



2013 | 2014 ANNUAL REPORT



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On The Horizon



MISSION

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

VISION

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.

OBJECTIVES

Providing a research-related co-ordination function so that FASD research in Canada reflects the needs of families, caregivers and policy makers.

- Catalyzing and participating in the research environment to foster effective policy and practice that ultimately improves the lives of those affected by FASD.
- Effectively translating information in a meaningful way to stakeholders.

MESSAGE FROM THE BOARD CHAIR

The Canada Fetal Alcohol Spectrum Disorder (CanFASD) Research Network has thrived in its first year as an independent National organization. It has been an exciting year to build clear policy for the organization, expand our roles as board members, and branch out across Canada. We have been thrilled to have New Brunswick join the CanFASD Research Network this year and continued our partnerships with British Columbia, Alberta, Manitoba, Northwest Territories, Nunavut, Saskatchewan and the Yukon. In January we held our Board of Directors meeting in Moncton, NB and were able to meet with many researchers, clinicians, government leaders and families while in the province.

In the past year we have been very impressed with the strength of the research community and their ability to work together and deliver important and relevant information for families, caregivers, individuals and service providers. We have worked hard to ensure that knowledge translation of this important work is meaningful to our partners and from this work, the Network has developed issue papers on a wide range of topics. These evidence-based papers have become a practical and useful tool to help inform policy and practice.

The establishment of a Family Advisory Committee has been another great accomplishment for the Research Network and they have been charged with the task of guiding us in research priorities, providing that important lens for all of our work.

The past year has been a productive one with many new partnerships, more research funding, attention and collaboration from international organizations, and growing interest from central and eastern Canada, but it has also been a year of challenges as we are a very small organization with a big agenda. We have been slow to address corporate sponsorship and involvement and need to continue to work on finding our national voice. These issues are being addressed in the upcoming year. Our biggest challenge has been in reorganizing ourselves as our long time dedicated, and much loved Scientific Director – Dr. Sterling Clarren prepares for retirement at the end of March 2014. Dr. Clarren has been the face of the organization since its inception and made the CanFASD Research Network a reality. We will be honoring Dr. Clarren's work and legacy at a Gala event in 2015 in conjunction with the International FASD conference in Vancouver.

The future for CanFASD looks bright as we move forward to ensure our partners are well informed and engaged while stimulating more research in prevention of FASD, diagnosis and intervention supports; translating this knowledge into meaningful tools; and working towards our goals for improved outcomes.



Audrey McFarlane | Chair of the Board of Directors

EXECUTIVE SUMMARY

This has been another remarkable year for the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD). We have welcomed a new province (New Brunswick) and new staff. 2013-2014 marks our first year as an independent not-for-profit charity and it was a year of developing processes, policies and procedures as well as continuing to raise awareness about FASD and about CanFASD across the country. Members of the Network were busier than ever securing funding for research projects, sharing data and research results at conferences and working with students and trainees to increase our capacity for FASD-related research in Canada.

This year also marked the year of revising the Diagnostic Guidelines for FASD, bringing together experts to identify priority research areas for prevention and the establishment of the first-ever national clinical database for FASD. We will continue to work together with our partners on these, and other emerging initiatives, as we move into a new fiscal year.

It is with thankfulness for all he has done and sadness in our hearts that we finally agreed to allow Dr. Sterling Clarren to retire. After more than 40 years in the field of FASD, Dr. Clarren's reward of spending more time with his beloved family and friends is finally here.

He was a pioneer in the field and contributed doggedly as a researcher and a clinician to dramatically improve the lives of people living with FASD and those that care for them.

Dr. Clarren dedicated his career to clinical research, especially related to FASD diagnostics, and I remember being intimidated by his knowledge (and maybe a bit by his bow tie) when I was a student over 20 years ago. His contributions to the field have been internationally recognized and have spurred important work around the world. The FASD field will miss Dr. Clarren. On a personal note, it has been such a pleasure to have the opportunity to glean his wisdom and his ideas over the past two years and I am forever grateful to have made such a wonderful friend in the process.

