

FASD | ontario news

The Newsletter of FASD Ontario Network of Expertise



Chair's report

I have more to reflect on in this Chair's Report than usual. My term ends this month after four years leading FASD ONE. I am exhilarated by the passion and commitment of our members and those who inform our work. It has been an honour to be at the helm of this dynamic group of volunteers. I am profoundly grateful to my colleagues who gave me latitude when I needed it, attended meetings when asked, and who had faith in the vision of FASD ONE. Working Groups have led studies and initiatives that have expanded the body of knowledge in Ontario and internationally. This has contributed to our understanding of the disability, substance use in pregnancy, and effective practices. I thank them for contributing their expertise to move this issue through the halls of government, agency boardrooms, classrooms, courtrooms, and street corners.

FASD is a critical factor in the social and health issues we face in Ontario. We know what causes it and how to diagnose it. We know effective interventions to prevent it and we know how to improve outcomes for those living with it. We know that provincial government leadership is vital to reduce the incidence rate and poor outcomes of this preventable disability. We know Ontario remains the only province without a coordinated response. I have had the opportunity to talk with Ministers and government staff and feel a degree of momentum and hope. There is recognition that FASD is too costly to continue to ignore.

Meetings with ministries and others will continue. Support from the Public Health Agency of Canada will enable FASD ONE to host a provincial conference in early 2011. This will provide a platform for information on research, promising practice, and discussions that can inform policy and effective program design and delivery. This will help drive action on FASD and help Ontario catch-up on this public health issue.

Best wishes to all,
Sheila Burns

Purpose:

This newsletter was developed to help people in Ontario work together to address FASD. It reports on the activities of FASD Ontario Network of Expertise (FASD ONE) and shares news of relevance to individuals, caregivers and service providers who work on FASD across Ontario. For submission requirements and previous editions visit: www.beststart.org/projects/index.html

Fetal Alcohol Spectrum Disorder (FASD)

"FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and learning disabilities with lifelong implications."

FASD: Canadian Guidelines for Diagnosis, 2005

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FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

JUSTICE COMMITTEE



Justice Committee Postcard

The focus of the Justice Committee continues to be the Justice website: www.fasdjustice.on.ca which has received well over 600,000 visits and is linked by many websites. The most recent is the European FASD network, www.eufasd.org/EN/justice_en.php

With the exception of its Aboriginal section, which will be revised this year, the Justice website was completely revamped in spring 2010. Subject to funding, the committee also plans a full translation into French, yearly update of case law, new sections on policing and corrections, and strategic planning for future development. The Justice Committee thanks PHAC and the Department of Justice – Youth Justice Fund for their support.

Significant news this summer was the Canadian Bar Association resolution about FASD, announced at their annual meeting in August. In essence it states that normative assumptions and sentencing principles are not valid for people with FASD. It therefore urges all levels of government to pursue existing initiatives for access to justice for people with FASD, to put more resources into creating alternatives to criminalizing individuals with FASD, to develop policies to assist and enhance the lives of those with FASD and to prevent their over-representation in the criminal justice system. Finally, they urge the federal government to amend criminal sentencing laws to accommodate the disability of those with FASD. Full text is at www.cba.org/CBA/resolutions/pdf/10-02-A.pdf

Lead: Jonathan Rudin, Aboriginal Legal Services, rudinj@lao.on.ca

INTERVENTION AND SUPPORT WORKING GROUP

On September 9, 2010, the Intervention & Support Work Group officially launched three reports. A press release announcing the launch was distributed to media across Ontario. The three reports are based on the priorities identified in a 2008 provincial survey of caregivers and service providers, and include:

- Advancing Effective Educational Practices in FASD
- Advancing Effective Respite Services in FASD
- Towards a Provincial Strategy Advancing Effective Service Provider Practice in FASD.

