia, Manitoba, the Northwest Territories, Nunavut, Saskatchewan and the Yukon) has been committed to achieving a better approach to FASD.

Efforts of the CNFASDP created the new, national Canada FASD Research Network (CanFASD) to facilitate the creation and uptake of policy-relevant FASD research. Since its inception in 2005, the Research Network has catalyzed the field and built a niche of expertise, making a significant impact on FASD diagnostics and surveillance, intervention, prevention and policy development.

5. State of Alaska Department of Health and Social Services, Division of Public Health. Alaska Birth Defects Monitor. Volume III, Issue 2, July 2010.

6. Chersich MF, Urban M, Olivier L, Davies LA, Chetty C, Viljoen D. Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: a multicentre before-after study.

7. For review, see: Bertrand J; Interventions for children with fetal alcohol spectrum disorders (FASD): overview of findings for five innovative research projects. Interventions for Children with Fetal Alcohol Spectrum Disorders Research Consortium Res Dev Disabil. 2009 Sep-Oct;30(5):986-1006. Epub 2009 Mar 26.

The Research in Diagnostics NAT completes a comprehensive research study to determine the normal distribution of palpebral fissure lengths in Canadian school-age children. Research paper then published in 2010.

The Partnership supports our evolution to a National entity. The organization changes its name to the Canada FASD Research Network, hires an Executive Director and begins the process to seek National charitable status.

2008

Research Network hosts a Brain Summit Symposium to further define diagnosis of brain domain function according to Canadian Diagnostic Guidelines, and then publishes a consensus report.

2009

2010

NATs and central office obtain \$3.M in external funds, publish 38 articles, reports and book chapters and give 56 presentations in Canada as well as South Korea, Scotland, England, Australia, and the United States.

2011

What We Do

The Research Network's primary purpose has been to advance clinical and applied quantitative and qualitative research to improve understanding of diagnostics, intervention and prevention related to FASD. In support of our mission and to achieve our goals, the Network operates under three main business lines:

1. To provide a research-related coordination function so that FASD research in Canada reflects the needs of families, stakeholders and policy makers;
2. To catalyze and to participate in the research environment to foster effective policy and practice that ultimately improves the lives of those affected by FASD; and
3. To effectively translate information in a meaningful way to stakeholders.

Providing a Coordination Function

Presently there is no single, Pan-Canadian coordinated force with the vision for FASD research in Canada. Coordination must occur on the level of the research itself (research networks), messaging and education, capacity development, prevalence, knowledge translation, evidence-based decision-making and incorporation of evidence into policy and practice.

Governments will benefit from increased capacity for meaningful FASD research in their jurisdictions which will improve the effectiveness of diagnosis, prevention and intervention. Fragmented and incomplete information on which to base decisions will be reduced and researchers will benefit from coordinated expertise and leveraged resources. Canadians, especially those affected by FASD, will benefit from better, more meaningful information and more effective policies and programs that can lead to improved outcomes.

Recognizing the importance of coordinating relevant research along thematic areas, CanFASD has provided a leadership role to support the cross-jurisdictional coordination of FASD research by defining and supporting Network Action Teams (NATs) working in the areas of diagnostics, intervention and prevention. The NATs are lead by Internationally-recognized expert researchers and have been very successful at leveraging resources, creating research capacity and have made significant contributions to the field of FASD.

The Network also works collaboratively with partners and stakeholders federally, provincially and locally to define policy-relevant research questions and priorities, to ensure that research results will be meaningful to end users and to facilitate sharing of information across jurisdictions and sectors. Collaborative opportunities have lead to funding submissions, co-hosting events and workshops and synergistic efforts among researchers in the field.

Participating in the Research Environment

Members of CanFASD contribute significantly to knowledge generation and exchange in to the FASD research field. The NATs have broad agendas and are continuously moving from organizing ongoing projects and developing leadership direction to developing more sophisticated studies and seeking external funding and partnerships to leverage resources. Members of CanFASD have been approached to lead specific projects and activities, including revision of the Canadian Diagnostic Guidelines for FASD, a national survey of allied health professionals on knowledge and attitudes toward FASD and alcohol use during pregnancy, and measurement of FASD prevalence in the justice system of the Yukon.

The members of each NAT are responsible for answering specific research questions in their areas of expertise, either through a review of existing data or by developing new research projects. Each team evaluates the data collected within the contexts of cultural diversity, gender, community, geography, and pertinence to policy change. The NATs are:

Research in Diagnostics: This team is engaged in research activities to help promote increased consistency, clarity and accuracy to the diagnosis of FASD. They are also collaborating with NeuroDevNet, the first pan-Canadian initiative dedicated to studying children’s brain development (Lead: Dr. Sterling Clarren, University of British Columbia).

Intervention on FASD: This team’s focus is on the intervention needs of individuals with FASD across the lifespan. They have established a cross-jurisdictional advisory panel of FASD experts in the areas of research, policy and practice who are using a virtual community of practice as a central place where ideas, interventions, and research can evolve collaboratively (Lead: Jacqueline Pei, University of Alberta).

FASD Prevention from a Women’s Health Determinants Perspective: This team’s research is focused on building the knowledge base for FASD prevention through work with women and their support systems on a range of health and social issues (Lead: Nancy Poole, Centre of Excellence for Women’s Health).