2014-15 will be a year of expansion for CanFASD with new scientific leadership and additional research leaders coming on board. We hope to see more provinces join us and remain dedicated to ensuring that the work that we do is meaningful to governments, individuals living with FASD and their families.

Thank you to all CanFASD's amazing staff for your commitment, passion and perseverance. Thank you to our Board of Directors and our Research Leads for

your advice, your willingness to help and your great ideas. And thank you to all the partners and researchers we have worked with over the past year and who have unconditionally offered up their time and expertise to CanFASD. Finally, thank you for all of those Canadian who are or have been touched by FASD for believing in us.

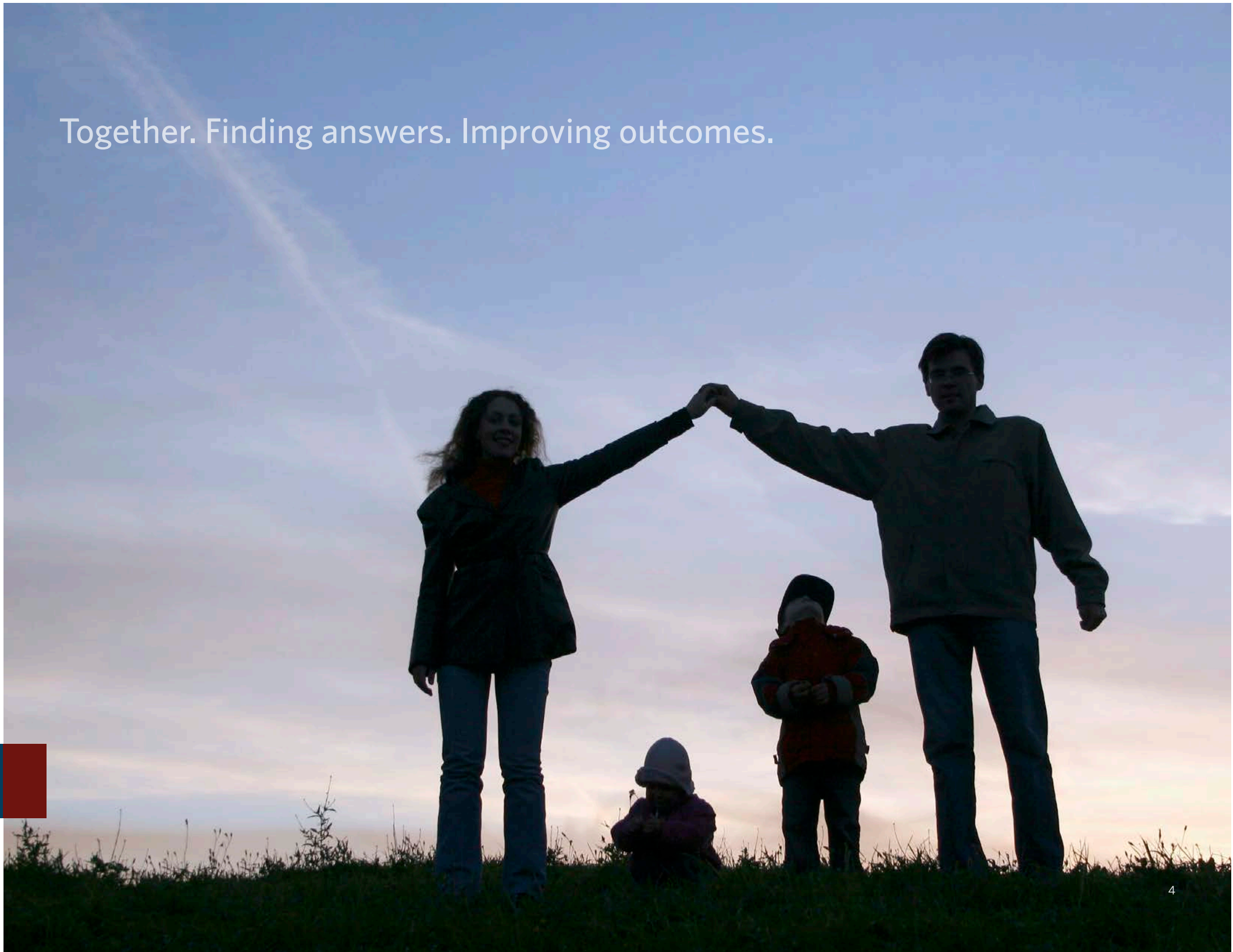
Here's to continued success and progress in 2014-15.

