CanFASD
CANADA FASD RESEARCH NETWORK

Annual Report 2012-2013

Together: finding answers,
improving outcomes.

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A NOTE FROM

THE BOARD CHAIR

It has been a fascinating year for the Canada Fetal Alcohol Spectrum Disorder Research Network; a year of growth and evolution. The Board of Directors was happy to meet the Canada North-West FASD Partnership Ministers and their staff at a reception in Saskatoon last Fall, hosted by Saskatchewan Minister, the Honourable June Draude. Interacting with the Ministries helps the Board to steer CanFASD in direction that continue to be policy-relevant. The Board has worked very closely with the CanFASD Executive over the past year to identify funding opportunities, put Board policies and procedures in place and plan events in collaboration with local FASD groups. A silent auction in partnership the Saskatchewan FASD Support Network in Saskatoon was a great success.

The Board will continue to support the Canada Fetal Alcohol Spectrum Disorder Research Network as it embarks upon its first year as an independent charitable not-for-profit organization. We wish to thank all of our friends in the community who have helped to make this process happen. The Board would especially like to extend its gratitude to the Provincial Health Services Authority of British Columbia (PHSA) who has worked tirelessly with us, since 2005 to provide crucial infrastructure and human resources - office facilities, technical and legal support services, and accounting, as well as contract and human resources negotiations – to ensure operations ran smoothly. The administrative oversight of the PHSA enabled CanFASD to leverage external funding of $3.4M dollars in 2012 to support research on diagnosis, prevention and interventions for FASD.

CanFASD is increasingly grateful to our funders – Alberta, British Columbia, Manitoba, Northwest Territories, Nunavut, Saskatchewan and Yukon – for supporting our unique partnership model and allowing us to do the critically important work that we do. We are thrilled to have New Brunswick joining the Network this year and to be expanding our membership to the East!

Here's to another year of new discoveries and new stories with our FASD community in our journey together toward meaningful research and improving outcomes.

Audrey McFarlane
Chair of the Board of Directors

THE EXECUTIVE

This has been an exciting year for the Canada FASD Research Network. February marks our first anniversary as a not- for-profit organization and we have worked hard to welcome new staff, expand our vision, and plan for a National presence. We obtained national charitable status in January 2013 and are looking forward to welcoming new investors and supporters. We would like to thank the Provincial Health Services Authority of British Columbia, and especially Dr. Stuart MacLeod, for their commitment and support as our host agency for the past 7 years; without their assistance with human resources, financial management and infrastructure we would not have been able to evolve to an independent national entity. The 2013-14 fiscal year marks the inaugural year of CanFASD as an independent organization.

At the time of this annual report, CanFASD researchers are leading over 25 major projects related to Fetal Alcohol Spectrum Disorder prevention, intervention and diagnostics. We are working in partnership across the country to catalyze, facilitate and support policy-relevant research in our quest to produce and maintain national collaborative research designed for sharing with all Canadians; research leading to prevention strategies and improved support services for people affected by FASD. We realize that FASD crosses sectors and disciplines, and the distinctions between our research pillars of prevention, intervention and diagnostics are continuously blurred. As a result, our Network Action Teams have become even more collaborative in their approaches and projects, sharing expertise to ensure that the complexities of intervention, prevention and diagnostics are meaningful and relevant across the research continuum. Together, we move into 2013 with renewed energy, fresh ideas and a commitment to intensifying our international leadership position in the field of FASD.

Our understanding of FASD is in a period of rapid expansion and change. We are beginning to understand the extent of the global impact of this lifelong disability. Research, and the answers it may provide, is critical for moving this field forward, changing the way we view this brain based disability and lessening its impact on individuals, families and society.

By working together we can help prevent the lifelong consequences of fetal alcohol spectrum disorder and provide support to Canadians already living with this disability. We look forward to this next year of growth and evolution as we welcome new members and new provinces on board. Thank You to our partners, collaborators and reseachers for an incredibly productive year.

Dr. Sterling Clarren, MD, FAAP
Scientific Director

Dr. Jocelynn Cook, PhD., MBA
Executive Director

ABOUT FETAL ALCOHOL SPECTRUM DISORDER

- The first indications that prenatal alcohol exposure was associated with birth defects was described in France in 1968 by Dr. Lemoine.
- In the early 1970's, researchers at the University of Washington (Jones and Smith) described a group of infants, born to mothers who had consumed alcohol in pregnancy, that shared uncommon physical features and developmental delay. The term "Fetal Alcohol Syndrome" (FAS) was coined to describe these patterns.
- Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol.
- Effects associated with FASD are lifelong and can include physical, mental, behavioural and learning disabilities.
- Depending on the amount and the timing of alcohol exposure, some individuals exposed will also develop a characteristic pattern of facial features, and some will have a growth deficiency.
- All those with FASD will exhibit some degree of neurobehavioral dysfunction, as a result of damage to the developing brain.
- It is important to note that most individuals with FASD are not visibly different, even though their brain is permanently damaged.
- The damage related to prenatal alcohol exposure can happen to anyone, regardless of age, culture or race.
- It has also been estimated that the total cost of FASD is an estimated $4 billion a year to Canada.
- There are currently no confirmed statistics on the number of people in Canada who have FASD, yet FASD is considered to be the leading known cause of developmental disability in Canada.
- No two people with FASD will have the same challenges due to the wide variation of alcohol's effects on brain development. They are at increased risk for mental health issues, school difficulty, serial employment and addictions.

- There are currently no confirmed statistics on the number of people in Canada who have FASD, yet FASD is considered to be the leading known cause of developmental disability in Canada.

THE HISTORY OF THE CANADA FETAL ALCOHOL SPECTRUM DISORDER RESEARCH NETWORK

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is a formally and informally connected group of professionals from a range of research scienceslocated across Canada. It is Canada's first comprehensive national Fetal Alcohol Spectrum Disorder (FASD) research network and has been in operation since 2005.

CanFASD was created as a main focus of a continuing government alliance of the four western provinces and three northern territories called the Canada Northwest FASD Partnership (CNFASDP). This Partnership has been working together since 1998 towards the development and promotion of an inter-jurisdictional approach to diagnosis, prevention, intervention and care and support of individuals who are affected by Fetal Alcohol Spectrum Disorder (FASD).

After 8 years of increasingly successful and high profile operation, CanFASD is now a national Canadian charitable organization whose vision is to support Canada's leadership in addressing the extraordinary complexities of FASD. Its mission 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.

CanFASD creates, nurtures, and sustains a collaborative environment and a unique partnership able to bring together many scientific viewpoints to address FASD, with a focus on ensuring that research knowledge is translated to community and policy action. It works through four cross-jurisdictional research teams (Network Action Teams) that are focused on the areas of diagnosis, intervention and prevention and connects researchers, graduate students and practitioners from communities and institutions across Canada and internationally.

Working in partnership across the country, CanFASD is collaborating with other individuals, researchers and organizations concerned with FASD. CanFASD researchers are currently taking part in most of the FASD research projects across Canada; our researchers currently lead 25 major projects related to FASD prevention, intervention and diagnostics.

OUR GUIDING PRINICPLES

Our Vision

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

Our Mission

To produce and maintain national collaborative research designed for sharing with all Canadians; research leading to prevention strategies and improved support services for people affected by Fetal Alcohol Spectrum Disorder.

In support of the mission and to achieve the goals, the Network operates under three main lines of activity:

1. Providing a research-related co-ordination function so that FASD research in Canada reflects the needs of families, care givers and policy makers;
2. Catalyzing and participating in the research environment to foster effective policy and practice that ultimately improves the lives of those affected by FASD; and
3. Effectively translating information in a meaningful way to stakeholders.

Who funds us?

The majority of CanFASD's funding comes from the provinces and territories of the Canadian Northwest FASD Partnership (AB, BC, MB, NWT, NU, SK, YK) according to a per capita funding model. New Brunswick recently joined the Network and makes an annual contribution. Provincial funding provides support for the Network and its research teams' infrastructure, human resources, networking activities, knowledge translation activities (i.e., policy papers, website, webinars, web-conferencing), administration, and workshops and seminars. External research grants fund specific projects and, in 2012, CanFASD research teams generated over $3.8M in external funding for research projects.

Why is research on FASD so important?

FASD is recognized as a significant issue in Canada; it is currently the leading known cause of developmental disability and has life-long impacts. Governments are working to measure prevalence and to determine the most effective intervention and prevention programs. Every year, millions of dollars are spent in an attempt to improve outcomes for affected individuals and their families. However, we do not have a clear understanding of the most effective supports nor the capacity required to deliver cost-effective, accessible and sustainable prevention, intervention and diagnostic services.

By working with researchers, partners, parents and caregivers, program and service delivery staff, communities, bureaucrats, and political leaders, the research evidence generated and translated by CanFASD can help answer questions that are meaningful about the prevention, diagnosis and treatment of FASD and help set the foundation for the development of increasingly effective programs and policy development.