Evaluation of FASD Mentoring Programs: This team’s focus is to understand the role of Parent-Child Assistance Programs, and other mentoring support programs aimed at preventing FASD, in the lives of women struggling with high-risk substance use (Leads: Linda Burnside, University of Manitoba and John McDermott, Vancouver).

In the last year, the NATs have generated over \$3.4M in external funding and have published 38 papers.

Members of CanFASD have been approached to lead specific projects and activities, including revision of the Canadian Diagnostic Guidelines for FASD, a national survey of allied health professionals on knowledge and attitudes toward FASD and alcohol use during pregnancy, and measurement of FASD prevalence in the justice system of the Yukon.

Knowledge Translation

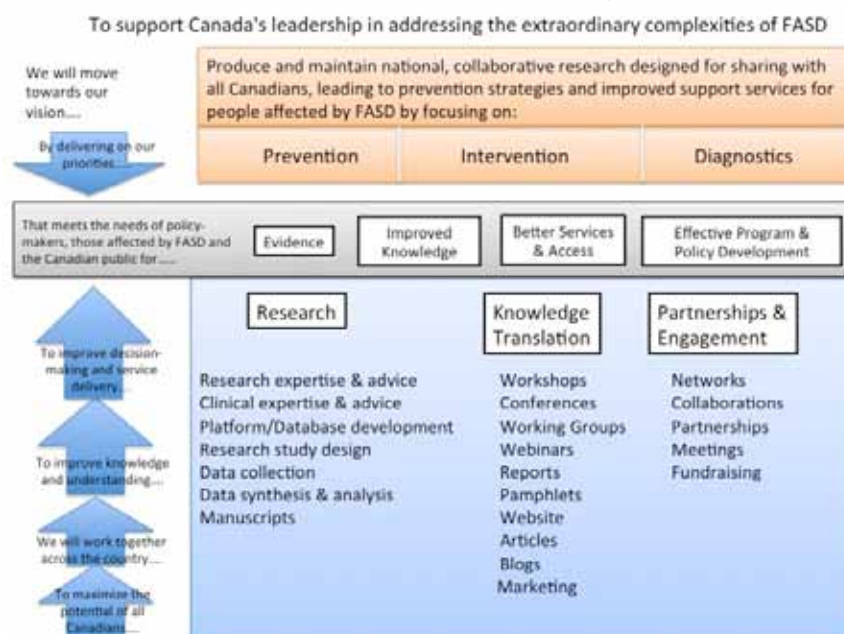
A major role of CanFASD is to enhance the reciprocal translation and transfer of knowledge from researchers to end-users and back again. Research results must be translated into meaningful information for policy-makers, program developers, service providers, other researchers and those living with FASD. To accomplish this, the Network uses products and services including:

- ▶ Knowledge translation documents and activities (i.e., workshops, conferences, working groups, webinars, reports, pamphlets, articles, publications, newsletters)
- ▶ Platforms and tools (databases, data forms, toolkits)
- ▶ Research expertise and advice
- ▶ Clinical expertise and advice
- ▶ Interactive website development
- ▶ Creating linkages and partnerships

Partnerships and Engagement

If nothing changes, as the Canadian population continues to increase, so will the numbers of individuals affected by FASD, thus demand for evidence-based practice in the field will continue to grow. Researchers and policy-makers will need to work together more than ever to leverage resources and to share research results and their implications. Partnerships and engagements have always been key to CanFASD’s success. CanFASD continues to work across levels of government, across sectors and jurisdictions and across disciplines in an attempt to facilitate knowledge generation, exchange and uptake to improve the lives of those living with FASD.

Canada FASD Research Network’s Strategy Map



Our Results

This section presents the results achieved by CanFASD in fiscal year 2011-2012, within its key priority areas of diagnostics, intervention and prevention.

National Research Presence

CanFASD is collaborating with national entities concerned with FASD, including the Public Health Agency of Canada (PHAC), Health Canada and NeuroDevNet. PHAC is the government of Canada agency responsible for public health in Canada and they fund a number of programs and activity related to FASD. Today, CanFASD researchers are currently taking part in almost all of the FASD research projects across Canada that are supported by PHAC.

CanFASD also works closely with Health Canada, especially the First Nations and Inuit Health Branch which has an FASD program that supports community based programming for mother mentoring, multi-disciplinary team-based diagnosis, prevention and education. CanFASD works with Health Canada to include Aboriginal components into approaches and the translation of knowledge as well as to working together to address FASD-related research questions that are important to First Nations and Inuit people.

NeuroDevNet is a Canadian Network of Centres of Excellence, dedicated to helping children overcome neuro-developmental disorders. Network investigators seek to understand the causes of neurological deficits, and to transfer this knowledge to health care professionals, policy makers, and communities of interest. CanFASD partners regularly with NeuroDevNet on projects that translate biomedical and clinical science to applied and community-level research in an effort to extend the research continuum. A member of NeuroDevNet currently sits on the CanFASD Board of Directors.

Leveraging Research Dollars

In fiscal year 2011-2012, CanFASD's Network Action Teams had 20 active research projects in progress, which generated millions of dollars in project specific external funding. See the table below for a breakdown of the Network's external funds.

Canada FASD Research Network's External Funding

Team	Funding Received
Diagnostics - NAT1	\$0.7M
Intervention – NAT2	\$1.38M
Prevention – NAT5	\$1.34M
Grand Total	\$3.42M

Expanding Senior Management

With the decision to move toward operating as an independent charitable research network, the Board of Directors recognized the need to bring on an Executive Director who had the skill set to carry the organization into the future. The Board of Directors recruited Dr. Jocelynn Cook, who has a long history in the field of FASD, in both an academic research and a federal program and policy management context.