Jocelynn Cook



Dr. Jocelynn Cook | Executive Director

Together. Finding answers. Improving outcomes.





THE END OF AN ERA: A FAREWELL FROM DR. STERLING CLARREN

In 2004, I came to Vancouver and the University of British Columbia for a sabbatical year, on leave from the University of Washington in Seattle. As I arrived, I was invited to help write a proposal to be submitted to the ministers of the Canada Northwest Fetal Alcohol Spectrum Disorder Partnership. This ministerial table was composed of members from the four western provinces and three northern territories and they had been working for several years already on developing programs that would improve Fetal Alcohol Spectrum Disorder (FASD) interventions and prevention efforts. They envisioned a research network that could provide data that would better inform their program developments. We were successful in our proposed application and I was offered a new job as Chief Executive Officer and Scientific Director of the Network. I grabbed the offer and never looked back.

Over the decade that followed, we were able to identify nearly everyone in western and northern Canada, and then later in all of Canada, interested in working across jurisdictions on the complex problems of FASD diagnosis, intervention, prevention and surveillance. We took a strategic approach and tried to organize consistent patient evaluations through standardizing clinical guidelines and tests, provide necessary normal data sets for comparative purposes, and developed models with strong business plans so that good ideas that translated into good program improvements could then be translated into more programs. This work involved creative clinicians and researchers who served on our Board and as project leaders and participants, thoughtful and determined parents and families of persons with FASD, dedicated governmental staffers and community leaders, and those with FASD themselves. I was amazed at their dedication, persistence, and hours spent, often without compensation, on these tasks. The Network

has also helped to guide knowledge dissemination by co-sponsoring internationally attended conferences on the clinical issues in FASD and through a well used website. As I write this I am proud that Canada is now seen as a world leader in identifying the key issues in the clinical realms of FASD and that so many Canadians are now working together to solve these problems.

FASD is often described as the tip of an iceberg. Working in the field often feels to me like mountain climbing in the Rockies. One works so hard to find the route to the top of the mountain and when one reaches the summit, the view is out to more peaks! We can briefly enjoy the trip back to base and the improvements that come from the climb, but we know that another ascent awaits us.

Much has been done and much more needs to be done, but it is time for me to leave the Canada FASD Research Network. Retirement calls and I will answer.

I leave knowing that the organization is in excellent hands and that the Canada FASD Research Network is ready to continue its leadership role in working with government to guide improvements for the patients and families that we serve and increase the success of prevention, intervention and diagnostics.



Dr. Sterling Clarren | Scientific Director

ABOUT FASD

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 life long 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.



