

FASD ONTARIO NEWS

THE NEWSLETTER

OF FASD

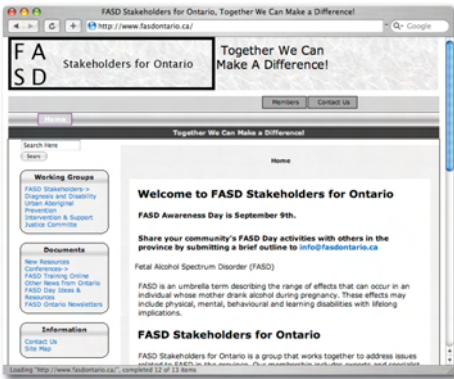
STAKEHOLDERS

FOR ONTARIO

EDITION 3, OCTOBER 2007



New Website for FASD Stakeholders for Ontario



www.FASDOntario.ca

FASD Stakeholders for Ontario is pleased to launch their new website. It will help people in Ontario keep up to date and work collaboratively. The website links people to information about FASD Stakeholders for Ontario, training, networking and support opportunities, as well as new research, resources and services. Visit the website at FASDOntario.ca. If you want your support group, event, training opportunity, or resource to appear on the FASD Ontario website, email info@fasdontario.ca

PURPOSE :

This newsletter was developed by FASD Stakeholders for Ontario to help people in Ontario work together to address FASD. This newsletter reports on the activities of FASD Stakeholders for Ontario and shares news of relevance to individuals, caregivers and service providers who work in the area of FASD across Ontario. Previous editions of FASD Ontario News can be viewed at: www.beststart.org/projects/index.html

Awareness of FASD in Ontario

The Public Health Agency of Canada contracted the Best Start Resource Centre to develop a brief report outlining the implications of awareness survey results to Ontario. Awareness about FASD and the risks of alcohol use in pregnancy is increasing in Ontario. The following messages are well understood by the general public: stopping or cutting back alcohol use in pregnancy is important, prenatal alcohol exposure leads to lifelong disabilities, and there is a direct relation between the level of alcohol use and the risk to the fetus. Some messages are less well understood in Ontario, including the risks of small, occasional and moderate amounts of alcohol in pregnancy, and the developmental, physical and behavioural consequences of prenatal alcohol exposure. Ontario populations with lower levels of FASD awareness include populations with higher socio-economic status, populations that are older than 35, populations with higher levels of alcohol use and men. There is solid general public support for a range of alcohol and pregnancy

warning strategies, government-sponsored advertising, information in clinical settings and in the media. Most women, if pregnant, plan to stop drinking alcohol, although many women indicate that they received no information, or misinformation from their doctor about alcohol use and pregnancy. The majority of men say they would encourage their pregnant partner to stop drinking, but would be less likely to stop drinking themselves. For more information about FASD awareness in Ontario: www.beststart.org/research/index.html

NEW ONTARIO FASD SUPPORT GROUPS

Fetal Alcohol Spectrum Disorder Caregiver Support Group
Location: Sault Ste. Marie
Contact: 1-705-253-1700 ext. 233

Kingston and Area FASD Learning & Sharing Group
Location: Kingston
Contact: etate@kdacl.on.ca

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

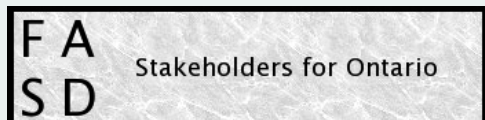
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LOOKING BACK



FASD Stakeholders for Ontario has now been in existence for 2 years, and has completed an incredible amount of work. The working groups have produced many new resources, and provided opportunities for networking, training and support. Collaboration is starting to occur on projects that are beyond the scope of individual working groups.