The overall recommendation in all three reports is for a provincial strategy to address FASD, developed in collaboration with FASD ONE, parents/caregivers, service providers and other stakeholders. It is recommended that the Ontario government assign a lead ministry to

work with other ministries to create a provincial FASD strategy and to ensure that effective practices are implemented. Local FASD networks/coalitions are encouraged to use the reports to encourage the government to move forward on the development of a provincial strategy to address FASD. There are also many recommendations specific to education, respite and effective practices. The reports can be found at: www.fasdontario.ca/resources/provincialstrategy.htm

The Intervention and Support Working Group would like to thank the Communication Department at the Children's Aid Society of Toronto for its generous support in preparing and distributing the press release, as well as the Public Health Agency of Canada for supporting the survey development.

Lead: Pat Spadetto, pat.spadetto@tcafs.org

THANKING SHEILA BURNS

The Public Health Agency of Canada and members of FASD ONE wish to acknowledge Sheila Burns, the chair of FASD ONE, for her never-ending effort and commitment to FASD. Her strong and dedicated leadership to FASD ONE over the last four years has been instrumental in moving the FASD portfolio forward in Ontario. We wish her much success as her term as chair ends and she moves on to other great work. Her passion, determination and enthusiasm will be missed.

LIFETIME AWARDS FOR BONNIE AND BRIAN

Bonnie Buxton and Brian Philcox are well known in Ontario for their long-term dedication to the issue of FASD. Over the years they have worked on conferences, media campaigns, articles, workshops, support groups, websites, awareness activities and a range of other strategies to help in preventing FASD and improving the lives of individuals and families affected by FASD. Bonnie and Brian raised a child who has FASD, and are now raising their grandchildren. They are co-founders of FASworld Canada, and collaborated to create International FAS Awareness Day. In June, Bonnie and Brian were presented with the Lifetime Achievement Award by the Ontario Association of Children's Aid Societies for their work on FASD.

ONTARIO GRANDPARENT WINS 2 AWARDS

Lynn Cunningham from Toronto received a Gold Award for Personal Journalism and a Silver Award for the Health and Medicine at the National Magazine Awards in June 2010, for her piece *Cause and Effect* in The Walrus magazine. This article is about her relationship with her grandson, Andrew, who has FASD. Lynn raised Andrew since before the age of two. Andrew is an excellent musician, and is in the music program at Mohawk College. Lynn is a director of FASworld Toronto. To read her article, go to: www.walrusmagazine.com/articles/2009.10-memoir-cause-and-effect/

PHAC – ONTARIO AND NUNAVUT REGION

The Public Health Agency of Canada (PHAC), Ontario Regional Office, has been working diligently to raise FASD awareness within our province. Over the last few years, our Regional Office has helped create a network known as the FASD Intergovernmental Action Network of Ontario (FIANO). This network is made up of representatives from different government departments and ministries, including: Children and Youth Services; Community Safety and Correctional Services; Education; Health Promotion and Sport; and, most recently, the Ministry of Health and Long-Term Care. This is non-delegated network shares information to move forward around FASD issues in a coordinated approach and enables a complementary way of working. In addition, the PHAC assists FASD ONE (FASD Ontario Network of Expertise) by supporting their work and providing funding for identified FASD priorities. This is a province-wide network made up of parents, caregivers and service providers concerned with FASD. PHAC congratulates the Justice Working Group, a working group of FASD ONE. The European FASD Network has recognized the FASD ONE justice website as one of only three available resources in the world providing information on FASD and systems of justice – a wonderful accomplishment.

Submitted by: Donna De Filippis, Donna.De.Filippis@phac-aspc.gc.ca

ALCOHOL USE AND PREGNANCY CONSENSUS CLINICAL GUIDELINES

In the August edition of the *Journal of Obstetrics and Gynaecology Canada*, new consensus clinical guidelines were released on alcohol use and pregnancy. The Guidelines were funded by the Public Health Agency of Canada through the FASD National Strategic Projects Fund and developed by the Society of Obstetricians and Gynaecologists (SOGC).