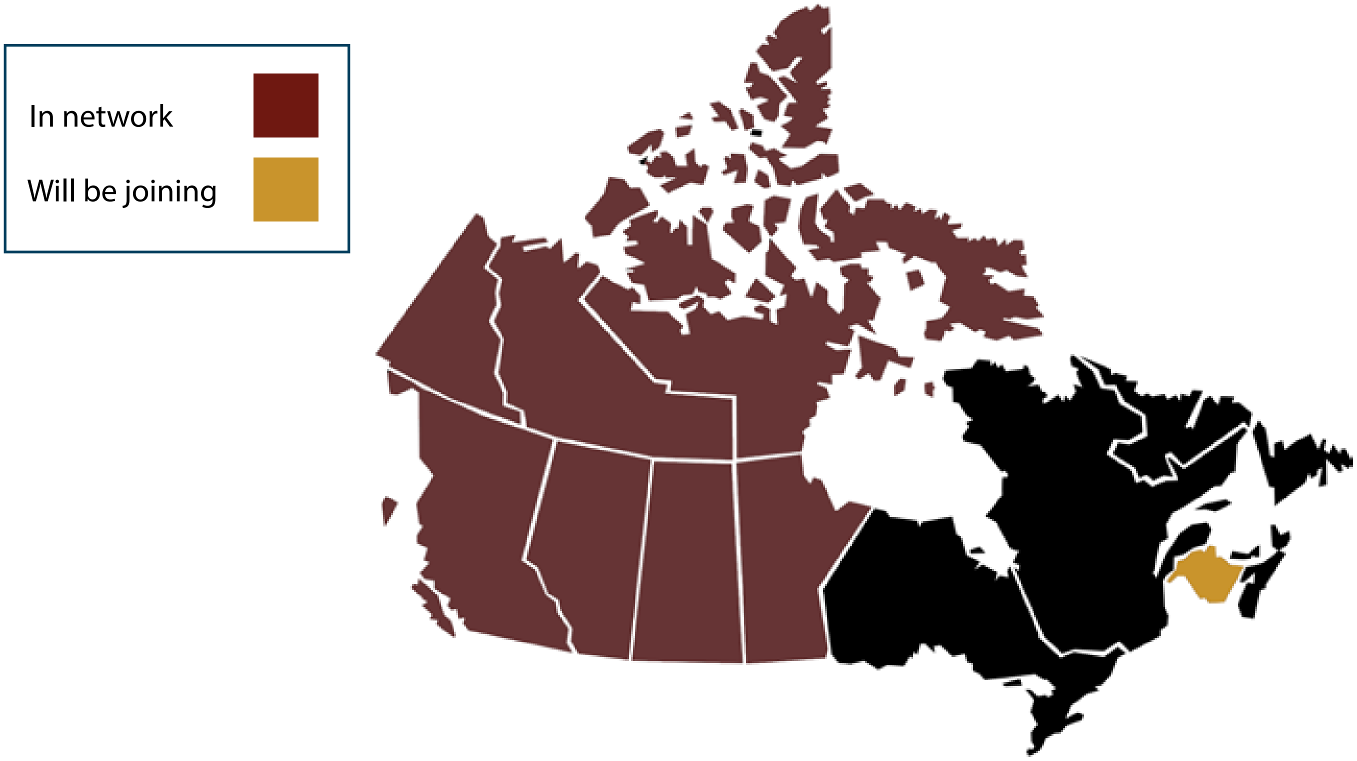
WHY BE A MEMBER OF CanFASD?

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, messaging and education, capacity development, prevalence, knowledge translation, evidence-based decision-making and incorporation of evidence into practice.

Ultimately, the work of the Network will benefit member governments by increasing capacity for meaningful FASD research in their jurisdictions having the potential to reduce longer-term costs associated with 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, more effective policies and programs that can lead to improved outcomes.

Member provinces benefit from increased research capacity, advice and input on how to move forward in the field, learning from the work and experiences of other provinces, policy-relevant information and recommendations on topics and issues related to FASD. They can also access researchers and research programs through the Network. Better, more meaningful information that matters to families and service providers is becoming increasingly available to guide evidence-based decision-making that will lead to new, and more cost-effective programs and services.

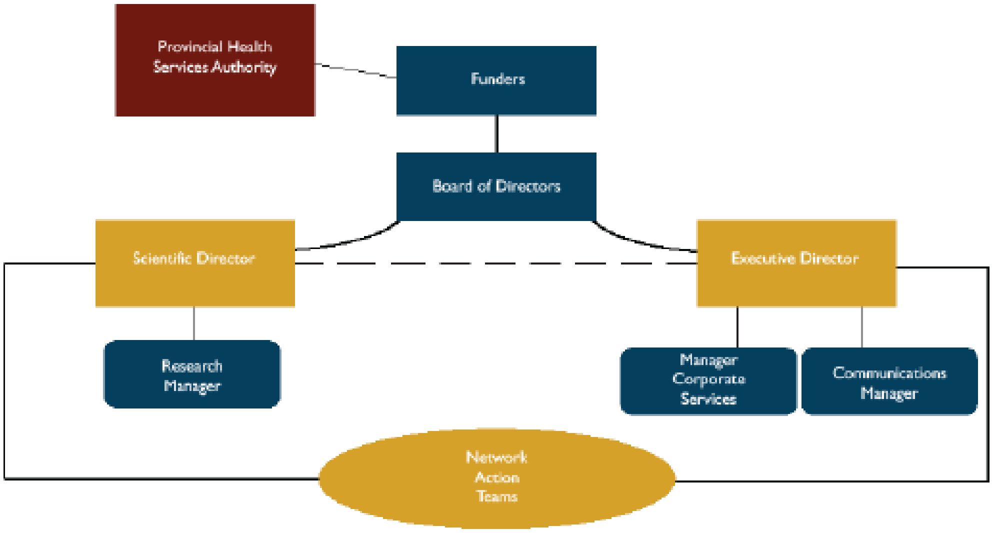
Current members of CanFASD include Alberta, British Columbia, Manitoba, Northwest Territories, Nunavut, Saskatchewan and Yukon. CanFASD is pleased to welcome the newest provincial member, New Brunswick, who will be joined the network in April, 2013.



For their membership, the contributing provinces and territories can receive:

- ✓ A trusted organization to seek answers to important policy questions
- ✓ Answers to direct requests for information (i.e., policy/position papers on FASD research to provide potential policy implications for governments)
- ✓ Opportunities to have input into the research direction/agenda
- ✓ Annual reports
- ✓ Invitation to CanFASD symposia, workshops and learning events
- ✓ Annual visits and presentations by CanFASD staff
- ✓ Opportunities to collaborate and participate in CanFASD research projects
- ✓ Travel awards for their researchers and trainees
- ✓ Leadership in FASD
- ✓ Access to member researchers and governments
- ✓ Access to platforms and tools developed by the Network
- ✓ Opportunity to have membership on the National Family Advisory Committee
- ✓ Mentoring between provinces
- ✓ Assistance with identifying funding opportunities and preparing proposals
- ✓ Assistance with preparing and submitting abstracts for presentations
- ✓ Venues for sharing information and experience, as well as a platform for learning.
- ✓ The most current evidence to utilize in the development of provincial services

Our Organizational Structure



Our Staff

DR. STERLING CLARREN, MD, FAAP - Scientific Director, Diagnostics Research Lead

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.

DR. JOCELYNN COOK, PhD., MBA, - Executive Director

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 from Bishop's University and a PhD in Physiology from the Medical University of South Carolina. She also completed an MBA from the University of Saskatchewan. Dr. Cook has held a number of leadership positions in the federal government and 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. Dr. Cook 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. She also chaired the former FASD Provincial Consultation Group to the Province of British Columbia, co-wrote and instructed the two on-line FASD curricula of the Justice Institute of BC, and instructed the MCFD social work core curriculum on FASD. 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.

LIZ ELLWOOD BECKSTED, BA - Corporate Services Manager

Liz Becksted received her BA in Business Communications and has a Post-Graduate Certificate in Interactive Multimedia. Liz founded and is the former Executive Director of Fertile Future, a non-profit charitable organization for young cancer patients wishing to preserve their fertility prior to undergoing their treatment. Liz provides leadership for operations including, budgeting and resource allocation, financial tracking, logistics, report preparation, project facilitation, and supporting the operations of the Executive staff. Liz joined CanFASD in 2012.

FASD FACTS:

The first published literature that linked prenatal alcohol use with birth defects was in France, in 1968, by Dr. Paul Lemoine.

Our Research Leads

DR. LINDA BURNSIDE, PhD., - Prevention: Mother-Mentoring

Dr. Linda Burnside is a social worker whose career has focused on the needs of children, youth and families involved with the child welfare system. A specific area of interest is children with disabilities involved in child welfare, including children affected by FASD. This interest led to numerous research projects with Dr. Don Fuchs from the Faculty of Social Work, University of Manitoba, on the experiences of children with FASD in child welfare care. After more than 25 years of employment with the child welfare system and with disability programs in Manitoba, including 8 with the provincial Child Protection Branch (Manitoba Family Services), Dr. Burnside now works in private practice with her company Avocation: Counselling, Consulting, Research and Training. She continues to conduct research with Dr. Fuchs on children in care with FASD. She also has worked with the Canada FASD Research Network as co-lead of one of the research teams examining the role of mentoring in the lives of women with high risk substance misuse.

DR. JACQUELINE PEI, PhD., - Intervention

Dr. Jacqueline Pei is an Assistant Professor in the Department of Educational Psychology and Associate Professor in the Department of Pediatrics at the University of Alberta. Also a practicing Registered Psychologist for the past ten years, Dr Pei began her career as a criminologist and forensic counselor working with incarcerated youth. Motivated by this early work, she returned to academia to study youth at risk, child development, and neuropsychology, leading to her current focus on interventions for individuals with Fetal Alcohol Spectrum Disorders. Building on her work with various community and government agencies, including serving on the FASD Clinical Diagnostic Team at the Glenrose Rehabilitation Hospital.