She has also held a number of leadership positions in the field and was responsible for leading the project that culminated in publication of the Canadian Guidelines for Diagnosis on FASD ¹. Her full biography is featured under the Staff section of this report. As a result of her efforts, CanFASD is defining its niche in the FASD world and is actively pursuing new, national collaborations and partnerships.

Presentations and Publications

Members of our research network are active across the country, making presentations to a wide range of audiences and have published many manuscripts, chapters, abstracts and reports. In the last year alone, the Network has achieved the following results.

Our Results



Our Research Teams

CanFASD Research Teams (Network Action Teams) are organized along the themes of Diagnostics, Intervention and Prevention.

Research in Diagnostics

FASD occurs across Canada in all communities and within all populations. The prevalence of FASD is unknown, but conservative estimates suggest that at least 1% of the general population may be affected by FASD ².

1. Chudley AE, Conry J, Cook JL, Looke, C., Rosales, T., LeBlanc, N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. CMAJ 2005;172(5 Suppl):S1–21.

2. Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM Jr. Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. Teratology. 1997 Nov;56(5):317-26.

Without an accurate diagnosis, the strengths, weaknesses and potential of the individual cannot be determined, neither can effective treatment or intervention plans. Assessment and diagnosis is complex and relies on both a multidisciplinary assessment and a comprehensive battery of cognitive and performance tests examining many domains of brain function.

The Research in Diagnostics team is engaged in research to help promote increased consistency, clarity and accuracy to the diagnosis of FASD. This team is currently engaged in a Canada-wide pilot project utilizing a common data form that was developed by the team in 2007-2008. Use of the data from this common data form will allow us to increase the consistency and quality of the FASD diagnosis, and to evaluate what is happening for individual patients over time.

Intervention on FASD

FASD can have a significant impact on the lives of those affected and many negative outcomes have been reported (e.g. substance abuse and incarceration). However, this impact can be altered by our response to the needs of those affected and their caregivers. Specifically, through a combination of targeted (e.g. improving memory) and supportive (e.g. improving teacher education) intervention practices we can positively influence the outcomes for many individuals.

Research has demonstrated that provision of interventions can result in increased likelihood that individuals may experience success in their lives, and decrease the likelihood of costly negative outcomes. Consequently it is crucial that we continue to investigate and provide evidence-based intervention services to those affected by FASD.

The Intervention on FASD team is focused on the intervention needs of individuals with FASD across the lifespan and has established a cross-jurisdictional advisory panel of FASD experts who are utilizing a virtual community of practice where ideas, interventions and research can evolve.

Prevention

Prevention of FASD is a complex, yet crucial component of our work. In the last fiscal year the Research Network had three teams working in the area of prevention. One team has been looking at prevention messages and programs to determine how these campaigns may change women's alcohol use patterns during pregnancy. A second team has been gathering information about FASD prevention via the Canadian Parent Child Assistance Program model to see how mentoring may benefit a specific population of women at risk. The third team has been looking at prevention by working with women and their support systems on a range of health and social issues.

Moving forward, CanFASD has plans to lead the development of a National Prevention Strategy (for more information, please refer to the Future Directions section of this report).

The Universal Data Form Project

Investigator: S. Clarren

Dates: 2010 – 2013

Funded by the Public Health Agency of Canada, \$200,000

Brief Summary

The field of FASD is limited because of insufficient capacity for diagnosis. In order to meet demands for screening, diagnosis and follow-up, diagnostic capacity must be increased approximately 10-fold. A streamlined, efficient approach is required as well as effective data collection and management. Passive surveillance will not be effective if diagnosis and consistent coding does not occur.

The Network has developed a platform for standardized data collection. A set of common forms have been developed that can be used by participating FASD diagnostic teams in Canada. These forms will provide data input into a future common database that can be used for reporting, research and surveillance.

Clinics and their researchers will be able to share the specific numbers of diagnoses, the functional diagnoses and the treatment recommendations. This will be the first time such data is available from multiple sites nationwide anywhere in the world and will provide the foundation for building more effective and more efficient diagnostic and treatment programs.

Prevalence of FASD in a Prison System

Investigator: S. Clarren

Dates: 2011 – 2012

Funded by Justice Canada and the Yukon Government, \$30,000

Partners: Yukon College

Brief Summary

An exploratory study was conducted to determine the feasibility of estimating the prevalence of FASD among individuals within the corrections system. The results of this study demonstrated that several important aspects were not yet in place. These included diagnostic capacity, full agreement with all First Nations within the Yukon, and functioning linkages to treatments that could respond to the data on brain damage that was ascertained in the assessments. Further follow up will be needed.

Strength-Based Interventions for Fetal Alcohol Spectrum Disorders

Investigators: C. Bertram, K. Keiver, A. Pritchard-Orr, J. Reynolds, S. Clarren, R. Mandryk, B. Gooch, S. Dunne

Dates: 2010 – 2012

Funded by NeuroDevNet and GRAND NCE's, \$150,000, \$150,000

Brief Summary

Solid research in laboratory animals suggests that positively reinforced exercise can bring cognitive aptitude into the normal range in animals with brain damage caused by prenatal alcohol exposure. In this study, children with confirmed forms of FASD are enrolled in regular physical exercise programs based on sports that they enjoy playing. The children have a broad cognitive battery to determine baseline at the inception of the program and then are retested 3 months later at the end of the exercise period. Exercise is done for ½ an hour, 3 times per week. The preliminary results are promising and show general improvement in multiple measure of brain performance in most individuals.