HISTORY AND GOVERNANCE

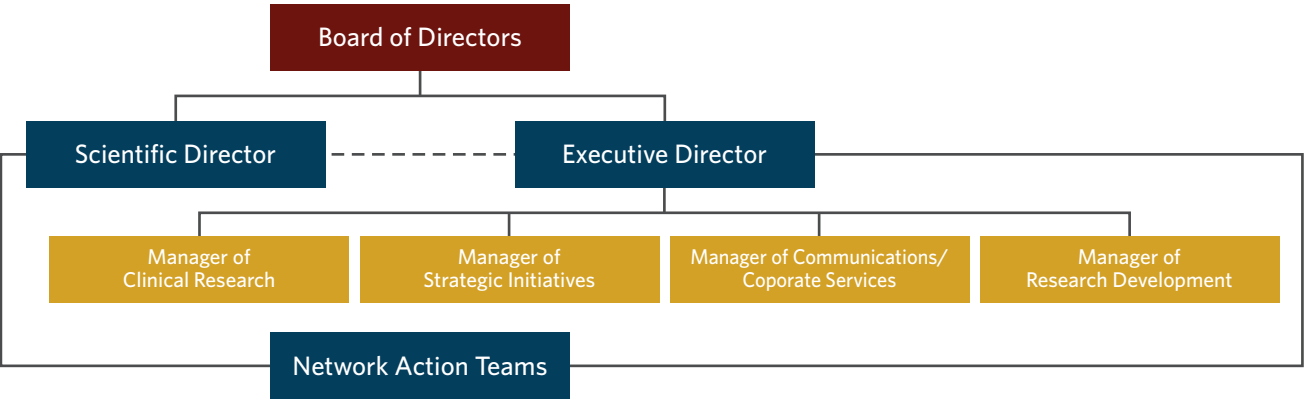
CanFASD is a formally and informally **connected group of professionals** from a range of research sciences located across Canada. It is **Canada’s first comprehensive national Fetal Alcohol Spectrum Disorder (FASD) research network** and has been in operation since 2005.

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

It’s 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.

ORGANIZATIONAL STRUCTURE



BOARD OF DIRECTORS



Audrey McFarlane
Chair



Michelle Dubik
Co-Chair



Jim Bookes



Lisa Brownstone



Tim Moorhouse



Stacy Taylor

EX-OFFICIO



Holly Gammon

MANAGEMENT & RESEARCH TEAMS



Dr. Sterling Clarren
Scientific Director



Dr. Jocelynn Cook
Executive Director



Liz Ellwood
Manager of Communications



Courtney Green
Manager of Research Development



Jan Lutke
Manager of Clinical Research



Kathy Unsworth
Manager of Strategic Initiatives



Dr. Jacqueline Pei
Intervention Research Lead



Nancy Poole
Prevention Research Lead

MEMBER BENEFITS

Current members of CanFASD include Alberta, British Columbia, Manitoba, New Brunswick, Northwest Territories, Nunavut, Saskatchewan and Yukon.

Ultimately, the work of CanFASD 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.

PROVINCIAL PARTNERSHIPS



OPERATIONAL REPORT

The Canada FASD Research Network has had another eventful and industrious year across the board. Our administrative structure has grown with the addition of a Manager of Research Development as well as a Manager of Strategic Initiatives. This has allowed the network and research teams to further our goal of working together as a cohesive, enthusiastic team over the last year. Highlights of our accomplishments in 2013-2014 are outlined in the following sections.

Operations and Administration

After being hosted by the Public Health Services Authority of British Columbia since its our inception in 2005, CanFASD has operated as it's own independent not-for-profit charitable organization since April 1, 2013, the first day of the 2013-2014 fiscal year.

The website, www.canfasd.ca, underwent a major overhaul; applicable sections and resources have been translated into French.

Issue papers were produced on the following topics:

- FASD & Employment
- FASD & Stigma
- FASD & Gaming Interventions
- FASD & Justice
- FASD & Nutrition
- FASD & Children in Care

Staff representatives and members of the Board of Directors traveled to the majority of our provincial jurisdictions, meeting with ministers, public servants, researchers, partners and communities to strengthen the network's connections and relationships.

The first independent fiscal audit completed and the auditor reported that the financial statements present fairly the financial position, operations and cash flows of the organization.

Implemented standard financial procedures and adopted human resources policies for new and existing staff members.