NANCY POOLE, MA - FASD Prevention, Women's Social Determinants

Ms. Nancy Poole, MA, PhD candidate, works with the British Columbia Centre of Excellence for Women's Health and with BC Women's Hospital on knowledge translation, network development, and research related to improving policy and service provision for women with substance use problems and addictions. Nancy is well known for her collaborative work on FASD-related research, training and policy initiatives with governments and organizations on local, provincial, national and international levels. She is the Lead of the Network Action Team on FASD Prevention from a Women's Health Determinants Perspective for the CanFASD Research Network. She has edited two books – Becoming Trauma Informed (2012) and Highs and Lows: Canadian Perspectives on Women and Substance Use (2007) both published by the Centre for Addiction and Mental Health in Ontario Canada. Nancy is also known for leadership in piloting online participatory methods for knowledge generation and exchange, including virtual networks and communities of inquiry/practice.

CanFASD BOARD OF DIRECTORS


Ms. Audrey McFarlene, Chair, Executive Director, Lakeland Centre for FASD


Ms. Michelle Dubik, Co-Chair, Executive Director, Manitoba Family Services and Consumer Affairs


Mr. James Brookes, Chief Development Officer, NeuroDevNet


Ms. Lisa Brownstone, Occupational Therapist, Ranch Ehrlo Society and Brownstone Consulting


Mr. Tim Moorhouse, Assistant Deputy Minister, Alberta Tourism, Parks and Recreation

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Ms. Ginny Lane
Cognitive Disabilities Consultant, Government of Saskatchewan


Ms. Stacy Taylor
Health Consultant, New Brunswick Department of Health

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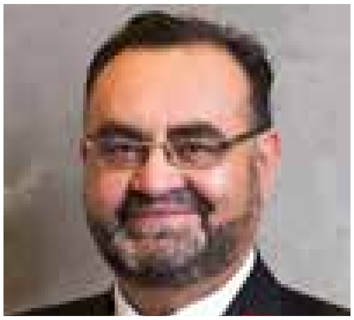
Minister of Human Services

British Columbia
Honourable Stephanie Cadieux
Minister of Children and Family Development

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



Northwest Territories
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Nunavut
Honourable Keith Peterson
Minister of Health and Social Services

Saskatchewan
Honourable June Draude
Minister of Social Services

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Honourable Doug Graham
Minister of Health and Social Services

OUR HOST AGENCY

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> ***'Thanks to the PHSA for their commitment and support - we wouldn't be where we are today without you!'***
> - Dr. Jocelynn Cook,
> Executive Director, CanFASD

After eight years of support and stewardship from CFRI and PHSA, the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) has now become Canada's first independent, national research network on Fetal Alcohol Spectrum Disorder (FASD).

CanFASD is a collaborative, interdisciplinary research network that brings together scientists from across the country to develop effective prevention strategies and improve support services for people with FASD.

From CanFASD's creation in 2005 to its launch this year as an independent national body, CFRI and PHSA have been integral to the network's success. The initial proposal was to establish the Canada Northwest FASD Research Network for Canada's four western provinces and three northern territories. The Network, which later became CanFASD, was a collaboration between PHSA, BC Children's, CFRI and UBC's Department of Pediatrics. The proposal was developed by Dr. Stuart MacLeod and Dr. Robert Armstrong. At the time, Dr. Macleod was CFRI's Executive Director, PHSA's Vice-President for Academic Liaison and Research Coordination, and Associate Dean of Research for the UBC Faculty of Medicine. Dr. Armstrong was the Head of Pediatrics at UBC and BC Children's.

During CanFASD's first eight years of operations, CFRI and PHSA provided critical infrastructure and administrative support enabling the network to secure grants and support research on diagnosis, prevention and effective interventions for FASD. In 2012 alone, CanFASD's members received over $3.8 million in external grants.

"We'd like to extend a heartfelt thank you to everyone at CFRI and PHSA, and, in particular, the finance team at CFRI," says Dr. Jocelynn Cook, Executive Director of CanFASD. "Your support enabled CanFASD to prosper and grow into an independent research network poised to make significant and meaningful contributions in the lives of children and adults with FASD."

"CanFASD would not be where it is today without the commitment and vision of Drs. MacLeod and Armstrong and the ongoing support of the CFRI and PHSA," said Dr. Sterling Clarren, Scientific Director, CanFASD.

WHAT CanFASD DID IN 2012-2013

The Canada FASD Research Network has had a busy year across all business lines. The administrative component has grown, as has our capacity for science and research and knowledge translation. Highlights of the efforts of the Network are outlined in the following sections.

ADMINISTRATION AND OPERATIONS

After obtaining not-for-profit status in February 2012, achieving charitable status was the next logical step and would expand the possibilities for new funding opportunities in the future. Industry Canada approved CanFASD's application and we became a national charitable organization in January 2013 – a great way to start off the new year!

Staff administered a survey to partners and stakeholders to determine how best to restructure our website. The information and advice provided formed the basis of a major restructure to www.canfasd.ca. The website continues to be refined and updated, and content is in the process of being translated into French.

With CanFASD's move to independence came the requirements for policies and procedures for travel and business expense reimbursements, human resources, finances and other operational activities. CanFASD staff worked with the Board of Directors, lawyers, accountants and a bookkeeper to draft and finalize a policies and procedures manual.

SCIENCE AND RESEARCH

Researchers and staff of CanFASD have been busier than ever in 2012-2013. Some of our notable achievements include:

- **60,000+** BLOG VISITS
- **14** YOUTUBE VIDEOS
- **15** PEER-REVIEWED PUBLICATIONS
- **64** CONFERENCE PRESENTATIONS

CanFASD researchers have been busy conducting research in the areas of FASD Diagnostics, Intervention and Prevention. The pages to follow will highlight our work.

WORK IN DIAGNOSTICS

The Research in Diagnostics team is engaged in research activities to help promote increased consistency, clarity and accuracy to the diagnosies within Fetal Alcohol Spectrum Disorder. Accessible and accurate diagnosis is key to understanding brain function, identifying interventions, measurements of prevalence, FASD prevention and obtaining access to systems and services. Results of research in diagnostics will lead to better, more efficient screening and diagnosis.

Diagnostic Guidelines

Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis were published by a panel of experts in 2005 in the first international attempt to provide simple-but-thorough evidence-based guidelines for diagnoses related to FASD. Health Canada (now the Public Health Agency of Canada) facilitated drafting of the Guidelines from 2002-2004.

Since that time, the field has evolved and there is now additional evidence, expertise and experience to suggest that revision of the 2005 Guidelines is essential to improve diagnoses and outcomes for affected individuals and their families. Practicing diagnostic teams have nearly all embraced the use of the 2005 Guideline principles. These teams have identified gaps and inconsistencies in the 2005 Guidelines as well as areas for improvement. In order to accurately define and to specify the areas for update and revision, a broader consultation process as well as coordination with professional organizations to ensure buy-in, relevance and knowledge translation/uptake is essential.

CanFASD has been awarded funding from the Public Health Agency of Canada to update and revise the 2005 Fetal Alcohol Spectrum Disorder: Guidelines for Diagnosis based on current evidence and the addition of sections pertaining to diagnosis of small children and adults and a significant revision of the brain-related assessment. These will be the first Guidelines in any country that provide best practice recommendations for diagnosis of FASD-related disabilities throughout the lifespan. Work has started and the updated Guidelines should be completed in Spring 2014.

The Honourable Colin Carrie, Parliamentary Secretary, announced the Diagnostic Guidelines project in a press release in Toronto in February, 2013.

Dr. Bruce G. Pollock, Dr. Jocelynn Cook, Dr. Svetlana Popova, and the Honourable Colin Carrie at Diagnostic Guidelines announcement.

The Universal Data Form Project

The uniform collection of clinical data on patients from FASD diagnostic programs around the country can provide information to help governments develop improved policy and programming. As a first step, CanFASD has been funded by the Public Health agency of Canada to trial the collection of some information from all interested clinical programs in all provinces who have FASD diagnostic services (AB, BC, MB, NB, ON, SK). At this time, 44 programs have agreed to collaborate. The following anonymous data will be securely transferred:

- The age and sex of the patient
- The FASD diagnosis and the diagnostic schema used to derive it
- The functional diagnoses that were identified
- The treatment recommendations that were made

For the first time ever, in any country, this study will reveal the frequency of the different diagnoses made within FASD and the frequency of each functional problem (how many individual with FASD have ADHD, memory deficits, social communication disorders, planning difficulties, sleep disturbances, etc and what the most common patterns of functional problem are. Further, how similar or dissimilar are treatment recommendations?

This data will be of enormous importance in developing improved services and therapies for these conditions. The project will also be the first step in a partnership among all clinics interested in developing more consistent diagnostic services and an ongoing attempt to collect other group information that would help with improving services for the FASD community. This work will also establish a precedent for data collaboration among the clinics that will assist in answering other important clinical questions.

The Treatment Improvement Protocol: Advancing FASD Recognition and Prevention in Canada

Adults with an FASD-related diagnosis may have increased difficulties with substance use and mental health conditions compared to the general population. Therefore, it is reasonable to involve mental health agencies and substance use treatment centres in screening for the possibility that their clients have FASD, have children with FASD, or are at risk to have children with FASD.   There are many reasons why screening within substance use and mental health services has not as yet been put in place including: lack of training of clinicians to do this type of screening, lack of referral routes to obtain an FASD diagnosis if it is suspected, lack of administrative support, and a general lack of understanding of the potential importance of this approach.