Evaluating The Effectiveness, Impact and Best Practices of Specialized Classrooms for Youth with FASD

Investigators: D. Goodman, J. Pei, G. Koren, J. Millar, D. Schwab

Dates: 2011 – 2013

Funded by the Canadian Foundation for Fetal Alcohol Research, \$78,840

Brief Summary

The goals of this project are as follows:

To examine the educational and mental health outcomes of youth receiving a specialized FASD classroom compared to a cohort of youth with FASD who do not receive the service, to understand educational and mental health outcomes related to this specialized classroom approach;

To establish an evidence-based “baseline for practice” curriculum for educators and other school practitioners; and

To create a national community of practice network related to youth with FASD and best practices related to their educational needs.

Mathematics Intervention for Children with Fetal Alcohol Spectrum Disorder

Investigators: C. Rasmussen, C. Coles, J. Kable, E. Taddeo

Dates: 2011 – 2012

Funded by the Alberta Centre for Child, Family & Community Research, \$40,000

Brief Summary

The goal of this project is to conduct a replication and extension of the Math Interactive Learning Experience (MILE) program with a sample of Alberta children. The following research questions will be examined:

Do children with FASD in the MILE intervention program improve in mathematics compared to children with FASD in a different behavioral/social skills intervention? Does the MILE intervention also improve other cognitive skills like working memory and visual-spatial abilities? Are improvements (in both mathematics and behavior) maintained 3 months after the intervention? Do children in the behavioral/social skills intervention improve on social skills and behavior?

Investigation of the Utility of Computerized Cognitive Training in Children with FASD

Investigators: K. Kerns, J. Pei

Dates: 2010 – 2013

Funded by NeuroDevNet, \$100,000

Brief Summary

The purpose of this study is to further research by the following:

Expanding and modifying the existing computerized training materials;

Examining the efficacy of the expanded materials in a second group of children using a mixed design controlled intervention study; and

Developing a web-accessible host server for the interventions materials allowing for pilot research on in-home caregiver delivery of this intervention, and the outcomes in children receiving it.

This study was previously funded by the Alberta Centre for Child, Family, & Community Research. Executive Functioning Training in Children with Fetal Alcohol Spectrum Disorders. Investigators: K. Kerns, C. Rasmussen. (Amount: \$38,881.60)

The Intervention of Victim and Offender Within the Criminal Justice System

Investigators: J. Pei, B. Alsbury, F. Jampolsky

Dates: 2010 – 2012

Funded by Yukon Law Foundation, \$5,000

Brief Summary

The specific objective of this project is to research the intersection of the FASD offender and victim within the Canadian Criminal Justice System, in order to further understand the dynamic of the client with FASD and their dual relationship with the criminal justice system. Ideally, our purpose is to further understand and determine best practices to prevent individuals who have FASD from becoming involved with the criminal justice system as either offender or victim.

Interventions Recommendations After FASD Assessment

Investigators: C. Rasmussen, J. Pei

Dates: 2011 – 2013

Unfunded Study

Brief Summary

This project has two goals. The first goal is to summarize the intervention strategies recommended after assessment for all children assessed at the Glenrose Rehabilitation Hospital FASD clinic. The second goal is to determine the functionality of the intervention recommendations being made. This project will be extended to other clinics across Canada to support connections between assessment and intervention.

Perceptions of Fetal Alcohol Spectrum Disorder: Identifying and Developing Systems for Healthy Living

Investigators: J. Pei, L.Walls

Dates: 2011 – 2012

Funded by Killam Research Fund, \$6166.66

Brief Summary

This project looks at the experiences of caregivers of individuals with FASD and their interactions with systems of care. Individuals affected by FASD often encounter daily challenges functioning effectively, and due to the complex nature of their disability, current systems of care and support may not always meet their needs. This project is an examination of how caregivers of individuals affected by FASD perceive and are impacted by existing resources and services or a lack there of.

An Evaluation of an Intervention Program for Youth with Fetal Alcohol Spectrum Disorders (FASD)

Investigators: J. Pei, C. Rasmussen, C. Poth

Dates: 2008 - present (ongoing)

**In-kind Funding by Catholic Social Services and the University of Alberta Faculty of Education,
Department of Educational Psychology**

Brief Summary

The objective of this project is to use evaluative inquiry to measure the effectiveness of the McDaniel Youth Program for improving the functioning of adolescents with FASD. This evaluation will provide data intended to inform ongoing program decisions as well as measure program outcomes. The project will add to the knowledge of best practices by working hand in hand with a current program that provides prevention services and support to high-risk youth affected by FASD. Research findings will be shared on an ongoing basis with the McDaniel Youth Program. These findings will not only provide mentorship support to youth affected by FASD, but will inform practice and policy locally through engagement with the Edmonton Fetal Alcohol Network, and provincially with other FASD intervention programs.

