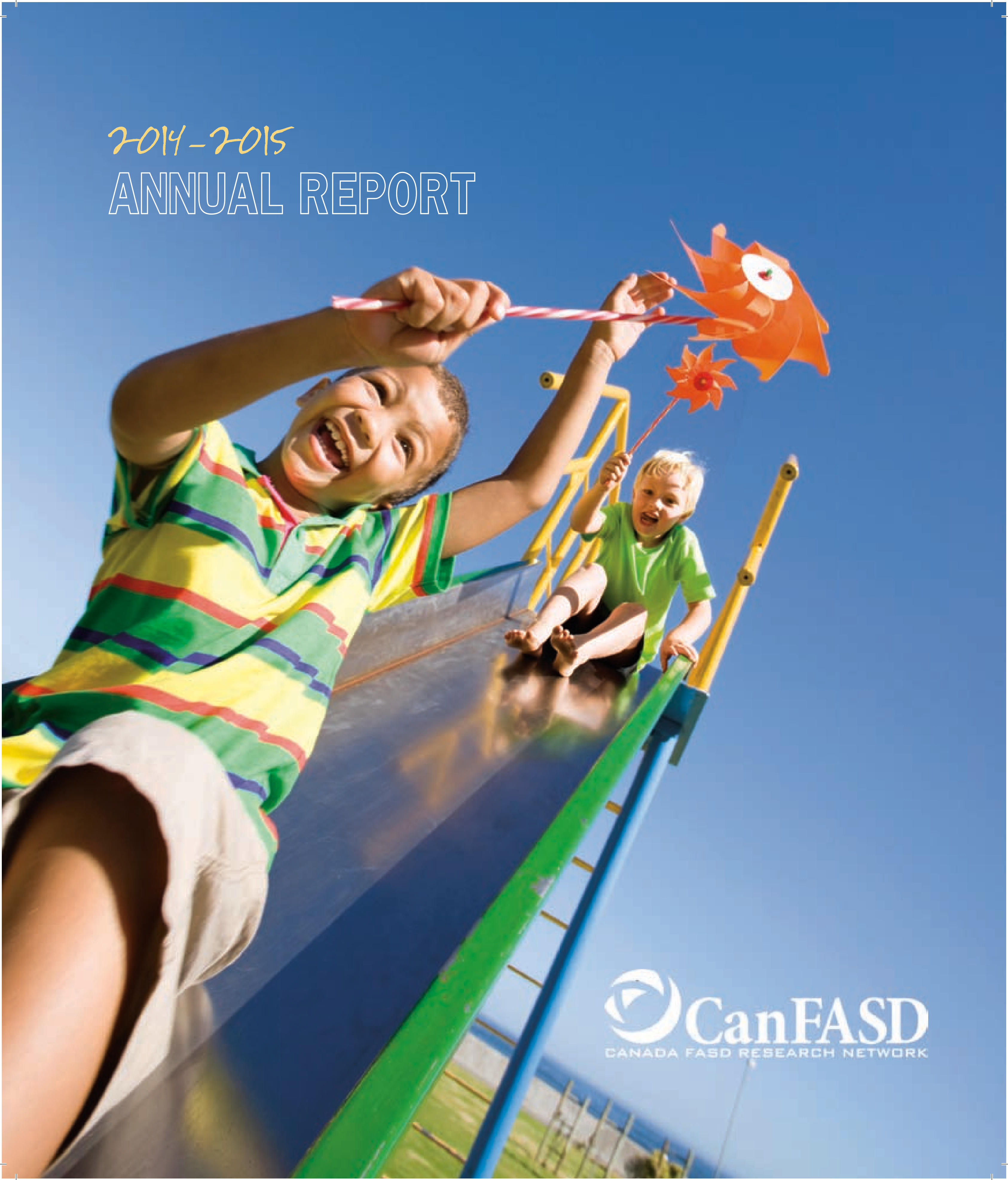
2014-2015

ANNUAL REPORT



CanFASD
CANADA FASD RESEARCH NETWORK

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Together. Finding answers.

Improving outcomes.

CanFASD

WHO WE ARE

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is Canada's first comprehensive research organization dedicated to addressing the extraordinary complexities of FASD. After a decade of increasingly successful and high profile operations, CanFASD is now a national charitable organization. Our mission is to produce national, multidisciplinary, collaborative research that can be shared with all Canadians, leading to effective prevention strategies and improved outcomes for people affected by FASD.