The network established formal partnerships with NeuroDevNet and the Canadian Centre on Substance Abuse.



Science and Research

Researchers and staff of CanFASD were busy in 2013-14. Some of our notable achievements include:

- 60,000 + Blog Visits
- 14 YouTube Videos
- 15 Peer Reviewed Publications
- 64 Conference Presentations
- 72 Invitations to Speak at Events

CanFASD researchers continue to conduct research in the areas of FASD Diagnostics, Intervention and Prevention. The pages to follow provide a synopsis of this work.

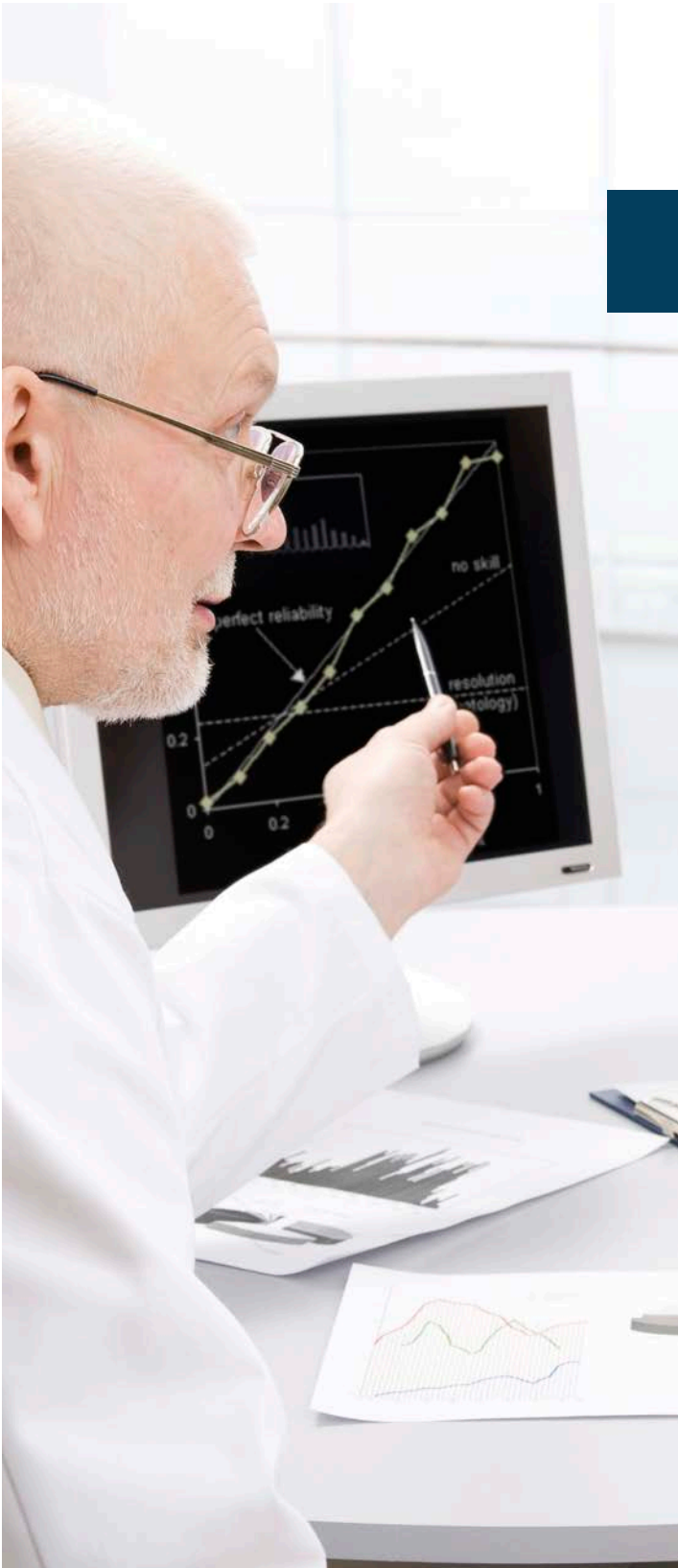
FINANCIAL SNAPSHOT

CANADA FETAL ALCOHOL SPECTRUM DISORDER RESEARCH SOCIETY

Statement of Operations and Net Assets

Year ended March 31, 2014 with comparative figures for 2013.