A Fetal Alcohol Center of Excellence is housed within the Substance Abuse and Mental Health Services Administration (SAMHSA) of the United States Public Health Service. SAMSHA occasionally publishes treatment improvement protocols (TIPs) for service providers. Within the next few months it is expected that they will release a TIP entitled "Addressing Fetal Alcohol Spectrum Disorders (FASD)", their first TIP on FASD.

FASD FACTS:

No two people with FASD will have the same challenges due to the wide variation of alcohol effects on brain development. They are at increased risk for mental health issues, school difficulty, difficulties maintaining employment and addictions.

WORK IN INTERVENTION

The focus of the Network Action Team on Interventions (iNAT) 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. Researchers are currently working on several research studies to contribute to a growing body of FASD intervention research across Canada, including a school-based intervention program aimed at enhancing teachers' capabilities to accommodate the needs of students with FASD. Building connections is essential to the distribution and efficacy of intervention information. The iNAT has made bridge-building a priority in our undertakings, including between stakeholders within the community, and between research findings (knowledge) and intervention options (practice). They have intertwined knowledge building and communication efforts in several outreach projects, including an e-newsletter, blog and interactive website.

Research

Toward enhanced teacher preparation for meeting the needs of students with FASD:
Given the lifelong challenges faced by individuals with FASD across a diverse continuum of difficulties, it is imperative that service providers and caregivers are equipped with the knowledge of how to best support the individual needs of students in the classroom. This study responded to the need for greater communication among teachers with respect to the unique learning needs of students with FASD and effective school-driven interventions targeted to meet their personalized needs. Teachers in this study took part in a collaborative professional development process aimed at generating opportunities to discuss challenges, share strategies and create tools that encourage the teaching team to reflect, communicate, and act in ways that would best help students with FASD experience more positive school environments.

Teachers of youth with FASD in an urban high school took part in four sessions across four months, learning about the project itself and the deficits associated with FASD that cause difficulties in the classroom. Teachers were encouraged to identify areas where misinterpretation of behavior may have occurred. They were urged to discuss with their peers the successes and challenges of dealing with behavioural incidents and ways in which they could incorporate reflection and collaboration (communication) into their regular activities. The result was a conversation that provided evidence regarding enhanced understanding, reflective practice, and shifts in how teachers made decisions regarding actions. In this way, the following model was implemented:

A case study research approach was applied to analyze the resulting data, including field notes from researchers, meeting summaries, audio recording from sessions, and a post collaborative training survey. Two types of findings have emerged from this study: immediate project outcomes and anticipated longer-term project outcomes. Immediate project outcomes included developing and implementing an innovative approach to professional learning, characterized by responding to emerging needs. This contrasts traditional models of professional learning where the goals are pre-determined and the experience facilitated by experts. Working together, researchers and educators had an opportunity to discuss and brainstorm, provide feedback about what is helpful and relevant to classroom-practice, and generate tools to support their work with students with FASD. The educators felt these tools were useful as they evaluated their practice and considered new ways of understanding the true root of the behavior they were seeing – in order to conceptualize best responses. All participants reported agreement that the approach was useful for increasing their knowledge of FASD, and FASD-related classroom strategies, as well as increased understanding of their colleague’s challenges. Furthermore, all participants indicated an interest in remaining involved in the group and were motivated to learn further about FASD.

Communications and Knowledge Exchange

iNAT E-news

The goal of the iNAT e-newsletter is to connect researchers, policy makers, and service providers in a conversation about emerging best practice and community needs. The newsletter provides highlights on new intervention-related research findings and publications, educational links, networking opportunities, featured organizations, upcoming events, and opportunities for investigators to share their research. This information was distributed to a list of subscribers that self-identified as having an interest in the FASD community. Contact information for investigators, organizations, and individuals is provided whenever possible to enhance communication and encourage discourse.

The newsletter has received increasing readership, from 124 subscribers in the first edition to over 300 in the most recent edition. A preliminary analysis of reader access to links provided in the newsletters was recently completed in order to gain insight into the interests of stakeholders, which will guide future distribution of information in the newsletters. From this analysis, it was apparent that that readers showed a high response to research and learning opportunities. Future analyses of reader response will continue to guide the newsletter content.

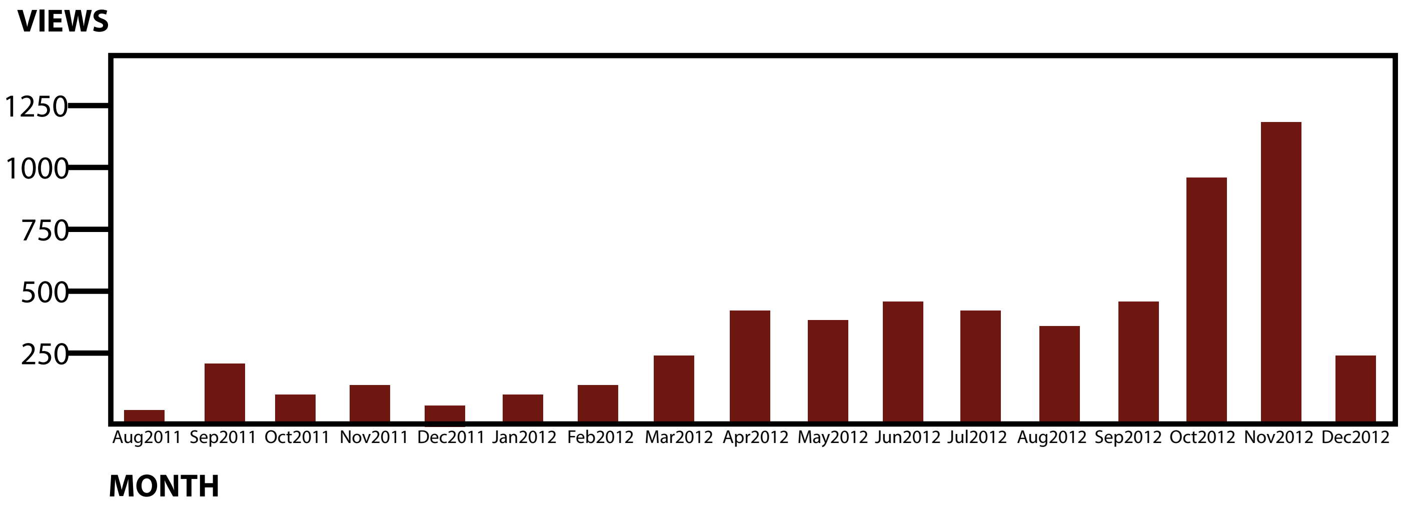
Interventions Across the Lifespan Blog: http://fasdintervention.wordpress.com

The goal of the iNAT blog is to share current news, events, research, resources, and perspectives on interventions for individuals affected by FASD across the lifespan. Given the high number of people looking to the internet as a source of information, another goal of the blog is to create a source that is easily accessible to any population through the internet. Whereas the newsletter is sent to subscribers, the blog is accessed by anyone with an interest in FASD intervention. In this way, the blog responds to a clear need for current accurate information online, given that approximately 50% of viewers are finding the blog through search engines. In order to make the blog accessible to the general public, posts are written in everyday language and distributed in a way that caters to the public's use of modern information sharing technology.

Blog posts include topics such as (in order from most common to least common): resources and links to relevant information or sites, new intervention research papers and research opportunities, events/learning opportunities (Conferences, webinars, workshops), current news articles, and perspectives on FASD (i.e. personal stories, other blogs or information sources). Viewer access to these topics (as analyzed through "clicks" on links within each topic) is distributed proportionately to the amount of information posted on each topic, suggesting an appropriate distribution of information to meet the demands of viewers.

Increasing page views across months were seen, with an average month to month percent increase of 44% for the past 3 months. Viewer distribution has become increasingly widespread, with viewers in 76 countries. Communication was encouraged in blog posts, and positive viewer feedback was received through comments and emails.

INTERVENTIONS ACROSS THE LIFESPAN BLOG TRAFFIC



KnowFASD Interactive Website: http://www.knowfasd.ca

The goal of this website is to provide accurate and reliable information on the neurobehaviorual deficits associated with FASD. Given the iNAT's role with CanFASD, it is important that we do not simply educate about the disorder, but move beyond the basic FASD facts into potential solutions, focusing on bridge building between research and practice. The KnowFASD site endeavours to provide a resource where information, explanations, and solutions are unified in one online location. Moreover, it is important that the site be, and is engaging and relatable for users.

All educational information provided on the wiki was acquired from current research findings, therefore ensuring accuracy and reliability of the information presented. The wiki site works in a similar fashion to Wikipedia, with each page highlighting the presentation, potential causes, and potential outcomes of a specific neurobehavioural effect of FASD. From each wiki page, viewers can link to related topics and access resources, links, and tips for possible interventions. Thus, the wiki moves beyond solely educating about research findings, to providing potential solutions to the issue at hand.

The KnowFASD site remains under development as we continue to add content. Input and contributions are welcome and discussions have begun regarding collaboration with other researchers and professionals in the field.

WORK IN PREVENTION

Prevention research was led by two Network Action Teams (NATs) this year; the Mother-Mentoring NAT and the Prevention from a Women's Health Determinants Perspective NAT. The NATs will be combined into a single Prevention NAT (pNAT) moving forward.