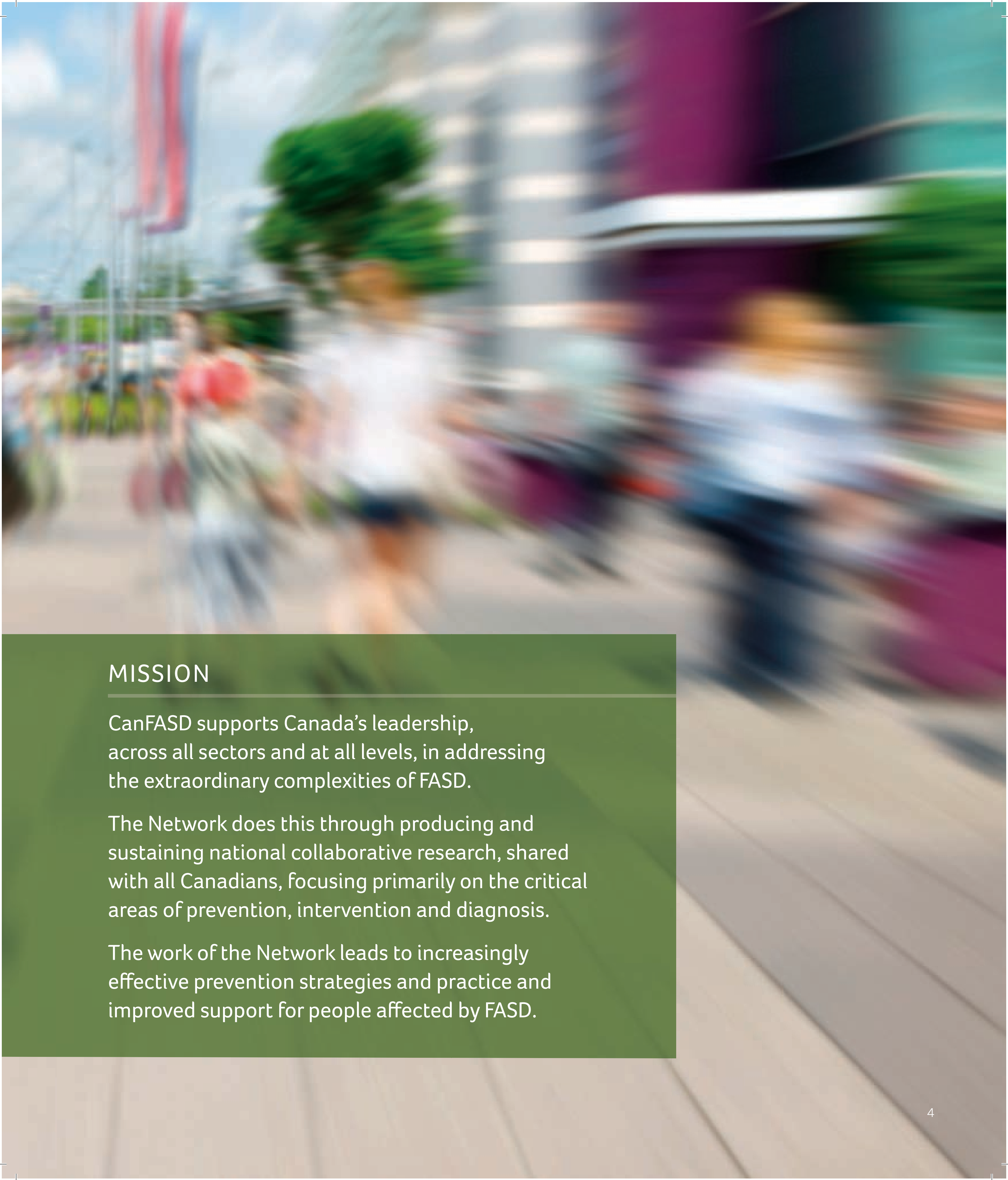
CanFASD is a unique research organization, in that we have a primary focus on supporting the research and knowledge exchange activities that are needed for evidence-based decision-making in policy and practice. In so doing we complement and extend, but do not duplicate, basic science and pre-clinical research carried out elsewhere. We support research teams that are focused on the areas of diagnosis, intervention and prevention. Our researchers currently lead 35 major projects, connecting researchers, students, practitioners, policymakers, families, and communities across Canada and internationally.

CanFASD

TODAY & TOMORROW

VISION

All Canadians are engaged and united with awareness, evidence and knowledge and are effectively addressing the complexities of FASD.



MISSION

CanFASD supports Canada's leadership, across all sectors and at all levels, in addressing the extraordinary complexities of FASD.

The Network does this through producing and sustaining national collaborative research, shared with all Canadians, focusing primarily on the critical areas of prevention, intervention and diagnosis.

The work of the Network leads to increasingly effective prevention strategies and practice and improved support for people affected by FASD.

Social MEDIA

CanFASD.ca website

Website visits: 17,000
(up 3000 from last year)

Users (unique visitors to the site): 12,000
(up 2300 from last year)

Total pages viewed: 42,000
(up 6000 from last year)

Intervention (INAT) Blog, Enews, and website:

Blog:
2011: 537 views
2012: 6278 views
2013: 9126 views
2014: 8292 views
2015 (so far): 3202 views

Enews:
124 subscribers initially.
Currently 392 subscribers.

Website:
52479 total views since 2012 from 9249 users.

pNAT (Prevention)

Blog stats:
The Girls, Women, Alcohol, and Pregnancy Blog was started in July 2010. In 2014, the blog was viewed about 53,000 times (up from 38,000 times in 2013) by 30,000 visitors, averaging about 150 views a day. In 2014, there were 78 new posts, growing the total archive of this blog to 450 posts.

Viewers came from 165 countries. Most were from Canada (21,957) followed by the USA (18,128), Australia (3,738), and the UK (2,625).

The blog has 90 Wordpress followers (who subscribe through Wordpress) and 40 e-mail only followers who receive an email every time there is a new post. While on the site, the most clicked links were to the Best Start Resource Centre, the Public Health Agency of Canada, Canada FASD Research Network, the BC Centre of Excellence for Women's Health, the government of Manitoba, and the government of British Columbia.

Top referring sites

canfasd.ca
facebook.com
twitter.com
huffingtonpost.ca
bccewh.bc.ca

@CanFASD Tweets

"Parliament one step closer"
Fetal Alcohol Spectrum Disorder & the Criminal Code
canfasd.ca/blog/2015/05/20/parliament-one-step-closer/

#CanFASD key stakeholder in federal government's work and learning on FASD.
Parliamentary Standing Committee Report: *bit.ly/1FaxFyv*

The biggest rise in drinking has been amongst women of childbearing years.
Read more at news.*natiopnalpost.com/life/how-we-drink-from-how-much-to-how-often-heres-everything-you-need-to-know-about-canadians-boozy-habits*

Excellent resources available from the Institute of Health Economics

Powerful video for #FASD prevention.
Let's keep the discussion alive. *#cdnpoli #ytpoli @CanFASD @FASDprevent vimeo.com/117245377*

Youth with #fasd are 10-19 times more likely to be incarcerated than youth without #fasd. Changing the justice system can change outcomes.

Congratulations to Dr. Sterling Clarren,
winner of the Starfish Award at #FASD2015

Great news for youth living w/#FASD... need to think creatively as adults. *@SaskFASDNetwork @ryanleefmp @CanFASD market wired.com/press-release/government of-canada-supports-young-offenders-living-with-fasd-1991458.htm*

#GivingTuesday. Go to canfasd.ca and make a donation to support #fasd research in Canada.

@CanFASD released issue paper past week on #FASD & justice. Check it out! *Canfasd.ca/wp-content/uploads/2014/11/FASD-and-Justice-Nov-16.pdf*

New study led by Dr. Philip May, shows prevalence of #fasd in American children may be much higher than we thought. *Paediatrics. aapublications.org/content/early/2014/10/21/peds.2013-3319*

Today is #fasdawarenessday #nosafeamount. September 9th, 2014.

Minister June Draude @kwmla1 speaking at the FASD at the Frontline Conference yesterday @universityofregina.

Message from the
BOARD CHAIR

Tim Moorhouse

The Canada Fetal Alcohol Spectrum Disorder Research Network has experienced and embraced a year of significant change, of exceptional work by staff and board members and of results that have created positive consequences. Our strategic priorities continue to serve us well, assisting in our direction setting and decision making, communicating who we are and what we are about and giving us benchmarks to measure our results and success against.