Fetal Alcohol Spectrum Disorder: An Institutional Ethnography Examining Communication Pathways Between Multidisciplinary Support Systems and Diagnosed Pre-adolescent Youth

Investigator: M. Morton-Ninomiya

Dates: 2010 – 2014

Funded by Canadian Institutes of Health Research, Research & Development Corporation, Doctoral Award, \$105,000 and the Memorial University's F.A. Aldrich Fellowship, \$30,000

Brief Summary

This qualitative research project will map both human and policy relations between pre-adolescent youth with FASD diagnoses, their families, their communities and relevant institutional systems (health, education, child welfare, corrections) – to identify gaps and best practices. Using institutional ethnography, experiences of families/caregivers of pre-adolescent youth diagnosed with FASD in two communities (one Aboriginal community in Labrador and one in St. John's) will be documented. Pathways of communication between these families and their network of supports and services will be investigated. Data generated from interviews, observations and texts (including policy and procedural documents) will be used to:

Analyze implications of an FASD diagnosis from family and caregiver points of view;

Document how beliefs, opinions and practices influence management and intervention strategies; and

Identify effective formal and informal services and practices.

Conversations with Women About Alcohol Use During Pregnancy

Investigators: S. Deshpande, M. Cismaru, N. Agrey

Funded by Canada FASD Research Network

Brief Summary

Data analysis on conversations with women about alcohol use during pregnancy project, which was funded by the Canada FASD Research Network is complete. This research is currently being written into an article for submission to the Journal of Social Marketing.

Assessing English-speaking FASD Prevention Campaigns for Adherence to PMT Variables

Investigators: S. Deshpande, M. Cismaru, N. Agrey

Funded by Canada FASD Research Network

Brief Summary

During this study campaign resources from Canada, United States, England, and Australia were compiled. They were then examined and cataloged and coded for adherence to Protection Motivation Theory (PMT) variables. Data collection and analysis is complete. A draft article of the research findings has been submitted for feedback.

Development and Testing of PMT FASD Prevention Materials

Investigators: S. Deshpande, M. Cismaru, N. Agrey

Funded by Canada FASD Research Network

Brief Summary

This project applied PMT in a lab experiment setting to identify the most appropriate conditions in which the audience might be convinced about alcohol abstinence during pregnancy. The objectives of Study are to assess the effectiveness of each of the variables of PMT in a campaign, the strength of these variables, and the relevance of the message to the motivations for why women drink during pregnancy or while contemplating pregnancy. Data collection and analysis has been completed.

Honouring Our Strengths – Indigenous Culture as Intervention in Addictions Treatment

Investigators: C. Dell, J. Thompson, P. Menzies, S. Acoose, P. Butt, E. Costen, J. Dumont, M. Farag, J. Gone, C. Hopkins, M. Martin, R. McCormick, D. Mykota, N. Poole, B. Rush B. Shea, D. Stoneadge, V. Tobias

Dates: 2012 – 2015

Funded by the Canadian Institutes of Health Research, Operating Grant, \$1.2 million

Brief Summary

The purpose of the study is to examine the effectiveness of First Nations culture as a health intervention on alcohol and drug treatment client wellness. Objectives are:

- ▶ To improve and promote the health of First Nations through innovative health intervention research;
- ▶ To document and generate knowledge on indicators of the impact of Indigenous cultural interventions on client wellness; and
- ▶ To design a culturally valid instrument to measure change in client wellness.

Repairing Holes In the Net: Responding to the Mental Health Needs of Northern Homeless Women

Investigators: N. Poole, P. Ponik, A. Browne

Dates: 2011 – 2013

**Funded by the Canadian Institutes of Health Research and the Mental Health Commission of Canada
\$499,519.16**

Brief Summary

Repairing the Holes in the Net is an applied health services study designed to improve the mental health of northern women who have unstable housing or are homeless, through the development of research-based models for more effective health services delivery and policy development in Canada's three northern territories. The research is designed to foster collaboration between individuals, organizations and territorial governments, including key decision makers and mental health service providers in both the government and non-government sectors.

Towards an Evaluation Framework for Community-Based FASD Programs

Investigators: N. Poole, D. Rutman, S. Hume, C. Hubberstey, M. VanBibber

Dates: 2011 – 2012

Funded by Public Health Agency of Canada, \$246,048

Brief Summary

The objectives of this study are to do the following:

- ▶ Compile evaluation methods, tools, and indicators of success being used by Canadian community-based FASD prevention programs, and supportive intervention programs directed to adults and older youth;
- ▶ Seek feedback on the usefulness, strengths and gaps of these evaluation methods, tools and indicators from community-based program providers/administrators and evaluators; and
- ▶ Develop resources for Canadian FASD prevention and intervention program providers to support their capacity to undertake evaluation.

This project was granted a 2-year extension, from 2012 to 2014 for an additional \$300,000.

"From Stilettos to Moccasins" Workshop

Investigator: C. Dell

Dates: 2011 – 2012

Funded by Canadian Institutes of Health Research, Meetings, Planning & Dissemination Grant, \$100,000

Brief Summary

Building upon our national, interdisciplinary team's success, the aim of this proposed project is to effectively translate our study's findings through the implementation of a health intervention workshop. The workshop, as piloted, is one outcome of a CIHR-funded study that examined the role of identity and stigma in the healing journeys of over 100 criminalized First Nations, Métis and Inuit women in National Native Alcohol and Drug Abuse treatment programs.

The workshop builds upon our team's earlier achievement in knowledge translation where the research findings were composed into a song and music video, titled From Stilettos to Moccasins. The workshop extends our team's knowledge translation efforts and will serve as a self-sustaining support program for improving Aboriginal women's health.