The NAT on Mother-Mentoring's research focused on understanding the role of Parent-Child Assistance Programs (PCAPs), and other mentoring support programs aimed at preventing FASD, in the lives of women struggling with high-risk substance use. A report outlining two research projects was completed in June 2012. The first study examined the file information of 100 women in Alberta and Manitoba who completed a PCAP mentoring program. Despite some challenges in utilizing the administrative data, there was evidence that women are making progress in key areas, such as reducing harmful substance use, feeling less mental health distress, securing stable housing, and utilizing reliable birth control. The second project was a qualitative study of ten women who completed a mentoring program in Alberta or Manitoba. Their interviews revealed many common themes about their experience of mentoring, demonstrating the benefits of mentoring in these women's lives and how mentoring can help to reduce the risk of giving birth to a child with FASD. As a follow-up to these studies, several conference presentations have been made. Additionally, the qualitative study featuring the voices of women describing their experience of being mentored will be a book chapter in Reinvesting in Families, the 2014 publication by the Prairie Child Welfare Consortium.

The second NAT on prevention: Prevention from a Women's Health Determinants Perspective meets monthly via web-meeting to share information on individual work and to plan collaborations on research projects, practice improvements, policy advocacy and knowledge exchange. This NAT has over 66 members from across Canada. 2012 marked the expansion of the Network Action Team (NAT) to include members from Atlantic Canada as well as a commitment from Ontario's FASD ONE Network to link in. The addition of the Atlantic members added greatly to the NAT discussions and plans for action. The Prevention from a Women's Health Determinants Perspective NAT looks forward to contributing to the FASD conference in September 2013 in St John's, Newfoundland.

Research

NAT researchers and research collaborators have been involved directly in leading 8 research projects this year, and collaborating on a number of others. Key topics include:

- investigation of patterns and trends of alcohol consumption by women of child bearing years
- alcohol warning labels as a strategy for FASD prevention
- community perspectives on FASD prevention in Dene and Inuit communities in NWT
- Indigenous culture as an intervention for people with substance use problems
- building an evaluation framework for community-based FASD programs
- responding to the mental health needs of northern women with housing and related health concerns
- community perspectives on interventions to support pregnant and parenting women facing substance use and related challenges in Victoria, BC
- approaches to the support of women and neonates in neonatal intensive care units

2012-2013 annual review

1 face-to-face meeting

66 members

NETWORK ACTION TEAM ON FASD PREVENTION FROM A WOMEN'S HEALTH DETERMINANTS PERSPECTIVE

54,911 blog visits

11 research projects conducted

10 virtual meetings

14 YouTube videos

10 reports and other publications

37 conference presentations

14 peer-reviewed papers

50 organizations

www.canfasd.ca

FASD FACTS:

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol.

Toward an Evaluation Framework for Community-based FASD Prevention Programs project

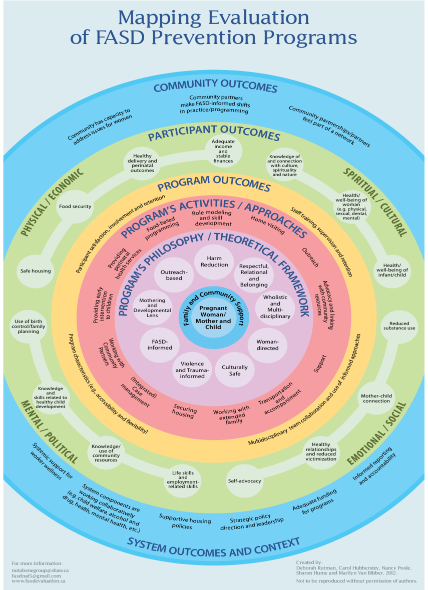
This project was conceived with the intent of bringing researchers, evaluators, program managers and staff, and funders together to identify promising evaluation methods and to create common evaluation frameworks and tools for FASD prevention programs serving pregnant women and mothers, and for FASD supportive intervention program serving youth and adults living with FASD. The Public Health Agency of Canada's Fetal Alcohol Spectrum Disorder (FASD) National Strategic Project Fund is funding this project, which provides an opportunity to consider what works - for whom and in what context - and to build understanding about various approaches to evaluating these types of programs.

Three "Maps" (one for FASD Prevention programs, one for FASD Supportive Intervention programs, and one for FASD programs in Aboriginal communities) were developed as tools for conceptualizing evaluation and describing the connection between program philosophy and program approaches/activities, program outcomes, and client, community, and systemic outcomes.

The project's approach was highly collaborative, guided by a 13-person National Advisory Committee. The main focus to date has been delivery of 6 consultations in different regions of Canada in order to obtain input on:

- Key, realistic client outcomes and program outcomes;
- Indicators of success and data requirements of program funders;
- Respectful and effective approaches and tools for collecting evaluation data

Another aspect of the current year's agenda was to support four sites in using the evaluation framework. To date there have been discussions with FASD Life's Journey in Winnipeg, Fetal Alcohol Syndrome Society of Yukon in Whitehorse, Herway Home in Victoria and the Kermode Friendship Centre in Terrace to pilot aspects of the framework, with mentoring support from the project team. Feedback from workshop participants and project advisors was extremely positive, indicating that the Maps were useful in planning and undertaking evaluation, in program planning and as communication tools with funders, policy makers, and/or community members. The Maps - along with definitions of concepts, examples of relevant indicators, and data collection tools - will soon be accessible via a website. The project team received funding to continue this work until March 2014.



Communications and Knowledge Exchange

Blog

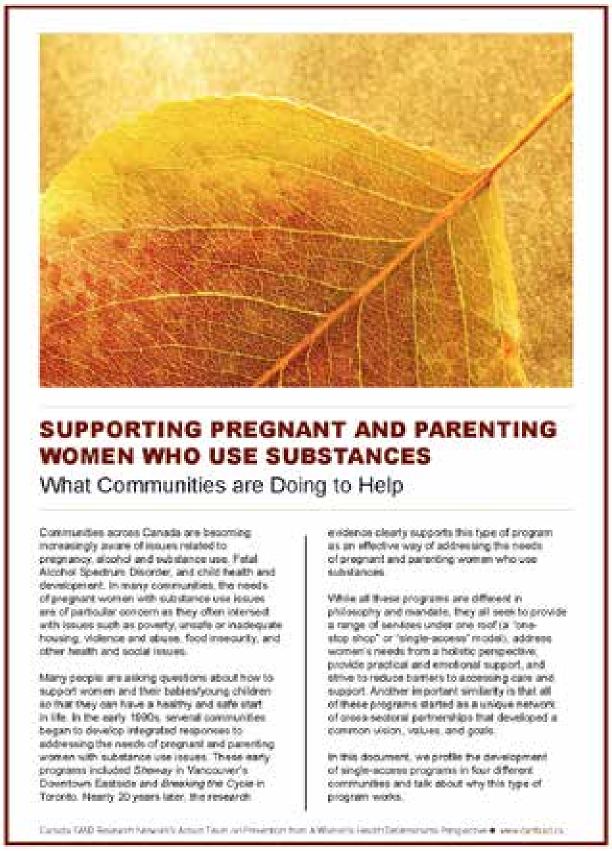
Our blog is a resource for learning about prevention work around the world as well as specific topics such as approaches to screening, the connections of violence to FASD prevention, and linking discussion of contraception with discussions about alcohol use. The blog has approximately 5000 views per month. Check in to the blog regularly to learn about FASD prevention at *http://fasdprevention.wordpress.com/*

New Resource

A group of NAT members recently collaborated to create a resource designed to assist communities which are developing services for women at high risk of having a child affected by FASD. Representatives of four programs in Edmonton, Surrey, Victoria, and Winnipeg shared ideas about the process and lessons learned in the development of "one-stop" services. While all these programs are different in philosophy and mandate, they all seek to provide a range of services under one roof (a "one-stop shop" or "single-access" model), address women's needs from a holistic perspective, provide practical and emotional supports, and strive to reduce barriers to accessing care and support. See *http://www.canfasd.ca/wp-content/uploads/2013/02/What_Communities_Are_Doing_to_Help_February_7_2013.pdf*

FASD FACTS:

There are currently no confirmed statistics on the number of people in Canada who have FASD, yet, prenatal alcohol exposure is considered the most common known cause of developmental disability in the western world. The latest research on prevalence, conducted in several countries, indicates that these rates are believed to be as high as five out of every 100 live births.



SUPPORTING PREGNANT AND PARENTING WOMEN WHO USE SUBSTANCES

What Communities are Doing to Help

Communities across Canada are becoming increasingly aware of issues related to pregnancy, alcohol and substance use, Fetal Alcohol Spectrum Disorder, and child health and development. In many communities, the needs of pregnant women with substance use issues are of particular concern as they often intersect with issues such as poverty, unsafe or inadequate housing, violence and abuse, food insecurity, and other health and social issues.

Many people are asking questions about how to support women and their babies/young children so that they can have a healthy and safe start in life. In the early 1990s, several communities began to develop integrated responses to addressing the needs of pregnant and parenting women with substance use issues. These early programs included *Sheway* in Vancouver's Downtown Eastside and *Breaking the Cycle* in Toronto. Nearly 20 years later, the research evidence clearly supports this type of program as an effective way of addressing the needs of pregnant and parenting women who use substances.