	2014	2013
Revenues:		
Canada Northwest FASD Partnership	\$ 437,337	\$ 2,000
Diagnostic Guidelines Project	169,000	75,790
FASD Education Project	74,700	75,200
First Nations and Inuit Health Branch Project	58,355	—
Prevention Symposium	58,650	—
Research Priorities Workshop	14,658	15,342
Treatment Improvement Protocol	141,846	—
Other contributions	11,325	—
Amortization of deferred capital contributions	929	—
Donations and fundraising	125	1,138
Interest income	142	65
	967,068	168,535
Expenditures:		
Advertising and promotions	\$ 11,6466	\$ 470
Amortization	929	—
Insurance	1,274	600
Knowledge translation	6,333	—
Miscellaneous	9,378	7,658
Network action teams	124,779	—
Office	12,979	5,499
Professional fees	6,369	5,009
Printing and translations	7,515	7,571
Research expenses	39,970	—
Salaries	346,599	59,589
Subcontract consultants	156,994	20,510
Telephone and web conferencing	5,820	851
Travel	201,267	31,651
	931,852	139,408
Excess of revenues over expenditures	35,216	30,127
Net assets – beginning of the year	30,127	—
Net assets – end of the year	65,434	30,127



RESEARCH IN DIAGNOSTICS

The Research in Diagnostics team is engaged in research activities to facilitate increased consistency, clarity and accuracy to the diagnosis of FASD. 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. Below is a summary of CanFASD's major diagnostic projects.

Diagnostic Guidelines

CanFASD has spent the last year leading the update and revision of the Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis. It is anticipated that the new Guidelines, Fetal Alcohol Spectrum Disorder: Guidelines for Diagnosis Across the Lifespan will be released in Fall 2014.

Treatment Improvement Protocol

This research project aims to Advance FASD Recognition and Prevention in Canada. The United States occasionally publishes Treatment Improvement Protocols (TIP) for service providers. A first TIP on FASD was to be released in the United States in spring of 2014, with a focus on identification and referral of individuals who may have FASD or may be at risk for having a child with FASD from substance abuse and mental health treatment centres. Prior to its release, Dr. Sterling Clarren, who was a Co-editor of the TIP, obtained permission to amend the document for the Canadian systems and to pilot the project in Canada. The Alberta government (Alberta Health) agreed to this pilot in 2013. It is anticipated that data from the Alberta TIP are to be released in Fall 2014.

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. The data collection phase was completed in December 2013. The data are comprised of 400 clients who received diagnoses of FASD from 44 diagnostic clinics in Canada across 4 provinces. This project is also the first stride towards establishing a partnership among clinics interested in developing more consistent diagnostic services; allowing for the collection of other group information that would help with improving services for the FASD community.

Women's Health Research Project on FASD Prevention in First Nations Communities

This project will inform community, program and policy developers, addressing the need for culturally-responsive and culturally safe approaches tailored to the unique needs of First Nations peoples in rural and remote communities. The data from this project are anticipated for released in Summer 2014.