I will attempt to highlight some of the major changes that the Network has undergone. The Network hosted a wonderful retirement event for Dr. Sterling Clarren in early March in Vancouver. The packed house both acknowledged and celebrated Dr. Clarren's significant contributions to the Network and to the science and practice of FASD intervention, prevention and diagnosis in Canada, North America and internationally. He will of course be greatly missed and we do wish him well in his next adventures. The Network Executive Director, Dr. Jocelynn Cook, also resigned from her position over the summer to take on new challenges at the Society of Obstetricians and Gynaecologists of Canada. Jocelynn had a huge impact on the Network during her time with the organization and we also wish her well in her new role. Dr. Courtney Green has also left the organization to take up a role with SOGC. Dr. Green has also been a key player in the Network and I am sure that both Jocelynn and Courtney will make significant contributions to their new organization. Mr. Jim Brookes resigned his position with the Board of Directors in part due to increased time demands as he took on an interim role as Executive Director of NeuroDevNet.

On the plus side, the Network was delighted to select Dr. Amy Salmon into the role of Executive Director. Dr. Salmon has a wide range of experience working with organizations as a researcher and held a position with the Network in a previous iteration. We are also delighted to have Dr. Alan Bocking step into the role of Scientific Advisor, particularly as the research priorities of the Network begin to evolve in concert with our overall strategic direction. Our Board of Directors has been significantly strengthened by the addition of two new members this year. Ms. Claudette Bradshaw and Ms. Helen Klengenberg have joined the board and both bring exceptional knowledge, experience and energy to the Board and to the work of the Network.

The Family Advisory Committee has continued to develop and clarify their role and relationship with the Network. This is a tremendous group of people who ensure that the family perspective is at the forefront of all of the work that the Network undertakes. The experience and energy of this group provides a huge resource to the Network as a whole.

The Network had an opportunity to report to the Canada Northwest FASD Partnership Ministers last November. The discussions confirmed our strong and ongoing relationship with the Partnership and we continue to work very closely with the Partnership Steering Committee as we interrelate the research activity of the Network with the policy and practice needs of the partner jurisdictions. New Brunswick has renewed their partnership with the Network and we continue to enjoy a strong working relationship with that province.

The Research Network has made significant progress in some of our key strategic areas including initial development of a comprehensive communications plan for the organization that will increase the profile and position the Network as the go to place for information on FASD. We are also continuing to refine the organization structure and operation to ensure we are operating as effectively as possible. A new focus this year is the creation of an "Ambassadors" group, within the Network, that will work to make those high level connections that facilitate the broadening of the scope and reach of our work. We continue to identify ways to increase the national scope of the Network and to be increasingly able to support FASD interests and needs internationally. Finally, we brought together our research and scientific leads last summer to begin to refine and align our research agenda.

In this way we continue to work in the areas, and in the directions, that best serve those families, practitioners, organizations and governments that are doing such great work in resolving issues and building capacities that create better outcomes for persons with FASD, their families and communities and in increasing the level of prevention resulting in a reduction in FASD births across Canada.

The past year has been exciting, demanding and rewarding. The year to come is full of great potential for continued results and progress on reducing the impacts of FASD and to continue, through research and investigation, to find more effective ways to increase support and create better outcomes.

Tim Moorhouse

Message from the EXECUTIVE DIRECTOR

Dr. Amy Salmon

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) has enjoyed another successful year. As Canada's first comprehensive research organization dedicated to fetal alcohol spectrum disorder and its prevention, we have remained focussed on our mission: **to produce national, multidisciplinary, collaborative research that can be shared with all Canadians, leading to prevention strategies and improved outcomes for people affected by FASD.** We have worked to increase our organizational profile, translate and disseminate new, high impact research into actionable public policy and front-line practice recommendations, and continued to establish our position as Canada's leading authority on FASD.

During the 2014-15 year, we have further expanded FASD research capacity in Canada with the establishment of three new Strategic Research Leads. Dr. Ana Hanlon-Dearman at the University of Manitoba will spearhead a program of research and knowledge mobilization in paeditric diagnostics, while Dr. Mansfield Mela will serve as CanFASD's first Strategic Research Lead in adult diagnostics at the University of Saskatchewan. Dr. Michelle Stewart, of the University of Regina, will be developing regional and national collaborations focussed on issues facing people with FASD in the justice system, another first for CanFASD.

In 2014, CanFASD's research teams in Prevention, Intervention, Diagnostics, and Justice lead 35 major projects, leveraging provincial and territorial government investments to generate over $4.5 million in external funding. Together, CanFASD has offered a return on investment of 9 to 1 for every provincial and territorial government dollar dedicated to this work.

2014 was also the year in which CanFASD was privileged celebrate the enormous contributions of our founding CEO and Scientific Director, Dr. Sterling Clarren, on the occasion of his retirement. Dr. Clarren has been a seminal figure in establishing and advancing FASD as a crucial area of concern in both the scientific and clinical realms for over 40 years. As a developmental paediatrician and a tireless and impassioned advocate for families living with FASD, Dr. Clarren's work has directly touched the lives of thousands, and indirectly, millions. The Sterling Clarren Research Award was created by CanFASD in his honour, to recognize a completed study that made a substantial contribution to understanding the human dimensions of FASD. This year we celebrated Dr. Kaitlyn McLachlan as the inaugural recipient.

While research and knowledge translation remain the core of our work, as a knowledge network we are committed to growing in directions that will allow us to share knowledge more widely. To that end, we made great strides this year in establishing a national Family Advisory Committee. Comprised of parents and caregivers who have collectively supported more than 220 children and youth living with FASD, the Family Advisory Committee is available to guide the development, implementation, and dissemination of findings in the FASD research community, and ensures families have a vehicle for communicating their needs, priorities, and concerns that matter most when working to improve outcomes for individuals. Taking a more proactive approach in our family and stakeholder communications has already yielded tangible positive, results. However there is still work to be done in regards to strengthening our national voice and increasing our membership across Canada.

Moving forward, CanFASD remains focused on using the momentum from the past year to further increase our profile on a national and international scale. We remain dedicated to ensuring that high-quality, meaningful, and relevant information that matters to families and service providers is made available to guide evidence-based decision making that will lead to new, and more cost-effective programs and services. We also look forward to continuing our work with our collaborators and partners across the country and around the world, to ensure research in FASD diagnosis, intervention and prevention is stimulated and disseminated in a way that leads to improvements in our country's ability to assist women struggling with alcohol use during pregnancy, and to enhance the well-being of individuals, families, and communities who are living with FASD.