Trauma, FASD Prevention, and Social Determinants of Women's Health (Brightening Our Home Fire: Women and Wellness Project)

Investigators: D. Badry, A. Salmon, A. Wight-Felske, S. Lockhart, A. Hache, M. Van Bibber

Dates: 2011 – 2012

Funded by Health Canada – First Nations Inuit Health Branch, \$152,420

Brief Summary

This project was developed to respond to the need for FASD prevention work in the North West Territories (NWT) as identified by NAT members living in the North. The study focused on the social determinants of health in four communities in the NWT and utilized PhotoVoice as the primary methodology.

Investigation of Patterns and Trends of Alcohol Consumption by Women of Child-Bearing Age

Investigators: N. Poole, L. Greaves, G. Thomas, L Bialystock, and C. Dell

Dates: 2011 – 2012

Funded by the Public Health Agency of Canada, \$34,665

Brief Summary

The goal of this study was to determine the patterns and trends, by age grouping, of women's use of alcohol, in conjunction with birth rates, reported violence statistics, smoking rates, other substance use, drinking contexts/ situations and motivations for drinking by women of childbearing years. The goal is to identify gaps in knowledge and to provide recommendations for research, program and policy development, and universal and targeted prevention efforts.

Future Directions

In the next fiscal year, the Canada FASD Research Network will implement the first year of its 3-year strategic plan, and finalize our business strategy for the period 2012 to 2015. CanFASD is moving towards independence as a new, national society. This involves new relationships with provincial and territorial governments and stakeholders, a new board of directors and new partnerships. CanFASD will begin by meeting with the provinces that have expressed interest in joining the Network to identify projects and areas of common interest.

By summer 2013, we hope to have achieved charitable status from Canada Revenue Agency (CRA), and will be working towards operation as an independent national research society, guided by our new goals and research directions. The following section highlights key areas which remain unexplored that CanFASD has identified as potential future projects. As we move forward, staffing and governance will be changing to align with our evolving business lines.

1 - Advisory Committees

Family Advisory Committee

The CanFASD Family Advisory Committee will inform and advise the ongoing work of the Canada FASD Research Network as it pertains to meaningful research and knowledge translation and provide advice on research directions and priorities to promote individual and family relevant outcomes.

Research Advisory Committee

The CanFASD Research Advisory Committee will provide ongoing and timely advice on current and emerging research and science issues in Canada and internationally, as it relates to FASD and the work of our researchers. This may include, but is not limited to the following: prevalence, diagnostics, prevention strategies and approaches, interventions, as well as standards and guidelines.

2 – A National Prevalence Plan and a National Prevention Strategy

Since the prevalence of FASD remains unknown, as does an accurate estimate of the number of pregnant women who consume alcohol during pregnancy, trends related to effectiveness of prevention campaigns and interventions are an enigma. Without the ability to show that the resources put into FASD are impacting health and related-service utilization, delivery and costs, it is difficult for governments to determine which programs and policies are most effective. Looking to the future, governments will increasingly require evidence-based, reliable information on which to base program and service development and implementation. To do this, a National Prevalence Plan and a National Prevention Strategy are required in order to create a common vision and goals and to maximize efforts and resources across Canada. These will serve as the foundation for strategic goals and priorities for Canada to work together across sectors and governments and to make strides related to FASD prevention and measurement of prevalence.

National Prevalence Plan

The prevalence of FASD, based on research studies primarily conducted in the United States and Europe in the 1980's and 1990's, is estimated to occur at a rate of 1 out of 100 live births. Recent epidemiological studies suggest prevalence rates as high as 2-5% ¹. Governments and communities in Canada have recognized that rising estimated prevalence rates lead to an increased need for units of service and rising overall costs. These costs are borne by all systems.

With the development of the standardized data form and a database as well as increased diagnostic capacity, it will become possible to begin to capture information about FASD prevalence across Canada. This will lend critical information for decision-making related to funding programs, diagnostic training and capacity and socioeconomic impact.

National Prevention Strategy

Some jurisdictions across Canada spend a significant amount of money on prevention/awareness campaigns about the risks of alcohol consumption during pregnancy. Very few of these campaigns have been evaluated for effectiveness, but in contrast, alcohol beverage companies continuously evaluate the success of each of their marketing campaigns.

CanFASD could assist governments and organizations with the evaluation and comparative effectiveness of targeted campaigns and messaging as well as facilitate the development of campaigns that are based on market research and testing.

3 - New Research Directions

Revision and Update of Canadian Diagnostic Guidelines

A proposal has been submitted to Public Health Agency of Canada to update the Canadian Diagnostic Guidelines which have been very popular since they came into use in 2005. It is recognized that the guidelines need to be updated to include work with young children and adults, revision to some of the diagnostic terms and reconsideration of the severity rating for diffuse brain damage.

Survey of Allied Health Professionals on Knowledge and Attitudes

A proposal has been submitted to the Public Health Agency of Canada to conduct a survey of allied health professionals asking about their knowledge, attitudes and beliefs about FASD and substance use during pregnancy. In 2002 – 2004, a similar survey was conducted with physicians as the sample. This new study will follow up with original participants as well as professionals who work in the field of FASD diagnosis to identify gaps and opportunities related to training and education.

1. May PA, Gossage JP, Kalberg WO, Robinson LK, Buckley D, Manning M, Hoyme HE. Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Dev Disabil Res Rev.* 2009;15(3):176-92.