RESEARCH IN INTERVENTION

The focus of the Network Action Team on Interventions (iNAT) is addressing the intervention needs of individuals with FASD across the lifespan. A cross-jurisdictional advisory panel of FASD experts has been established across Canada in the areas of research, policy and practice. The iNAT team is currently working on several studies to contribute to a growing body of FASD intervention research across Canada, including a study aimed at improving mathematical skills of children with prenatal alcohol exposure. Some of CanFASD's major intervention projects include:

Mathematics Intervention

This study is builds upon research from Emory university with the Math Interactive Learning Experience (MILE) — a program designed specifically for children with FASD to remediate math skills and build executive function (EF) skills while accounting for cognitive deficits. Members of the iNAT team are currently completing a modified MILE intervention program with children age 4-10 who had been prenatally exposed to alcohol, with a control group receiving a social skills intervention. Following the intervention, participants in the math group showed a significantly higher increase in raw scores on “total” math test scores and “basic concepts” math scores at post testing. Increased raw scores were also seen in “operations” and “problem solving” math subtests.

Experience in Canadian criminal justice system for Individuals with FASD: Double Jeopardy?

This study explores the experience of individuals with an FASD as offender and/or victim in the criminal justice system, particularly identifying the risk factors for this population. Semi-structured interviews were conducted to capture the voice of different participant groups: (a) individuals with an FASD, (b) caregivers, and (c) professionals who work with FASD clients.

An Evaluation of an Intervention Program for Youth with FASD

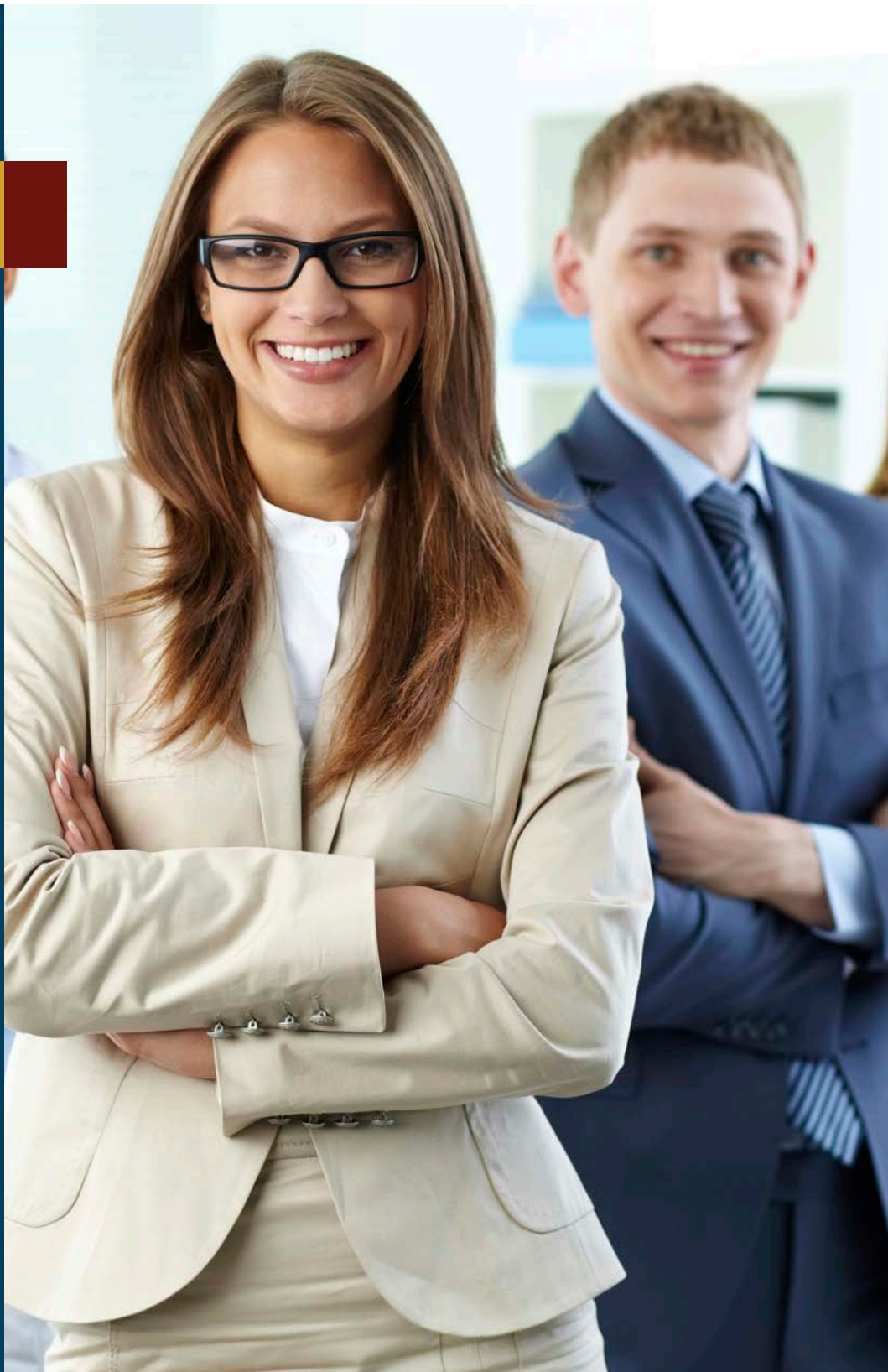
An evaluative inquiry to measure the effectiveness of the McDaniel Youth Program for improving the functioning of adolescents with Fetal Alcohol Spectrum Disorder — providing prevention services and support to high-risk youth affected by FASD.