HIGHLIGHTS OF WORK TO DATE:

Urban Aboriginal Working Group

- Four tele-education training events
- Manual: Initiating and Running a FASD Clinic
- Asset mapping of urban Aboriginal services re: FASD
- Reprinted: FASD Tool Kit for Aboriginal Families
- FASD housing study
- Manual for families on the process of FASD diagnosis
- Camp Resource Guide

Prevention Working Group

- Printed: Nurturing Change manual
- DVD version: Different Directions videos
- Forum: Prevention of FASD: Addressing Pregnancy and Addiction

Intervention & Support Working Group

- Two camps for children with FASD and their families
- Reports about the FASD camps

Diagnosis & Disability Working Group

- Report: Creating a Foundation for Diagnostic Capacity
- Video teleconference and face to face meetings of Ontario diagnostic clinics
- Study on the incidence/prevalence of FASD in Ontario
- Paper on the role of parents in the diagnostic process

Justice Committee

- CD for Justice about FASD
- Website for Justice about FASD

For more information about FASD Stakeholders of Ontario contact: Sheila Burns, Chair at info@fasdontario.ca

LOOKING FORWARD

In October 2007, FASD Stakeholders of Ontario met in Toronto with the FASD Intergovernmental Action Network of Ontario (FIANO) to discuss issues of interest to both groups. This meeting was made possible through funding from the Public Health Agency of Canada, Ontario Region. The Ontario Federation of Indian Friendship Centres helped by arranging for meeting space, AV, food, photocopying and an opening and closing ceremony. As a result of this meeting, FASD Stakeholders of Ontario has decided to concentrate on the following areas over the next year:

- Developing awareness materials about alcohol and pregnancy for Aboriginal people
- Sponsoring families affected by FASD to attend an Aboriginal mental health conference
- Developing awareness materials for women who drank alcohol before they knew they were pregnant
- Increasing FASD diagnostic capacity through online training and tele-medicine
- Investigating ways to train people to run FASD family camps
- Updating and promoting the FASD Justice website

NATIONAL FASD NEWS

New National Online Training for Health Care Providers:



We are pleased to invite you to an important CME event titled "Fetal Alcohol Spectrum Disorder (FASD) Module 1: Preventing and Addressing Alcohol Use in Pregnancy." This free program consists of an online learning module worth three (3) MainPro M1 credits or three (3) Category 1 credits. The course is also available as a DVD/CD if required.

To register go to: www.MDcme.ca



National Listserv has New Name

VON Canada's national listserv **FASD National Link** has changed its name to **FASD Canadian Link** to reflect its Canadian content and membership. This listserv is a place to share information and connect with other people working in the field of FASD across Canada.

http://lists.von.ca/mailman/listinfo/fasd_canadian_link

New Canadian Foundation on Fetal Alcohol Research

The Canadian Foundation on Fetal Alcohol Research (CFFAR) is an independent, non-profit foundation created to promote interest and fund research related to the short and long-term effects of alcohol use during pregnancy, and the prevention of FASD. It is the single largest non-governmental source of funding for FASD research in Canada. The foundation was launched in September 2007 through a five year \$1 million commitment by the Brewers Association of Canada. CFFAR awards research grants to eligible Canadian researchers annually.

www.fasdfoundation.ca

National FASD Projects Fund

Here are a few in-progress national initiatives funded through the National FASD Strategic Projects Fund:

- The Society of Obstetricians and Gynaecologists of Canada was funded to establish national consensus on screening women of child-bearing age and pregnant women for alcohol use.
- Canadian Association of Paediatric Health Centres was funded to determine the effectiveness of screening tools used to identify children for referral to an FASD diagnostic service, and to develop recommendations or a toolkit about screening tools.
- Canadian Centre on Substance Abuse was funded to improve the practice and impact for FASD training in Canada, and to provide access to trainers and training programs through a web-based tool.
- Pregnancy Related Issues in the Management of Addictions (PRIMA) and the Centre for Mental Health and Addiction (CAMH) was funded to develop guidelines, training and resources for care providers who work with pregnant women who struggle with substance use.

TIPS ON RUNNING FASD SUPPORT GROUPS



FASD support groups have been designed for adoptive and foster parents, birth mothers and for youth who have FASD. They are a hub for information sharing, compassion, friendship and mutual support. Some are led and funded by service providers, but most are organized by parents with little or no budget.