Amy Salmon

Message from the SCIENTIFIC ADVISOR

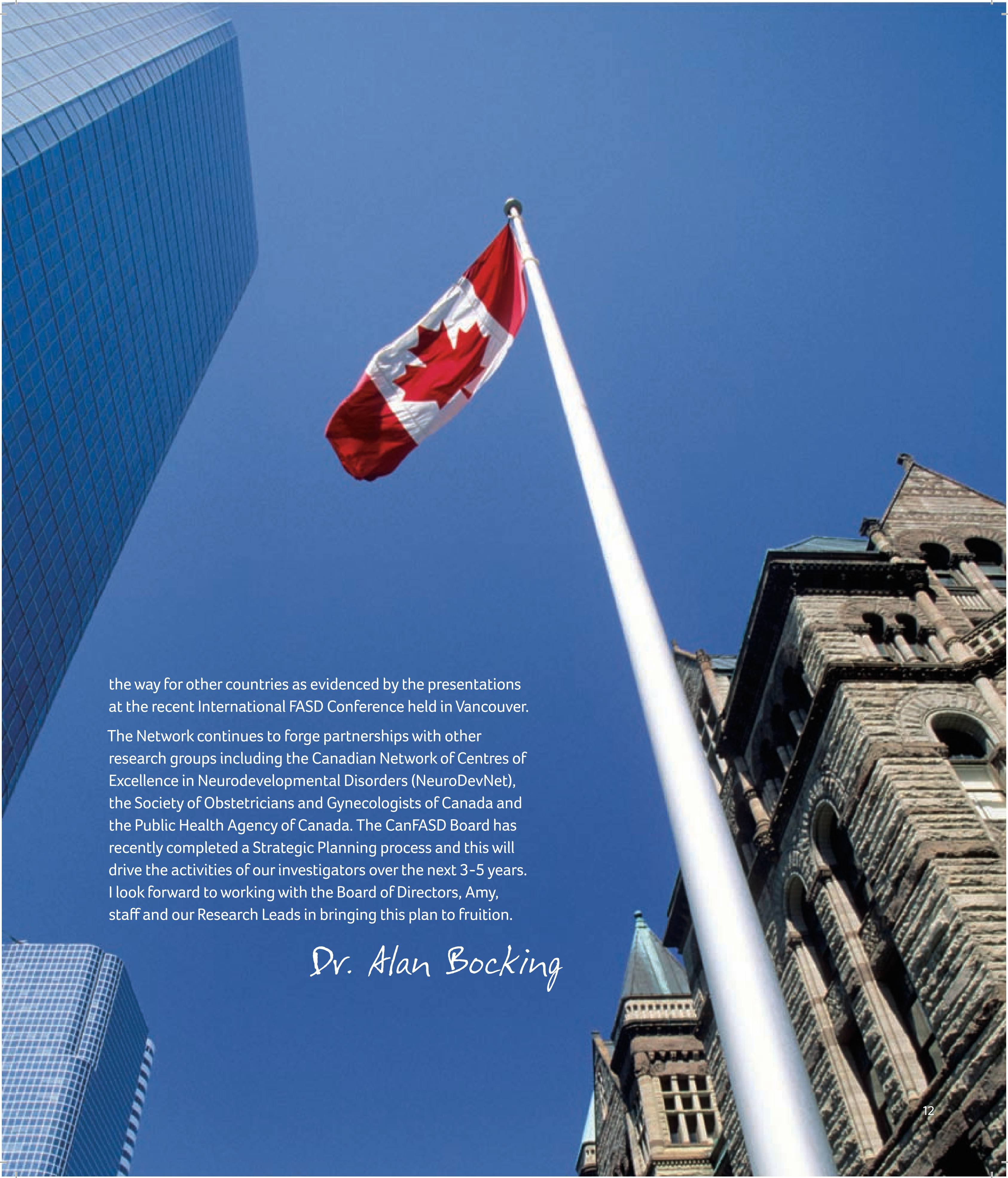
Dr. Alan Bocking

It is my distinct pleasure and privilege to have joined the CanFASD Research Network as its Scientific Advisor in August 2014. It is a particular honour to follow in the footsteps of Dr. Sterling Clarren who is an icon in the field of FASD and is a longtime colleague and friend.

As an Obstetrician by training, my work as it relates to Fetal Alcohol Exposure has largely been in the domains of prevention and understanding the mechanisms of action in order to develop new and innovative approaches to intervention. My experience in leadership roles within the Academic Health Sciences sector has however, reinforced to me, the importance of a multi-disciplinary approach to this issue and the need to be able to help inform policy based on sound evidence. This is exactly what the CanFASD Research Network does and we are very fortunate to have a number of highly skilled and knowledgeable investigators who are leaders both nationally and internationally in the areas of prevention, diagnosis and intervention.

I am particularly fortunate to have joined the network at the same time as Dr. Amy Salmon who has taken on the role of Executive Director.

This is an exciting time for research in FASD in Canada and in many aspects, we are leading

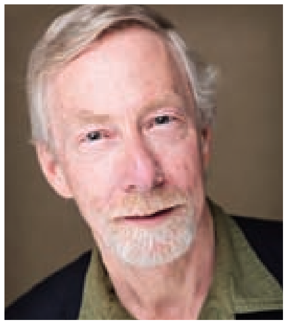


the way for other countries as evidenced by the presentations at the recent International FASD Conference held in Vancouver.

The Network continues to forge partnerships with other research groups including the Canadian Network of Centres of Excellence in Neurodevelopmental Disorders (NeuroDevNet), the Society of Obstetricians and Gynecologists of Canada and the Public Health Agency of Canada. The CanFASD Board has recently completed a Strategic Planning process and this will drive the activities of our investigators over the next 3-5 years. I look forward to working with the Board of Directors, Amy, staff and our Research Leads in bringing this plan to fruition.

Dr. Alan Bocking

Board of DIRECTORS



Tim Moorhouse – *Chair*

Audrey McFarlane

Michelle Dubik

Lisa Brownstone

Stacy Taylor

Helen Klengenberg

Claudette Bradshaw

Janice Penner

MANAGEMENT & RESEARCH *Teams*


Dr. Alan Bocking
Scientific Director


Kathy Unsworth
Director of Business & Partnership Development


Dr. Courtney Green
Manager of Research Development


Edward Swatschek
Manager of Corporate Services & Communications

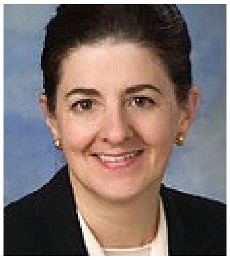

Dr. Jocelynn Cook
Consultant


Dr. Jacqueline Pei
Intervention Research Co-Lead


Dr. Nancy Poole
Prevention Research Lead


Dr. Michelle Stewart
Intervention Research Co-Lead


Dr. Mansfield Mela
Diagnostics Research Co-Lead


Dr. Ana Hanlon-Dearman
Diagnostics

FAMILY ADVISORY *Committee Members*

Left to right:
Ray Marnock – *Co-Chair,*
Simon LaPlante
Marsha Wilson
Dorothy Reid – *Co-Chair*
Françoise Corbin-Boucher
Tammy Roberts
Wanda Belland

Not pictured:
Sonja Schmidt
Marva Smith

CanFASD
RESEARCH

Why is research on FASD important?