The Guidelines are based on a comprehensive review of scientific evidence and best-practice methods related to prevention initiatives and screening tools, to encourage their appropriate use in clinical practice. The Guidelines will increase the ability of health professionals to offer information and counselling about risks of alcohol consumption prior to conception, throughout pregnancy and while breastfeeding.

These Guidelines represent a significant step forward in the prevention of FASD in Canada. They spell out that no alcohol is the safest choice during pregnancy to prevent alcohol affected births and promote healthier birth outcomes. They also recommend periodic screening for alcohol consumption for all pregnant women and women of child-bearing age by all health care providers. The screening and recording of alcohol use before and during pregnancy is considered to be a practical way to improve maternal-child health outcomes through:

1. early identification and reduction of problem maternal drinking;
2. early identification of exposed infants; and
3. earlier diagnosis of FASD.

Some health care providers feel uncomfortable asking about alcohol use. Others lack knowledge of the alcohol treatment and counseling services available in their community, are pressed for time, or believe that screening for alcohol use is beyond the scope of their practice. These new Guidelines seek to make alcohol screening and support for women at risk a routine part of any visit with a health care professional. It is a tool designed to promote consistent screening and advice that women of child-bearing age receive regarding alcohol use.

The SOGC led the consensus development process for the Guidelines. The Guidelines have been endorsed by the Canadian Association of Midwives, the Canadian Association of Perinatal and Women's Health Nurses, the College of Family Physicians of Canada, Motherisk, and the Society of Rural Physicians of Canada.

Following the publication of these Guidelines, medical education sessions will be offered at conferences and meetings, and a brochure will be developed for health care providers to use with their patients.

For more information about the Guidelines and the Public Health Agency of Canada FASD Initiative please visit: www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php. To view the Guidelines directly visit: www.sogc.org/guidelines/documents/gui245CPG1008E.pdf.

Submitted by: Public Health Agency of Canada



MIKEY

Having a child with FAS is not something that most people disclose joyfully, but in our house, we celebrate all the things which make us different, as well as valuing those which we have in common. Recently at dinner, we were discussing what diagnosis each of us had (FAS, Fibromyalgia, Bipolar etc.) and Mikey asked, "What does Dad have? Does he have grumpy?" I believe that laughter and enjoyment of one another makes our family strong.

Mikey is the youngest of my three boys at almost 15, and his brothers, at 24 and 19, are great role models for him. If Mikey is dubious about any item of food on his plate, we only have to say, "It's very healthy" and he'll eat it all, because his brother Sean believes in healthy eating. Yesterday, he brought me all the coins from his piggy-bank to pay for his food and clothing, because he knows his brother Rory was paying me grocery money while he was working.

Once I learned to apply the best FASD strategies for helping my child with FASD, and in my dealings with the professionals involved, I began to see people working effectively with Mikey. Life became much easier and happier for all of us.

Despite many physical fights and bullying episodes, my son has never been suspended from school. Instead, they look for ways to teach him how to avoid the situation in the future, and ask me to help them think of strategies to prevent such a situation from arising. Last year, we had some unpleasant episodes of racist bullying. The school staff were receptive to the idea that too much freedom on the playground was not a good thing for him, and they instituted a new lunch time routine. When lunch is finished, Mikey hangs out in the gym doing something constructive where the rules are well understood.

Mikey loves to play sports and his dad coaches his soccer team. Each year, the coach tells the rest of the team about Mikey's problems and each year, we have a team of boys who are all trying to help Mikey succeed. At the Championship games this weekend, I overheard some of them talking, saying that Mikey was cool because he can sign, and he's a good soccer player who tries really hard. Before each game, we remind our son about the rules. This has reduced the aggressive play to the extent that he recently came off the field and said, "Dad! You'll be so proud of me! I didn't elbow anyone!"

With so many people both at home and school, giving so much in the way of positive interaction, we have a boy who is confident and self-assured, and becoming his own best advocate. We are indeed, very proud of him.