While all these programs are different in philosophy and mandate, they all seek to provide a range of services under one roof (a "one-stop shop" or "single-access" model), address women's needs from a holistic perspective, provide practical and emotional support, and strive to reduce barriers to accessing care and support. Another important similarity is that all of these programs started as a unique network of cross-sectoral partnerships that developed a common vision, values, and goals.

In this document, we profile the development of single-access programs in four different communities and talk about why this type of program works.

Canada FASD Research Network's Action Team on Prevention from a Women's Health Determinants Perspective ◆ www.canfasd.ca

Patterns of Alcohol Use Among Women of Childbearing Age

FASD often arises against a complicated backdrop of social and economic influences on women's drinking patterns throughout the childbearing years. Recent data shows that risky drinking among women of childbearing age (15-44) is a large and growing concern in Canada. Both occasional and regular risky drinking is increasing for women of childbearing age across Canada.

The total % of women drinking at moderate and high risk levels is 58% for young adults and 45% for women ages 25-34 and these women account for approximately 80% of all live births in Canada

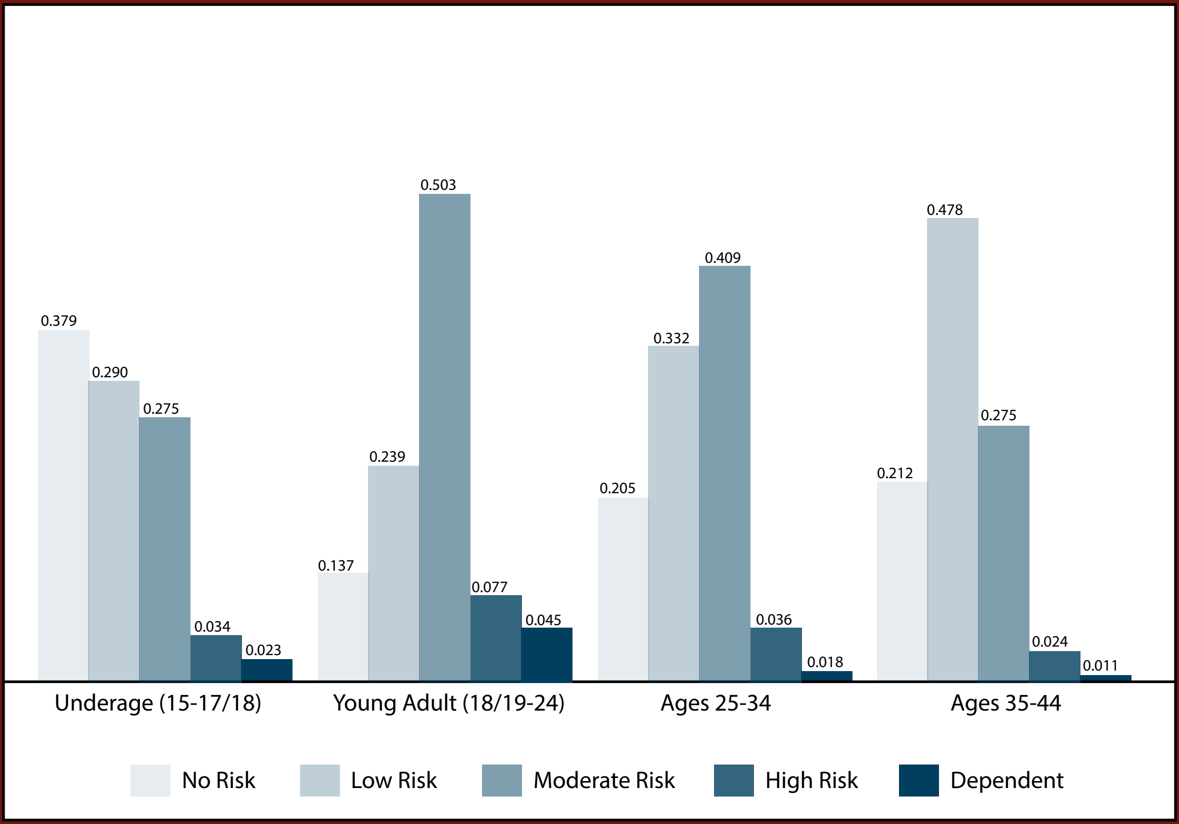


Chart: Distribution of alcohol-related risk, females age 15-44 years, Canada, 2009 and 2010 (Sources: Canadian Community Health Survey, 2009/10, Statistics Canada, no date b; Tjepkema, 2004)

KNOWLEDGE TRANSLATION AND COMMUNICATIONS

CanFASD worked with teams of researchers, clinicians, partners, governments, service providers, community groups and community members from across Canada around the issues of Fetal Alcohol Spectrum Disorder. The collaborative nature of this multi-disciplinary, multi-sectoral work required a flexible structure allowing for adaptation and response. Thus, the Network was well-positioned to increase the capacity for knowledge translation and continue to foster relationships that advance the research within provincial, territorial, and federal priorities context.

Audiences included the following groups:

- Policy and advocacy – policy makers, government, donors, press, families, individuals
- Research – researchers, knowledge managers, families, individuals, service providers and the public
- Practice and programs – clinicians, managers, supervisors, service provider, technical advisors, communicators, families, individual
- Training and education – trainers, educators, trainees, students, families, individuals

CanFASD had a three-pronged approach to communications:

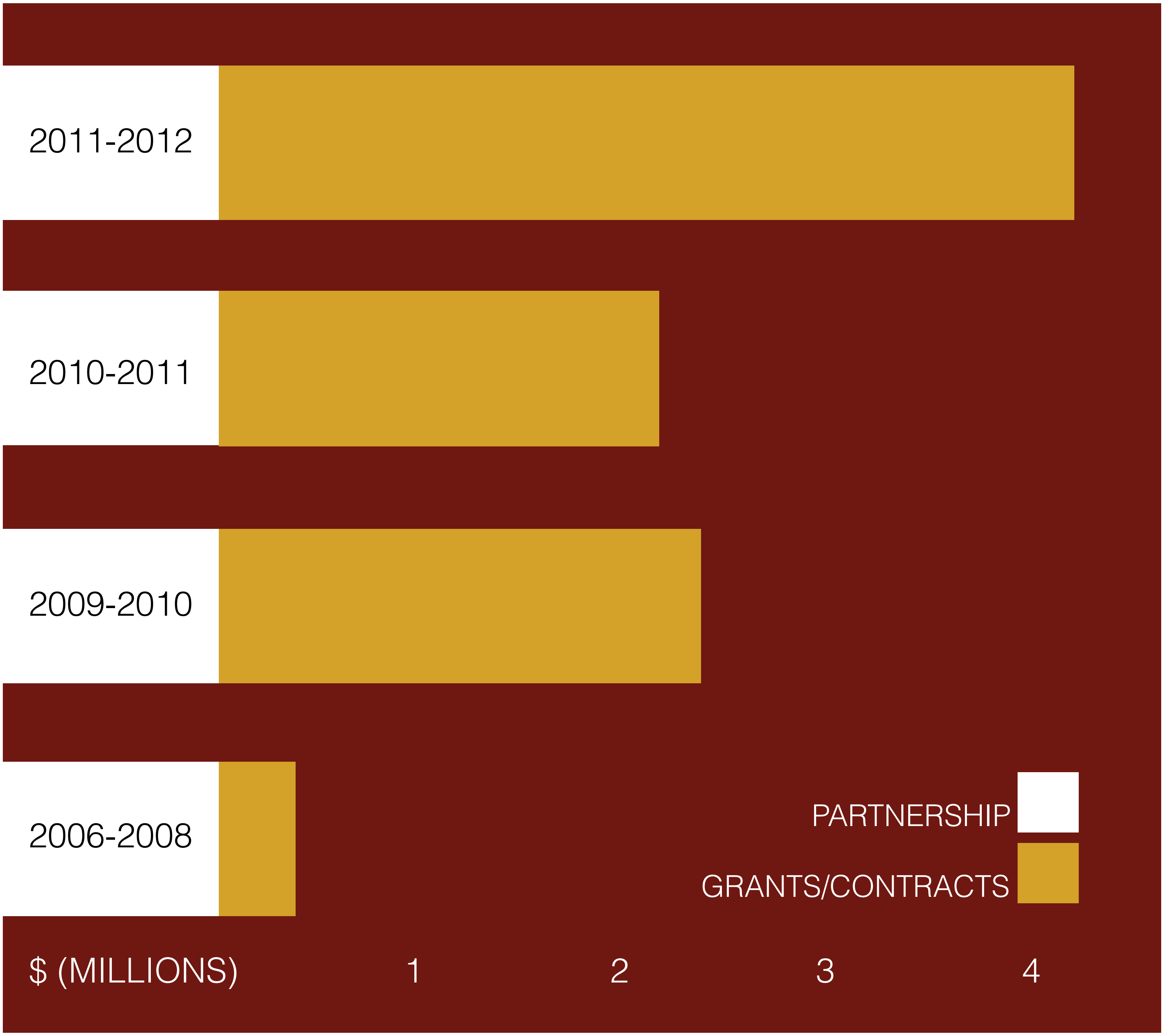
- To position CanFASD as a centre of expertise and source of credible, evidence-based information;
- To leverage further support for research that translates into meaningful outcomes for organizations, communities, families and individuals; and
- To provide research-based information and knowledge that results in improved policy and practice.