FASD is the leading known cause of developmental disability in Canada. One in every one hundred Canadians, or more than 380, 000 people, currently live with this disability. Despite 40 years of public health campaigns warning against the risks associated with alcohol use in pregnancy, prevalence does not appear to be decreasing. With an estimated cost of $4 billion dollars per year, governments are paying attention to the social, economic, and public health consequences of this devastating and lifelong disability, and are investing in much needed community-based programs to assist pregnant women and their families. However, there is presently insufficient evidence available to provide policymakers, service providers, or families with a clear understanding of how best to deliver this assistance, nor of the capacity required to deliver cost-effective, accessible and sustainable prevention, intervention and diagnostic services.

CanFASD is working to bridge this gap. By bringing together all stakeholders- including researchers, parents and caregivers, clinicians, front line service providers, community advocates, program planners, civil servants, political leaders, and people living with FASD, CanFASD is fostering the development of the high impact research initiatives needed to help answer today's most pressing questions about the prevention, diagnosis and treatment of FASD, and to help set the foundation for the development of increasingly effective programs and policy development.

Research in PREVENTION

CanFASD in the Atlantic Region

Prevention of FASD is complex and cannot and has not been accomplished by programs aimed to prevent drinking during pregnancy alone. Our research team on FASD prevention (pNAT) understands that FASD prevention has to be considered in the context of women's alcohol use and women's health overall. Preventing FASD requires collaborative action among women, families, service providers, decision makers, researchers and communities.

In November and December of 2014, six facilitated, action-oriented discussions across the Atlantic region were held among key provincial FASD stakeholders, including CAPC/CPNP/AHS leaders, primary health practitioners, alcohol policy and other government leaders, mental health & addictions health promoters and addictions counselors and researchers. These regional sessions were sponsored by the Public Health Agency of Canada (PHAC) and organized by local Family Resource Centres. Sessions were held in Grand Falls/Windsor and St. John's, Newfoundland and Labrador, Charlottetown, Prince Edward Island, Sydney and Halifax, Nova Scotia and Fredericton, New Brunswick.

Prevention Research Lead, Nancy Poole, shared current best practices in FASD prevention to stimulate discussion and guide planning at each of the regional events. A series of short videos on the four "levels" of FASD prevention was shown throughout the day. These videos were filmed at the 3rd European Conference on FASD, and were uploaded to CanFASD's YouTube channel to be shared widely. To check out these and other videos produced by CanFASD researchers, go to http://www.youtube.com/user/CanFASD.

The Four-Part Model of Prevention

LEVEL 1: Broad awareness building and health promotion efforts.

LEVEL 2: Discussion of alcohol use and related risks with all women of childbearing years and their support networks.

LEVEL 3: Specialized, holistic support of pregnant women with alcohol and other health and social problems.

LEVEL 4: Postpartum support for new mothers assisting them to maintain/intiate changes in their health and social networks and to support the development of their children.

Based on the discussions, an action and implementation plan for FASD Prevention in the Atlantic Region was created for each of the four provinces and shared with government partners to inform service and systems planning. Follow-up teleconferences and webinars provided an opportunity for attendees to receive support through an "action-reflection-action" model of practice.

Since 2006, the pNAT has used technology to develop and support a virtual community of practice across the country. This year, with the support of partners in the Atlantic region, we were able to find new ways of inspiring discussion and supporting collaboration and action on FASD prevention.

Learn more about FASD Prevention and what we doing at *https://fasdprevention.wordpress.com.*

Research in
DIAGNOSTICS

Alcohol-exposed individuals, both children and adults, have specific concerns that require assessment. Without an accurate and timely diagnosis, treatment plans based on individual strengths, problems and needs cannot be developed. The research is clear that early diagnosis and intervention lead to better long-term outcomes for children and their families. Appropriate access to diagnostic services can provide a "road map" leading to the identification of relevant and effective interventions. This in turn significantly improves functioning, adaptability, self-awareness and self-esteem, as well as relationships with family members.

CanFASD was delighted to welcome two new Diagnostic Research Leads in 2014. Dr. Mansfield Mela and Dr. Ana Hanlon-Dearman are leading the way in improving the quality and range of diagnostic assessments available to children and adults, and promoting evidence-based diagnostic practices across the country and internationally.

Dr. Hanlon-Dearman has been working collaboratively with a number of research teams to understand population health issues of children with FASD and to better integrate care for affected individuals and their families. Her clinical and research interests include neurodevelopmental patterns of children with FASD, as well as children with a variety of neurodevelopmental disabilities.

Dr. Mela and his team have been focussed on the assessment needs of those who may be affected by FASD but have reached adulthood without a formal diagnosis. Through work with clinicians, service providers, and families supporting people with FASD who are in contact with the justice system, Dr. Mela's research program includes efforts to understand specific neurobehavioral profiles of those affected by FASD, the development of FASD screening tools that can be used in forensic and community mental health services to identify individuals who may benefit from an assessment for FASD, and on increasing awareness of FASD among mental health practitioners, psychiatrists and other physicians who may be in a position to refer their patients to diagnostic services.

Research in INTERVENTION

The CanFASD Intervention Research Team is working to improve the quality of life of individuals and families living with FASD. While there is a growing body of research demonstrating a wide range of interventions that can improve outcomes for those diagnosed with FASD, little has been documented about the unique needs of family members and caregivers who are so crucial to supporting these successes. This year, Dr. Jacqueline Pei (CanFASD Intervention Research Co-Lead) and the University of Alberta FASD Research Team, completed the first comprehensive study examining at the needs and stress levels of caregivers of children and adults with FASD across Canada.