Longitudinal Study of Individuals Affected by FASD

Individuals diagnosed with FASD should be followed throughout their lifespan to determine factors such as how a diagnosis affects short- and long-term outcomes, mental health, types of diagnoses and interventions, transitions to adulthood, delineation between primary and secondary disabilities, etc. Sustainable funding for a national longitudinal study related to FASD will be sought.

Adults Affected by FASD

To date, there has been very little information related to transition to adulthood, adult-specific diagnosis and interventions. In spite of the problems that affected adults have related to transition to adulthood, daily living, employment, housing, basic health, parenting, mental health and addiction, there is very little meaningful information available to systems and to caregivers. How this disability impacts treatment, and how it differs from other disabilities in terms of treatment intervention and outcomes needs to be determined.

Families

Research investigating relationships such as those between stress and outcomes, between stress and relationship stability and between stress, relationship stability and the ability to parent are critical to understand. It is also important to accurately determine the impacts that FASD has on others in the household. Determining these relationships can lead to more effective interventions and services.

Financials

OPERATING BUDGET		2011-2012
SUPPORT & REVENUE		
Carryover from 2010-2011		\$77,334
Partnership		\$649,894
TOTAL REVENUE		
		\$727,228
EXPENSES		
Wages		\$345,738
Teleconference/cell phone		\$3,650
Equipment and software		\$6,305
Website		\$6,000
Courier		\$137
Printing		\$519
Travel		\$9,319
Board of Directors		\$11,852
NAT2		\$135,832
NAT3		\$55,698
NAT4		\$57,453
NAT5		\$58,168
TOTAL EXPENSES		
		\$690,669
<i>Net Surplus/(Deficit)</i>		
		\$3,220

Provincial Ministers of the Canada Northwest FASD Partnership

Alberta

Honourable Dave Hancock
Minister of Human Services

British Columbia

Honourable Mary McNeil
Minister of Children and Family Development

Manitoba

Honourable Kevin Chief
Minister of Children and Youth Opportunities
Minister Responsible for Healthy Child Manitoba

Northwest Territories

Honourable Tom Beaulieu
Minister of Health and Social Services

Nunavut

Honourable Tagak Curley
Minister of Health and Social Services

Saskatchewan

Honourable June Draude
Minister of Social Services

Yukon

Honourable Doug Graham
Minister of Health and Social Services

Board of Directors

Audrey McFarlane, Chair

Executive Director, Lakeland Centre for FASD

Jim Brookes, Director

Business Development and Stakeholder Management, NeuroDevNet

Lisa Brownstone, Director

Parent, Occupational Therapist - Ranch Ehrlo Society, and Brownstone Consulting

Michelle Dubik, Director

Executive Director, Manitoba Family Services and Consumer Affairs, Government of Manitoba

Ann Sturrock, Director

Consultant

Stacy Taylor (Ex Officio)

Project Coordinator, Health Addictions and Mental Health Services (Unit), Government of New Brunswick

Anne Fuller (Ex Officio)

*Provincial FASD Consultant
Children and Youth with Special Needs Policy
Ministry of Children and Family Development*

Steering Committee

Alberta

Laura Alcock
Director
Family Support for Children with Disabilities
Children and Youth Services

Amanda Amyotte
Project Officer
FASD Initiatives
Community Partnerships and Youth Strategies
Children and Youth Services

Denise Milne
Senior Manager
FASD Initiatives/Children's Mental Health
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Provincial FASD Consultant
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Patricia Living
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Communications and Social Marketing
Health and Social Services

Network Action Team Research Leads

Research in Diagnostics

Sterling K. Clarren, MD, FAAP
*Developmental Neurosciences and Child Health, Child & Family
Research Institute, Vancouver, BC*

Intervention on FASD

Jacqueline Pei, BA, MEd, PhD, CPsych
University of Alberta, Edmonton, AB

Prevention from a Women's Health Determinants Perspective

Nancy Poole, MA
BC Centre of Excellence for Women's Health, Vancouver, BC

Evaluation of FASD Mentoring Programs

Linda Burnside, BSW, MEd, PhD and John McDermott
University of Manitoba, Winnipeg, MB

Evaluating of FASD-Specific Health and Educational Materials

Sameer Deshpande, BComm, MA, PhD, Magdalena
Cismaru, BA(Hon), PhD
University of Lethbridge, Alberta

Host Agency

Provincial Health Services Authority

Dr. Stuart MacLeod, MD, PhD, FRCPC
*Executive Director, Child & Family Research Institute
Vice President, Academic Liaison & Research Coordination
Provincial Health Services Authority, Vancouver BC*

Staff

Dr. Sterling K. Clarren, MD, FAAP - Scientific Director

Dr. Sterling Clarren is a Clinical Professor, with the Division of Developmental Pediatrics, Department of Pediatrics, at the University of British Columbia, and an Investigator with Developmental Neurosciences and Child Health, Child & Family Research Institute. He is also a Clinical Professor of Pediatrics at the University of Washington. He received his BA from Yale University and his MD from the University of Minnesota Medical School. He then completed pediatric residency training at the University of Washington School of Medicine before going on to do fellowships in Biosciences, Dysmorphology, and congenital defects at the University of Washington School of Medicine. He was on the faculty at the University of Washington as the Robert A. Aldrich Professor of Pediatrics until the fall of 2004 when he assumed the lead of the Research Network.

Jocelynn Cook, PhD, MBA - Executive Director

Dr. Jocelynn Cook has a long history in the field of FASD, in both an academic and a federal program and policy context. She received a Bachelor of Science degree (Honours Biology) from Bishop's University and then a PhD in Physiology from the Medical University of South Carolina. She studied the effects of alcohol consumption on pre-term birth for her postdoctoral fellowship at the University of Alberta. She also completed an MBA, with a focus on Economics and Health Policy, from the University of Saskatchewan.