Quantitative Magnetic Resonance Imaging of Neurodevelopment

A research project identifying links between neuropsychological functioning in FASD and imaging. Funded through a Canadian Institutes of Health Research (CIHR) grant.

Caribbean Quest

This project is based on computerized intervention, undergoing continuing efficacy trials in partnership with Government of Manitoba and the Winnipeg School Division.



RESEARCH IN PREVENTION

The National Action Team on Prevention from a Women's Health Determinants Perspective (pNAT) has over 50 members from across Canada, including researchers, service providers, policy analysts, community advocates and experiential women. The pNAT works from the philosophy that it is important to include all these perspectives throughout research, policy development, service planning and knowledge translation processes.

Some of CanFASD's major prevention projects include:

- Community perspectives on FASD prevention in rural and remote Aboriginal communities.
- Building evaluation frameworks and studying initial outcomes in one-stop programs in Saskatchewan.
- Responding to the mental health needs of northern women with housing, mental health, substance use and related health concerns.
- Approaches to the support of women and neonates in neonatal intensive care units.
- Culture as healing for Indigenous people with substance use problems, and animal-assisted healing for people with trauma-related concerns.
- Evaluation research documenting the approach and success of the HER Pregnancy Program in Edmonton.

6th National Biennial Conference on Adolescents and Adults with FASD: Changing the Conversation

CanFASD was excited to once again co-sponsor this innovative conference in Vancouver, BC on April 9 - 12, 2014. It brought together a diverse group of international expert speakers who presented on a number of issues concerning adolescents and adults and FASD. Over 500 delegates with a specific interest in adults attended from across Canada and the world. The focus of this conference was need for a universal shift in the ethics surrounding the issues facing those living and working with FASD; the need that has emerged through time and experience to

change the conversation and move away from topics that are traditionally discussed to those that may be of more importance and consequence as individuals with FASD continue through life. This conference was framed around a quotation from American economist Walter Heller "Rise above principle and do what is right" so that delegates could begin to identify these new ethical questions that need to be considered. The objective of the conference was to act as a catalyst for necessary conversations that are difficult and challenging. Plenary sessions included Ethical

Perspectives on FASD, The Ethics of Child Protection Interventions with Parents Who Have FASD; Ethically Building Safety Nets for Vulnerable Young Adults; The Ethics of Access to Diagnosis; Human Rights, Self Determination and the Law - What About FASD? As in previous years, this conference continued in its tradition of adolescents and adults with FASD playing an instrumental role in delivering short keynote presentations throughout the conference, and in facilitating the closing ceremonies.





www.canfasd.ca