Findings of this national survey, with responses from 125 caregivers, revealed numerous factors that their impact wellbeing, and needs for support. The age of the individual with FASD had a significant effect on several aspects of caregivers' wellbeing. For example, those caring for adolescents with FASD reported higher levels of concern about well being than those supporting younger children. Caregivers who had been caring for individuals for a longer amount of time reported higher levels of concern about well being and less satisfaction with the supports they were receiving. Increased caregiver stress levels were significantly correlated with increased concern about wellbeing and decreased satisfaction with supports.

Caregivers of individuals with FASD in this study experienced high levels of need and stress, pointing to a need for new and expanded supports and services available to caregivers of individuals with FASD across the lifespan.

> "...those caring for adolescents with FASD reported higher levels of concern about well being than those supporting younger children."

More in depth results and conclusions will be communicated through CanFASD via the iNAT blog *https://fasdintervention.wordpress.com/* and newsletter. *https://www.mailoutinteractive.com/Industry/Subscribe.aspx?m=25286*

FINANCIAL *Snapshot*

CANADA FETAL ALCOHOL SPECTRUM DISORDER RESEARCH NETWORK

Statement of Operations and Net Assets
Year ended March 31, 2015 with comparative figures for 2014.

	2015	2014
Revenues:		
Canada Northwest FASD Partnership	666,710	437,337
Diagnostic Guidelines Project	307	169,000
FASD Education Project	73,700	74,700
First Nations and Inuit Health Branch Project	25,000	58,355
Prevention Symposium	—	58,650
Research Priorities Workshop	—	14,658
Treatment Improvement Protocol	258,154	141,846
Other contributions	22,650	11,325
Amortization of deferred capital contributions	1,897	929
Donations and fundraising	17,979	125
Interest income	130	142
	$1,060,487	$967,068
Expenditures:		
Advertising and promotions	9,127	11,6466
Advisory committees	18,622	—
Amortization	1,857	929
Fundraising expense	2,591	—
Insurance	1,274	1,274
Knowledge translation	—	6,333
Membership	1,461	—
Miscellaneous	3,579	9,378
Network action teams	131,832	124,779
Office	12,153	12,979
Professional fees	6,183	6,369
Printing and translations	2,322	7,515
Research expenses	44,694	39,970
Salaries	426,192	346,599
Subcontract consultants	—	156,994
Telephone and web conferencing	6,459	5,820
Travel	124,711	201,267
	803,057	931,852
Excess of revenues over expenditures	257,430	35,216
Net assets – beginning of the year	65,342	30,126
Net assets – end of the year	$322,772	$65,342

FAMILY ADVISORY Committee

CanFASD Research Network initiated a Family Advisory Committee in 2013, with an initial meeting in January 2014. The committee consists of representatives from British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Northwest Territories and Yukon. The purpose of the FAC is to advise on research priorities for families impacted by FASD and to assist in translating results of research to ensure they are accessible to families. The goals of the Family Advisory Committee are to:

- Identify and inform emerging research priorities as they relate to those who provide support to individuals with FASD
- Provide guidance on research design and desired outcomes so that the research is sensitive to and is useful to individuals and families
- Help to raise broad-based public and systems awareness about research needs and priorities for individuals and families
- Advise and aid in the development of communication processes to actively engage researchers with individuals and families
- Raise community and systems understanding of the importance of increasing investments in research that is relevant to supporting people with FASD and their caregivers
- Develop and foster relationships to guide FASD research in ways that are meaningful, accessible and respectful to those who provide support to individuals with FASD
- Provide input into the communication of research findings (and other related publications) and the development of practical documents that will inform families, support systems, and the community at-large
- Facilitate and enhance productive linkages across jurisdictions, communities and disciplines

The Family Advisory Committee has been meeting regularly and has focused on dialoguing with FASD researchers and building relationships with the research community. The committee has met with CanFASD research leads and has provided input into the development of the Can FASD research plan. We consulted with researchers in the development of the FASD Caregiver Survey recently completed and have hosted Parent/Caregiver networking sessions during two major FASD research conferences.

As individuals, Family Advisory Committee members have been very active in connecting with the larger community. We have participated in a variety of webinars, conferences and meetings promoting the Research Network activities and emphasising the need to involve parents and caregivers in all aspects of research into and services for individuals with FASD.

Examples of the FASD communities/organizations our members have been involved in are:

- FASSY
- FASD Canadian News
- Parenting FASD Teens and Adults (Virtual parent support network)
- Collaborative Roundtable on FASD (B.C.)
- Manitoba Foster Parents Network
- Manitoba Coalition on Alcohol and Pregnancy
- Alberta FASD Advisory Council
- NWR FASD Society- MacKenzie Network
- Parent Support Group for FASD Caregivers –High Level
- Fraser Valley Brain Injury Association
- Langley FASD Parent Support Group
- Langley Child Development Centre
- International FASD Conference on Research and Policy Committee
- National FASD Adult and Adolescent Conference Committee
- NB Centre of Excellence on FASD
- Greater Moncton Community of Practice on FASD
- NB Adoption Support Network
- Yellowknife Association for Community Living

The Family Advisory Committee has been very interested in the issue of FASD and the Law. The committee presented to the delegates at the FASD and the Law workshop held in conjunction with the 6th International Conference on FASD held in Vancouver, March 2015. The Committee also participated in two briefs to the Parliamentary Standing Committee on Justice and Human Rights on C-583, specifically the brief submitted by CanFASD Research Network and the brief submitted by FASSY (Fetal Alcohol Syndrome Society Yukon).

Family Advisory Committee members have also been involved in a variety of training sessions on FASD. Examples of such sessions are a one day FASD Basics training for practitioners, assisting in the development of on line FASD training for key workers through Douglas College, information sessions in New Brunswick in collaboration with the NB Centre of Excellence on FASD, presentations to education students at the Faculty of Education, University de St. Boniface and presentations to high school students.