Dr. Cook was an Assistant Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences at the University of Saskatchewan before joining the Public Health Agency's FASD Team. There she managed a large national survey of health professionals and lead the development of the Canadian guidelines for the diagnosis of FASD. She also worked with First Nations and Inuit Health Branch's FASD Team developing cost-benefit analyses for FASD diagnosis and intervention programming.

Dr. Cook has also held a number of leadership positions, including Chief Science Advisor for Assisted Human Reproduction Canada and Executive Director of the Canadian Institutes of Health Research's Strategy for Patient-Oriented Research. She is a past member of the Substance Abuse and Mental Health Commission's FASD Expert Advisory Committee, the National Institute of Health's Expert Advisory Committee on Terminology related to FAS and the Centers for Disease Control and Prevention's FAS Task Force. She also holds an adjunct professor appointment in the Department of Obstetrics and Gynecology at the University of Ottawa.

Jan Lutke - Clinical Research Manager

Jan Lutke is the past co-chair of the former National Advisory Committee on FASD to Health Canada, Government of Canada. She also chaired the former FASD Provincial Consultation Group to the Province of British Columbia. She is the founder and senior consultant of FASD Connections, an organization dedicated to helping adolescents and adults with FASD and their families. She also sits on numerous provincial and national advisory committees with respect to FASD.

Michelle Sherbuck - Research Communications Manager

Michelle Sherbuck coordinates and executes a wide range of design, knowledge translation and communications activities for CanFASD. After seven years of technical communication and design in the high-tech sector, she now contributes her expertise in the fields of technology, user interface, website management, business communication and design. Michelle has 15 years of experience in the field of FASD including: leadership, group facilitation, writing, public speaking and event planning.

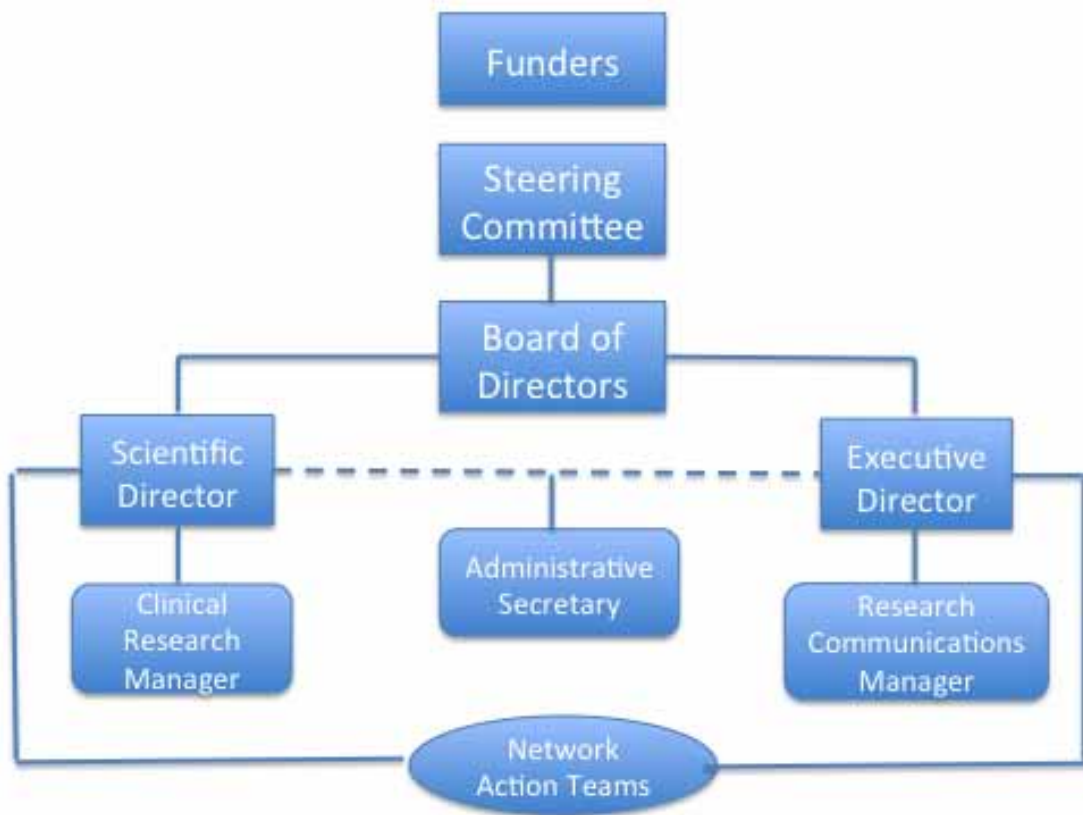
Krystina Tran - Administrative Assistant

Krystina Tran provides assistance, planning and support to all members of the CanFASD Research Network. She is also the administrative assistant to Dr. Sterling Clarren and has worked at Developmental Neurosciences and Child Health for over five years.

Canada FASD Research Network Organizational Chart

The chart below depicts the current organizational structure of CanFASD. As the Network expands and evolves over the next few years, it will be necessary to realign to support major strategic goals and directions. Additional capacity in research management will be required and additional efforts will be focused on training, education and knowledge translation.

CanFASD Current Organizational Structure



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