Knowledge translation and communications activities that CanFASD undertook included:

- Restructuring the CanFASD website
- Producing policy papers on meconium testing, dose-response and alcohol labeling
- Co-hosting the 5th International Research Conference on FASD
- Hosting a reception for invited international guests at the 5th International Research Conference on FASD
- Giving 64 presentations at national and international conferences
- Hosting 6 sessions at national and international conferences
- Disseminating 10 newsletters
- Publishing one press release
- Responding to controversial scientific articles
- Launching new website in English and French

FUNDING

CanFASD's operational funding comes from the member provinces and has remained relatively stable over time. Funding for specific projects led by CanFASD researchers is obtained from grants and contracts from governments, foundations and other funding agencies. The graph below shows CanFASD's total operational and project-related funding over the past 6 years.



	2006-2008	2009-2010	2010-2011	2011-2012	2012-2013
Partnership	$600,000	$650,000	$650,000	$649,894	$594,153
Grants and Contracts	$141,408	$1,720,000	$1,624,879	$3,420,000	$4,210,475
TOTAL FUNDS HELD	**$741,408**	**$2,370,000**	**$2,274,879**	**$4,069,894**	**$4,804,628**

LOOKING TOWARD THE FUTURE

The first steps in evolving a research network like CanFASD were to identify those researchers and clinicians in Canada who were already investigating questions about FASD. Where were they? What were their studies? How was data being captured? Were they interested in collaborating? From these early explorations arose the Network Action Teams, who now count among their members virtually all FASD investigators in Canada.

The results of these collaborations have been to understand the limits of FASD research resulting from insufficient funding, small sample sizes and isolated researchers. However, together we can now define the questions that lie ahead and work to answer them more effectively. How can FASD screening be implemented and more efficiently identify target populations for treatment or intervention? How can prevention efforts be more helpful and effective? How can we measure our success and costs? What programming will be most helpful to individuals with FASD and their families to prevent secondary disabilities? What programming can actually improve brain function in effected individuals? All of these questions must be incrementally approached and each step needs to be checked to assure that the next step is still moving in the right direction. Through primary work in Canada and collaborations with colleagues from around the world, we believe that the next few years will bring answers to these important questions and lead to the questions that will follow them.

Clearly, 2012-13 was a year of growth and CanFASD will continue to expand with the addition of new members. New Brunswick will be joined the Network in 2013 and it is anticipated that other provinces will follow. CanFASD will work to attract new investors and funders, allowing for expansion of initiatives and more sustainable funding for operations. We will focus on increasing knowledge about FASD, continuing to develop capacity and expertise across the Network, to not only facilitate policy-relevant research, but also to catalyze the uptake of the research results in a meaningful way. A number of activities are already planned or underway for 2013-14.

FASD FACTS:

The indirect and direct costs for supportive needs in health, mental health, social services, and education and negative costs through criminality and criminal justice are estimated to be $4B/year in Canada.

LOOKING TOWARD THE FUTURE

NATIONAL INVITATIONAL RESEARCH PRIORITIES WORKSHOP

Dr. Jocelynn Cook, in partnership with Dr. Sterling Clarren, Dr. Jacqueline Pei and Nancy Poole, received funding from the Canadian Institutes of Health Research (CIHR) and NeuroDevNet to host a National Research Workshop to set priorities to improve outcomes related to FASD. Eleven years ago, in 2002, two inaugural workshops of experts were sponsored by the Public Health Agency of Canada (PHAC) and CIHR to take stock of the FASD-related research landscape. Since that time, Canadian capacity for biomedical, clinical, and population research focused on FASD has increased and knowledge translation in the field has significantly expanded. Now, 10 years later, it is essential to measure FASD research-related efforts and successes as well as to revisit the priorities from 2002. This information will form the foundation of a National Fetal Alcohol Spectrum Disorder Research Agenda that will set evidence-based priorities to improve FASD-related outcomes and will catalyze research in areas that are important to Canadians.

DEVELOPING A PLAN FOR PREVENTION OF FASD

FASD can only occur from prenatal alcohol exposure and many efforts have been aimed at prevention of alcohol use during pregnancy. Unfortunately, 14% of Canadians still report drinking alcohol during pregnancy and since no data confirm a safe limit for any alcohol use during pregnancy, a comprehensive approach to effective prevention is necessary. In fact, three approaches to prevention are needed: universal, selected and indicated; all forms are already used in some places in Canada. However, the degrees of effectiveness vary and are largely unknown and it is now essential for evaluation to determine the value and costs of expansion. CanFASD plans to:

1. Perform an environmental scan to determine the current universal, selected and indicated FASD-related programming in Canada
2. Bring together experts to develop a plan for a five-year FASD prevention strategy for inclusion of like-programs for evaluation, including identification of methodologies and gaps in evidence
3. Develop high-level strategies, including evaluation, at community, provincial and federal levels to effectively evolve and expand the existing FASD prevention programming.

Following synthesis of the scan, a workshop will be held to bring together up to 30 expert participants to outline an evidence-based five-year Pan-Canadian FASD Prevention Strategy that crosses disciplines, sectors and governments. This information is essential to cross disciplines and to determine a cost-effective and efficacious approach to the prevention of FASD in Canada.

FAMILY ADVISORY COMMITTEE

A Family Advisory Committee for CanFASD is under development and will have its first meeting in late Fall 2013. 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 that can make a difference in individual and family relevant outcomes and quality of life and will be chaired by Ms. Jan Lutke. CanFASD and the Family Advisory Committee will be partners in the shared work to improve FASD research, policy, and practice. Family Advisory Committee membership will be from jurisdictions that provide funding support to CanFASD.

2014 SIXTH NATIONAL CONFERENCE ON ADOLESCENTS AND ADULTS WITH FASD/2015 SIXTH INTERNATIONAL RESEARCH CONFERENCE ON FASD

CanFASD will continue to play a major role in the planning, hosting, evaluation and follow-up for the 2014 National Conference on adolescents and adults with FASD. Ms. Jan Lutke will be the conference chair and will oversee a number of conference-associated committees. The conference will be held April 9-12, 2014 in Vancouver, BC. Planning for the Sixth International Research conference on FASD is in its beginning stages. For more information visit http://www.interprofessional.ubc.ca/AdultsWithFASD2014/

PREVENTION NETWORK ACTION TEAM: IDEAS FOR FURTHER ACTION

Knowledge Exchange

In general the Prevention Network Action Team (pNAT) is concerned with developing and implementing strategies for moving evidence about women's health promotion and FASD prevention into action, through a wide range of knowledge exchange mechanisms: from curricula development for health professionals, to Canada-wide and international conference presentations, to supporting pregnant women and many other mechanisms. In the area of knowledge exchange over the coming year, the pNAT will:

- continue to promote the Girls, Women, Alcohol, and Pregnancy blog as a space to highlight work by NAT members, provide links to resources and recent research findings, discuss innovative strategies and FASD prevention activities from around the world, and provide critical perspectives on challenges in the field
- continue to build the network as one inclusive of researchers, policy analysts, clinicians, community based service providers and advocates dedicated to FASD prevention, using monthly webmeetings and one face to face meeting per year to share expertise and evidence
- create print and web resources to inspire policy and practice improvement; write letters to the editor as key issues arise; and help make the CanFASD website a go-to place on FASD prevention knowledge.
- continue to explore mechanisms to improve the evidence-base related to supporting pregnant women to have an alcohol-free pregnancy

Influencing Policy and Service Provision

- The pNAT facilitates the incorporation of sex/gender-based analysis and traditional indigenous knowledge into women's treatment and support program development, as well as into epidemiological research, community alcohol policy and other policies that influence practice. To influence policy and program development we will be involved in committee work and policy advice with provincial governments, and in the preparation of policy briefs for the CanFASD Research Network. The pNAT has two funded policy/service provision related projects in progress:
- The Towards an Evaluation Framework project which involves compiling and sharing 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.
- A project with the BC government which involves collecting and synthesizing FASD prevention messages from the international literature, for the purpose of developing tailored health fact sheets to be utilized by health care providers as they counsel girls' and women about alcohol use.

Research

The pNAT focuses on in building multidisciplinary research teams, developing research proposals, conducting research projects and publishing journal articles related to FASD prevention. Key research-related initiatives to be achieved this year include:

- Seeking funding for a) cross site research involving holistic (one-stop) programs on an aspect of enacting the FASD evaluation framework, and b) for research on prevalence and and influences on women's alcohol use using data from the National Longitudinal Health survey.
- Holding a research planning workshop with prevention researchers, with funding support received from the Canadian Institutes of Health Research.

INTERVENTION NETWORK ACTION TEAM: IDEAS FOR FURTHER ACTION

Knowledge Translation and www.KnowFASD.ca

In addition to maintaining the successful iNat blog site and quarterly newsletter, the iNat intends to continue moving forward towards innovative intervention and communication efforts through the evolving website, www.KnowFASD.ca

In 2013, the "Intervention on FASD" Network Action Team (iNAT) of the Canada FASD Research Network launched their www.KnowFASD.ca on-line resource tool. Dr. Jacqueline Pei (iNAT Intervention Lead) developed the website in partnership with Rocketfuel Games as a mechanism to introduce the neurobehavioural difficulties that present throughout the lifespan for individuals with FASD. Website users are able to customize the information they receive based on the selected gender and age. This gives them the opportunity to obtain information that is most relevant to them and their situation. Additionally, a FASD wiki was also developed and contains information about 55 different neurobehavioural difficulties and secondary disabilities associated with FASD. These pages provide intervention tips, resources and links that are relevant to the issues at hand. The iNat is currently working with different provincial groups (e.g. province of Manitoba) in Canada to establish a map that allows for regional links and programs to be accessed. In this way both broad-band and geographical unique information is provided and linked across the lifespan.