Submitted by: *Shiona Watson*



Mikey Watson

FACE RESEARCH ROUNDTABLE

Over 125 delegates attended the 11th FACE Research Roundtable in Vancouver on September 14th, 2010. Organized by the Motherisk Program, the day-long conference featured presentations by leading researchers, and vigorous discussion among the delegates. Dr Susan Astley presented comprehensive clinical profiles of 1,400 Washington State residents (birth through adult) who received an interdisciplinary FASD diagnostic evaluation. The dataset demonstrated an array of clinical, research, and public health issues and dispelled some commonly held beliefs about FASD diagnosis. The new national Screening Tool Kit for FASD, a landmark project of the Canadian Association of Paediatric Health Centres (CAPHC) and Public Health Agency of Canada, was unveiled. Results were shared from the Society of Obstetricians and Gynecologists project to develop clinician guidelines for determining maternal alcohol use. The webcast is available at www.motherisk.org/FAR. The 3rd round of CFFAR grants was awarded:

- Catherine Rankin, University of British Columbia, gene expression profile analysis after embryonic exposure to alcohol
- Sara Stevens, Kelly Nash, Joanne Rovet, University of Toronto, social profile of FASD
- Myla Moretti, University of Toronto, fetal effects of low alcohol consumption

Submitted by: Susan Santiago, susan.santiago@sickkids.ca

FASD SKILLS BUILDING

The FASEout-Ottawa project was designed to build and enhance the skills of front-line workers who provide services to women who drink alcohol during pregnancy and/or clients affected by FASD. Ten community organizations participated in the project, representing education, housing, criminal justice, employment, children/family support, addictions and maternal health. Some of the outcomes of the FASEout-Ottawa Project from 2007 to 2009 include: 16 training workshops, 582 people workshop participants, 590 information packages and 3,500 bilingual FASD documents distributed, and the development of training manuals and tools. The project included extensive evaluation with recommendations and participant feedback. A follow-up survey of workshop participants indicated that the greatest barriers to improving services to individuals affected by FASD included the lack of: diagnosis FASD diagnosis, knowledge/skills in professionals, life skill programs, funding, and confirmation of prenatal exposure to alcohol. Funding for this project was provided by the Lucy Grossmann-Hensel Fund administered by the Community Foundation of Ottawa. This project was supported by St. Mary's Home and the FASD Coalition of Ottawa.

Submitted by: Diana Fox, diana.fox@sympatico.ca

SIMCOE TRAVELS TO VANCOUVER

In April 2010, Tonya Millsap and Sally Seabrook of Simcoe County partnered with Diane Malbin to present Simcoe County's FASD Initiative at the 2010 National FASD Conference in Vancouver. Simcoe County has an FASD organizational structure which includes working groups in key priority areas (Prevention/Awareness, Family Support, Diagnosis, Interventions, Youth Justice). Their FASD Leads Group includes 23 service providers/clinicians and parents with a focus on interventions. At monthly meetings FASD leads present cases for consultation and shared learning, problem-solve barriers and issues, and take part in training. The group wishes to acknowledge the funding provided by Ontario Trillium Foundation, Ministry of Children and Youth Services, Child Welfare Secretariat, Eliminating Barriers and Building Successes and six organizations within Simcoe County.

"We all contribute to improved outcomes for those affected and their families – we are better together than apart."

Submitted by: Tonya Millsap, tmillsap@catulpa.on.ca

FASD ACTIVITIES ACROSS ONTARIO

Simcoe County Reaches Students

Sept. 8, 2010 in Simcoe County there was an FASD Awareness Event at Georgian College for college and university students on campus.