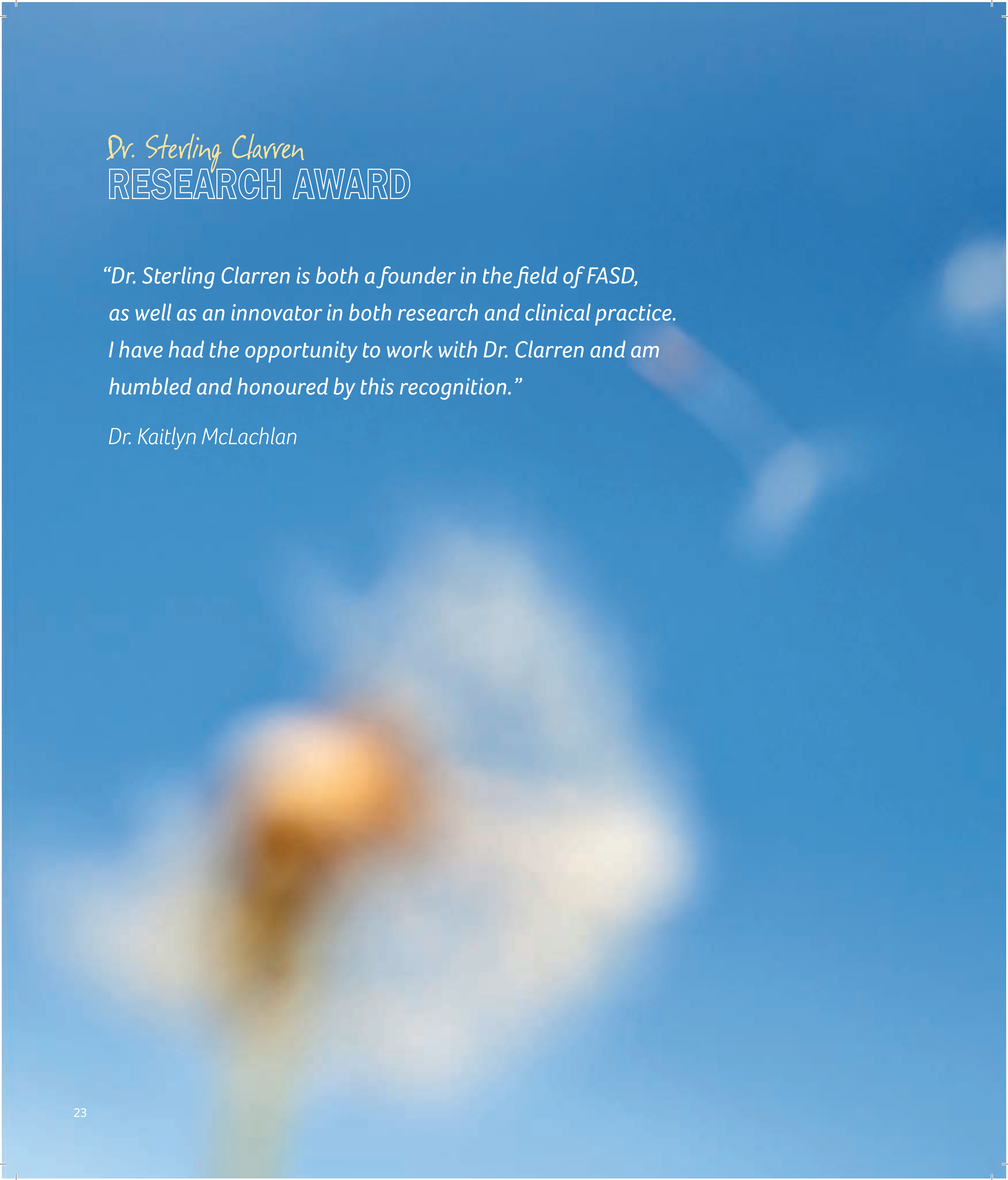
The Family Advisory Committee consists of individuals who are passionate about gaining and sharing knowledge about FASD and compassionate to the needs of parents and caregivers of individuals with FASD. We are excited to be involved with the activities of CanFASD and look forward to a year of connecting parents and caregivers with researchers to enrich the lives of all those who live with FASD.

The Family Advisory Committee members are: Ray Marnoch, Dorothy Reid, Marsha Wilson, Marva Smith, Tammy Roberts, Wanda Beland, Sonja Schmidt, Simon LaPlante and Françoise Corbin-Boucher.

Dr. Sterling Clarren RESEARCH AWARD

“Dr. Sterling Clarren is both a founder in the field of FASD, as well as an innovator in both research and clinical practice. I have had the opportunity to work with Dr. Clarren and am humbled and honoured by this recognition.”

Dr. Kaitlyn McLachlan



The Canada FASD Research Network was pleased to announce the selection of the inaugural recipient of the Dr. Sterling Clarren Research Award. The Award has been named in honor of Dr. Sterling Clarren to recognize his pioneering contribution to and leadership in the field of Fetal Alcohol Spectrum Disorder (FASD). The award will be presented annually in recognition of a completed study that has made a substantial contribution to understanding the human dimensions of FASD.

This year's recipient is Dr. Kaitlyn McLachlan. Dr. McLachlan is a Psychologist in the Forensic Psychiatry Program at St. Joseph's Healthcare Hamilton. She completed her Ph.D. in Clinical Psychology at Simon Fraser University, specializing in Forensic Psychology, with her dissertation focusing on the risks and needs of adolescents with FASD involved in the justice system.

Dr. McLachlan is a rising researcher in the field of FASD, at-risk youth, and justice-involved populations, currently evaluating the prevalence of FASD among adults in a forensic psychiatric setting, to inform the need for services among adults with complex psychiatric presentations in the criminal justice system. CanFASD congratulates Dr. McLachlan on her success and thanks her for her continued commitment to improving the lives of people living with FASD.

SNAPSHOT *CanFASD Research in 2014*

PROJECT TITLE	PI	FUNDING
Diagnostic Guidelines	J. Cook	PHAC
Education Curriculum	J. Cook, C. Green	PHAC/Lakeland Centre for FASD
Universal Data Form Project	J. Cook, A. Bocking	PHAC, NDN, CIHR
Treatment Improvement Protocol	J. Cook, C. Rasmussen	Government of Alberta
Caregiver Survey	J. Cook, C. Green, C. Rasmussen	Government of Alberta/CanFASD
Mathematics Intervention	J. Pei, C. Rasmussen	SSHRC
Mathematics Intervention in Schools	J. Pei, C. Rasmussen	SSHRC
Experience in Canadian criminal justice system for Individuals with FASD: Double Jeopardy?	J. Pei	Yukon Law Foundation
An Evaluation of an Intervention Program for Youth with FASD	J. Pei	Alberta Government
Quantitative Magnetic Resonance Imaging of Neurodevelopment	J. Pei	NeuroDevNet/CIHR
Caribbean Quest	J. Pei, K. Kerns	NeuroDevNet ACCFCR
Justice database project	J. Pei, M. Stewart	CanFASD
FASD MacKenzie housing	J. Pei	Alberta Government
Facilitating post-clinic support for children & adolescents diagnosed with FASD.	J. Pei	Alberta Government
Virtual Environments: An Effective social training setting for adolescents with FASD	J. Pei, P. Boechler	University of Alberta Faculty Grant - Support for the Advancement of Scholarship (SAS)
Meeting Them Where They're At: Social Skills Training for Adolescents with FASD	J. Pei, A. Salmon	NeuroDevNet Strategic Initiative Award
Fetal Alcohol Spectrum Disorder (FASD) Research program: Early life adversity, outcomes and secondary intervention.	J. Pei	NeuroDevNet Networks of Centres of Excellence
Impact of Pre and Postnatal Risk Factors on Secondary Diagnosis of FASD	J. Pei, C. Rasmussen	Alberta Centre for Child and Family Research (ACCFCR) Seed Grant
Working Memory Training Impacts on FASD and Preterm Children, Women and Chidlren	J. Pei, C. Rasmussen, G. Andrew, K. Kerns	Women and Children's Health Research Institute
Community perspectives on FASD prevention in rural and remote Aboriginal communities.	N. Poole, D. Badry, B. Bastien A. Wight Felske, M. Bennett, C. Tomah	FNIHB
The PCAP Women's Quilt – The Next Stitch	Co-Principal Investogators: N. Poole, D. Badry, K. Bonot, R. Delorme	Alberta Parent Child Assistance Program (PCAP)