Moving forward, and in response to the need for sound, electronic evidence-based FASD information, the www.KnowFASD.ca team is currently planning an exciting initiative that would expand the current platform to include a simulation "Game of Life". The "Game of Life" will give users the opportunity to see potential outcomes that result from the various actions and decisions they make. The game will be based on a finite set of scenarios structured into "choices" that the user will make followed by the realistic outcomes that would result in a "choose your adventure" type scenario. This novel approach will also ensure that www.KnowFASD.ca is committed to providing only evidence-based information to its users.

Once the "Game of Life" is developed, additional educational application will be explored. For example, the game may be packaged and applied as a training model for specific professional and nonprofessional groups (e.g. clinicians, educators, parents). The team is also investigating its potential to incorporate Game Artificial Intelligence in order to add variability to the decisions and outcomes that result from the user's choices. This would make the model more robust and adaptable over time.

www.KnowFASD.ca is well positioned to become the premiere FASD website for information and resources that are both current and empirically evaluated. The website continues to gain attention from provincial and territorial agencies, who are now interested in collaborating with the team to embed local information into the current site. This would mean including lists of services, supports and resources by province and territory, and even within specific geographical regions. Users can then click on a desired location and receive the appropriate links they need. In this way, www.KnowFASD.ca will engage in exciting and innovative knowledge translation and mobilization initiatives at the national level.

LOOKING TOWARD THE FUTURE

Mackenzie Supportive Living Initiative (Alberta)

The Northwest Regional Fetal Alcohol Spectrum Disorder Society (NWR FASD) – Mackenzie Network provides supports to individuals with the complex disability resulting from prenatal exposure to alcohol. The purpose of Mackenzie Supportive Living Initiative (Alberta) are five-fold:

1. Increase long term housing for persons with FASD
2. Increase housing stability for 75% of residents
3. Increase the health and mental health status and quality of life for 65% of residents
4. Assist at least 75% of program participants to obtain employment or structured volunteer activities
5. Decrease the use of correctional facilities for 80% of residents and repeat involvement of 70%.

The NWR FASD Society – Mackenzie Network has submitted a proposal to address the need for a supportive living facility for individuals affected by FASD. The NWR FASD Society – Mackenzie Network is proposing to model this type of facility with in-house supports and programming provided by existing and enhanced programming.

The University of Alberta Alberta Clinical and Community-based Evaluation and Research Team (ACCERT Team) in partnership with the CanFASD iNAT has been asked to support the development of this Supportive Living Initiative by structuring an evaluation plan that will facilitate an evaluation/research plan, and the team will provide a literature review detailing the need for this supportive living initiative. Building community engagement has been identified as a key goal for this initiative and will be supported by the team through attendance to community events and meetings. This Supportive Living Initiative is potentially the first of its kind around the globe.

The FASD Prevention Conversation

This project is an evaluation of the development and implementation of the FASD Prevention Conversation, an initiative being undertaken to support FASD prevention efforts in Alberta. The Prevention Conversation has two components focused on (1) raising public awareness about the risks of drinking alcohol while pregnant, and (2) supporting primary care providers and human services workers in developing the skills to engage in non-judgmental conversations about alcohol use during pregnancy with their clients/patients (women of childbearing age).

The evaluation component of this project is being undertaken by ACCERT, a team of doctoral student researchers and in partnership with the CanFASD's iNAT and prevention NAT. The evaluation will have developmental, formative, and summative elements. The developmental component will focus on the documentation of the process of developing the initiative while helping to identify, operationalize, and develop ways in which to measure the emerging outcomes. Once the Prevention Conversation is implemented, in 2014, a focus on formative evaluation will allow for the collection of data to gather information about the strengths and the weaknesses of this initiative and support ongoing improvement. Finally, summative information will be collected after the conclusion of this pilot project to evaluate its effectiveness at achieving intended outcomes.

The Alberta-wide Prevention Conversation initiative is the first of its kind in Canada and, if successful, has the potential to have far-reaching effects on the prevention of FASD across the country and around the world. Embedding an evaluative component its design and development from the beginning will allow for informed decision making, clear investigation of outcomes and impacts, and ultimately the ability to replicate/duplicate this program across Canada and internationally.

EVENTS IN 2013-2014

APRIL 2013

EDMONTON, AB: Meeting with the Honourable Frank Oberle, Associate Minister of Services for Persons with Disabilities, Alberta

APRIL 2013

OTTAWA, ON: Meeting with the Honourable Colin Carrie, Parliamentary Secretary

MAY 2013

OTTAWA, ON: Meeting with the Honourable June Draude, Minister of Social Services, Saskatchewen

JUNE 2013

ORLANDO, FL: Facilitating a roundtable and presenting posters at the Research Society on Alcoholism Annual Meeting

JUNE 2013

ACCRA, GHANA: Giving a plenary session at the GO-FASD Conference on FASD Prevention

JUNE 2013

QUEBEC CITY, QC: Presentations at the Canadian Psychological Association Annual Convention

JUNE 2013

BANFF, AB: Speaking at the conference of the Alcohol Beverage Distributers

JUNE 2013

OTTAWA, ON: Attending the Canadian Public Health Association Annual Conference

JULY 2013

AMSTERDAM, NETHERLANDS: Speaking at the International Academy of Law and Mental Health Conference

AUGUST 2013

WINNIPEG, MB: Meeting with the Honourable Kevin Chief, Minister of Children and Youth Opportunities and Minister Responsible for Healthy Child Manitoba

SEPT 2013

St. John's, NL: Speaking at the Fetal Alcohol Canadian Expertise Annual Meeting

SEPT 2013

EDMONTON, AB: Speaking at First International Conference on Prevention of FASD and the Consensus Development Conference on Legal Issues of FASD for the Institute for Health Economics

OCT 2013

EDMONTON, AB: Hosting a roundtable on diagnosis

NOV 2013

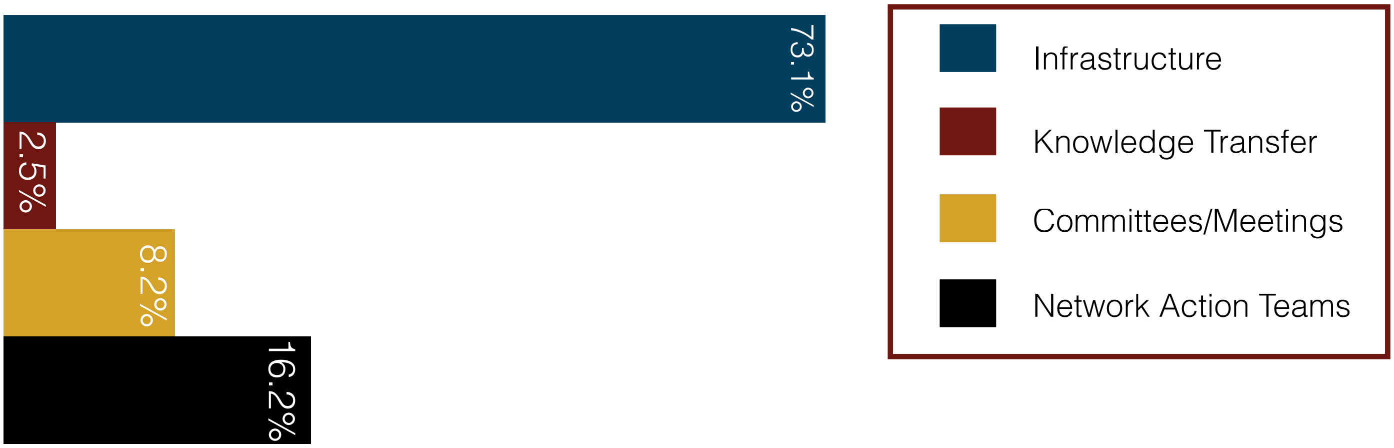
Ottawa, ON: Attending the Canadian Centre on Substance Abuse National Conference

JAN 2014

EDMONTON, AB: Hosting a workshop on prevention

FINANCIAL INFORMATION

CanFASD Spending



Income Statement

For the Year Ending March 31, 2013

	Project	Partnership
Revenues		
Carryover	-	-
Diagnostic Guidelines Project	$75,790	$22,953
FASD Education Project	$75,200	-
Research Priorities Workshop	$15,342	-
Fundraising	$1,138	-
Canada Northwest FASD Partnership	-	$596,153
Interest income	$65	-
TOTAL	$169,535	$619,106
Expenditures		
Advertising and promotions	$470	-
Insurance	$600	-
Miscellaneous	$7,658	-
NAT Research Teams	-	$105,268
Office	$5,499	$5,576
Professional fees	$5,009	$2,369
Printing and translations	$7,571	$704
Salaries	$59,589	$461,725
Subcontract consultants	$20,510	$15,393
Telephone and web conferencing	$851	$5,093
Travel	$31,651	$52,841
TOTAL	$139,408	$648,969
Excess of revenues over expenditures	$30,127	$-29,863
Net assets - beginning of the year	-	$22,953
Net assets - end of the year	$30,127	$-29,863
TOTAL NET ASSETS	$264	-