Peel Celebrates Babies

Don Herrold stated that, "Babies are such a nice way to start people" and everyone at Peel Children's Centre agrees. With funding from the Ontario Trillium Foundation, they hosted a *Celebration of Babies* on Sept. 9 to raise awareness of the dangers of drinking while pregnant. Posters of cherubic babies with key messages about FASD prevention greeted colleagues in the hallways, prizes were given to those with the most right answers on an FASD quiz, clinicians perused a resource table and selected fact and tip sheets appropriate for their clients, and two guest presenters had rapt audiences.

Kingston Rings its Bells

The Kingston FASD Action Network hosted the first annual FASD Day networking breakfast highlighting International FASD Day. The bells were ringing at 9:09 am in Kingston on Sept. 9th.



London Gives Away Blenders

On Sept. 9th a meet and greet was hosted at Williams Coffee Pub in London by the FASD (Elgin Lambton Middlesex Oxford) Network. Refreshments were available as well as an assortment of snacks and treats. Door prizes consisted of blenders and fancy mocktail glasses. The local radio station was at the event with music and some giveaways. A radio cut-in from the event helped create awareness and drew people down to the event. Mocktails were distributed with FASD educational materials and mocktail recipe booklets. Prepackaged mocktails were included in the giveaway bags.

NEW FASD RESOURCES

FASD Learning Series – Alberta

Online videos of recent presentations about FASD
www.fasd-cmc.alberta.ca/education-training/archived-sessions

New Interactive FASD Online Course

Online videos of recent presentations about FASD
www.nofas-uk.org/OnlineCourse/foetalalcohol.com.htm

FASD TRAINING

TRAINING EVENTS IN ONTARIO:

FASD Peterborough Conference

November 18 & 19, 2010, Peterborough
fasdpeterborough@cogeco.net

The Value of Therapy for Individuals with FASD

November 24, 2010, Mississauga
foundations_training@yahoo.ca

Video Teleconference: Effective Strategies for Supporting Individuals with FASD

Wednesday, November 10, 2010
www.community-networks.ca/uploads/2010%202011VC%20Training%20Schedule%20-%20Multit%20Page%20Flyer%20Style.doc

FASD ONE Provincial FASD Conference

Date and Location TBD
Check www.fasdontario.ca for updates

TRAINING EVENTS OUTSIDE ONTARIO:

4th International Conference on FASD

March 2-5, 2011, Vancouver
www.interprofessional.ubc.ca/FASD.htm

FASD ONE Awards

The 2010 FASD ONE Award winners for Ontario leadership and a significant contribution in the area of FASD include:

Individual Award:

Theone Collins is the adoptive mother of a young woman with FASD and pioneer in FASD in Algoma. She founded the *Fetal Alcohol Information and Support Network* in the 1990's and was a member of the ARBD Committee. Theone was a fearless advocate for her daughter and became an excellent resource for other families and professionals. She provided training about FASD and its management. Theone helped to create brochures and a website at a time when FASD resources were scarce and the disorder was poorly understood.



Agency Award:

The Southern Network of Specialized Care has provided leadership in the field of professional awareness and training. Manager Liz Froese had the foresight to include FASD in the Network's mandate. Her vision and leadership capitalized on the skills of community facilitator Nancy Hall. This has resulted in multiple workshops to diverse professional groups and the development of an FASD education strategy that will increase expertise across the South West district of Ontario. Ideally, this will be shared through the Community Networks of Specialized Care to increase FASD awareness, prevention and effective practice.

Community Award:

FASD Elgin, London, Middlesex, Oxford Network is a group of community agencies, individuals, and service providers in the Thames Valley area. The network has collaborated with the Thames Valley Board of Education and the Southwest Ontario Aboriginal Health Access Center to perform a Needs Assessment / Gap Analysis for southwest Ontario to help inform planning and funding for local diagnostic services. The E.L.M.O. Network also oversees the enhancement of programs and services for families and provides access to training, information and resources.

Feedback about FASD Ontario News:

If you have any comments about this newsletter, or suggestions for future editions, please contact: w.mcallister@healthnexus.ca

www.fasdontario.ca



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Also available in French