PROJECT TITLE	PI	FUNDING
BC Healthy Foundations Study	A.Gonzales, L. Marcellus	CIHR
FASD Prevention Gap Analysis	N. Poole	PHAC
PHAC Chronic Disease LOI	L. Popova	PHAC and CIHR
Enhancing Capacity for FASD Prevention-BC	N. Poole	BC Mental Health Foundation
Evaluation of the Herway Home Program	D. Rutman, C. Hubberstay, N. Poole	Island Health Authority
Identifying long-term outcomes associated with BC Ministry of Housing and Social Development funded supports for clients at Sheway	L . Marcellus	BC MHSD and the Vancouver Native Friendship Society
Support Recovery Home Project: Community Consultation Phase	D. Rutman, C. Hubberstey, S. Hume	Community Action Initiative
Environmental Scan of Current Level 1 and Level 2 FASD Prevention Efforts in Saskatchewan, Canada and the United States	Saskatchewan Prevention Institute	PHAC
Primary Prevention of FASD through Broad Awareness Building and Discussion of Alcohol Use with Women of Childbearing Age	Saskatchewan Prevention Institute	PHAC
Focus Testing an FASD Prevention Campaign for SK Professional Men	Saskatchewan Prevention Institute	PHAC
Insight Mentoring Program Evaluation	Manitoba Centre for Health Policy	
Integrated treatment for pregnant and parenting women with addictions	K. Mlilligan (Ryerson) and K. Urbanoski (CAMH)	CIHR and Ontario Ministry of Health and Long-term care
Women's Health FASD Prevention Project on First Nations in Canada Alberta, Manitoba and New Brunswick	D. Badry, B. Bastien, A. Wight Felske, M. Bennett, C. Tomah	FNIHB
Diagnosis of FASD and intervention among MDOs in the community	M. Mela	RUH Foundation
Determining the prevalence of FASD using the Alspac cohort	M. Mela	Molstad Intramural funds
The use of oxidative stress measurement as a screening method	M. Mela, B. Obayan	College of Medicine
Standardizing the new DSM criteria among diagnostic clinics	M. Mela	
Successful rehabilitation of Mentally disordered offenders with FASD in the community	C. Tait, M. Mela, B. Henry	Centre for forensic behavioral science and justice studies
Policing Risk: Understanding of Fetal Alcohol Spectrum Disorder through Networks of Police and Non-Police Practitioners	M. Stewart	SSHRC, University of Regina
Confronting the Challenge – Community Supports, Stability and the Role of the Mental Health Disposition Court	M. Stewart, B. Mario (Co-PI)	University of Regina
E-Scan of FASD and Justice in Canada	M. Stewart	CanFASD

Consider Supporting OUR WORK

CanFASD is a registered charity, funded by leading health and policy organizations across Canada. Your financial support helps to develop and share the evidence needed to inform the policies and programs that pregnant women, families, and people impacted by FASD need.

Decision-makers in governments, communities, and families need to know which initiatives will have the most impact and which are most cost-effective. Sound data provides a compass to guide those decisions. CanFASD is Canada's only national network focused on FASD. We bring a multi-disciplinary approach to the study of the disability, pooling together the findings of researchers, parents and caregivers, clinicians, service providers, community advocates, program planners, government officials, and people living with FASD.

Our goal is to ensure that the broadness of our approach is reflected in the breadth of our funding base so that we can continue to have a national reach. You have an important role to play in making sure the knowledge developed at CanFASD reaches the stakeholders who need it to make effective policy decisions, provide the best supports, and make the healthiest choices possible.

THANK YOU To Our Funders

The Canada Northwest FASD Partnership, Government of New Brunswick, Canadian Institute of Health Research, Public Health Agency of Canada, First National Inuit Health Branch, Alberta Human Services, Lakeland Centre for FASD, and a special thanks to our volunteer Board of Directors and Family Advisory Committee members, NeuroDevNet, Institute of Health Economics, Cennovus.

Member BENEFITS

Membership in CanFASD benefits governments by increasing capacity for meaningful FASD research in their jurisdictions, as well as offering the potential to reduce longer-term costs associated with diagnosis, prevention and intervention. Canadians, especially those affected by FASD, benefit from better, more meaningful information, and more effective policies and programs that can lead to improved outcomes.

Provinces who become members of CanFASD benefit from increased research capacity, advice and assistance in moving forward with evidence-based policy-making and program planning, learning from the work and experiences of other member jurisdictions. They receive policy-relevant information and recommendations on topics and issues related to FASD tailored to the needs and priorities of their jurisdiction, and gain access to researchers across the country who can assist them in meeting those needs. Better, more meaningful information that matters to families and service providers is made available to guide evidence-based decision making that will lead to new, and more cost-effective programs and services.

As members, contributing Provinces and Territories receive benefits such as:

- Access to a trusted agency to turn to for answers to important policy questions
- Responses to direct requests for information (i.e., Policy/position papers on FASD to highlighting policy implications for governments)
- Opportunities to have input into CanFASD's research direction/agenda
- Annual reports
- Invitation to CanFASD symposia, workshops and learning events
- Annual visits and presentations by CanFASD staff
- Opportunities to stimulate, collaborate and participate in CanFASD research and evaluation projects
- Travel awards for researchers and trainees
- Access to member researchers and governments
- Access to platforms and tools developed by the Network
- Representation on CanFASD's Family Advisory Committee
- Mentoring from other member jurisdictions, with venues for sharing information and experiences and learning from those of others

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