Parents who have a child with FASD can benefit from talking with parents in similar situations. Parents can share tips and coping strategies, encourage each other and laugh together. Support groups can help link participants to needed services and can provide up to date information that is timely and appropriate to current developmental strengths and challenges.

Many FASD parent support groups start with 1-3 keen parents who want to connect and share with other parents of children with FASD. They typically meet once or twice a month. Some groups have guest

Top 5 Tips for FASD Support Groups

1. *Keep the date and time consistent*
 2. *Do fun things together, share a snack or meal*
 3. *Visit other FASD support groups*
 4. *Establish guidelines for discussion*
 5. *Ensure that all participants have a task*
-

speakers, view and discuss videos and have facilitated discussions. They may also work together to address common concerns, such as raising awareness about FASD or advocacy for needed services. Other groups focus on free discussions about current parenting challenges.

A new support group may want to start with small goals, and build to more ambitious strategies as strength and numbers increase. It is helpful to revisit the purpose and expectations annually. Decide together who will lead the group, and for how long, and how other tasks will be accomplished (ie setting the agendas, making coffee, setting up chairs, cleaning up etc). As new members join the group, clarify the goals or purpose of the support group, and discuss participant expectations such as confidentiality.

Top 5 Challenges for FASD Support Groups

1. *Bringing the initial group together*
 2. *Choosing a day and time that works for the participants*
 3. *Recruiting new participants*
 4. *Reducing the stigma of FASD*
 5. *Keeping the experienced members coming back to help the new members.*
-

Partnerships can have many benefits. Partners may be able to contribute a speaker, group activity, photocopying, coffee supplies or meeting space. The meeting space should be central, suitable for confidential discussion, comfortable, accessible to people with disabilities, close to city transit and have adequate parking.

It is important to decide how the group will grow – do you want a closed group, with additional members added only by invitation, or do you want to advertise publicly? You can promote your support group through word of mouth, by talking to service providers, though public service announcements or flyers. Most support groups have periods of time where participation is low or high. Your support group may need to split in 2, or you may need to start promoting. Low numbers can be due to

seasonal activities, the need for a change in meeting location or time, changing family needs, or day to day challenges. Touch base with participants regularly to ensure that the group is meeting participant needs.

From time to time you will have parents in your support group who are upset, angry, frustrated or overwhelmed by the worries and challenges of parenting a child with FASD, or the struggles to access appropriate services. Conflicts can also occur in support groups. Think about the sort of individual and group responses that would be helpful and unhelpful in these types of situations. For example it can be helpful to listen respectfully, ask questions, ask what they need, offer to do some research, follow up by phone after the meeting, or respect that there are a range of effective approaches and opinions.

“The support group that Wabano hosts, has greatly improved my life. I look forward to seeing them each month, they have become a part of my life. I have gained so much knowledge from the group, as they are the ones living with FASD every day. They have also become important in each other’s life, they have made friends, and do other things outside of the group. It is an informal group, it feels like we are sitting at home, talking around the kitchen table.”

Cindy Peltier, Wabano Centre for Aboriginal Health

“Keep in mind that by helping others you will help yourself.”

Brian Philcox, FASworld

HELPFUL FASD SUPPORT GROUP RESOURCES

Fetal Alcohol Syndrome support group: A six module curriculum

Society of Special Needs Adoptive Parents (SNAP), 2002
www.snap.bc.ca

Guidelines for a Great FASD Support Group

FASworld, <http://fasworld.com/supportgreat.asp>

Start a Local FASD Support Group

FAS Community Resource Centre, 2003
www.come-over.to/FAS/SupportGroup.htm

Self Help and Peer Support Strategies in Maternal Child Health

Best Start Resource Centre, 2005
www.beststart.org/resources/howto/index.html

Self-Help for Parents of Children with Special Needs: A Tool Kit for Parents and Professionals

Canadian Association of Family Resource Programs, 1998
www.frp.ca

Frameworks and Skills for Keeping Self-Help Groups on Track

Ontario Health Promotion E-Bulletin, Feb 11, 2005
www.ohpe.ca

Self-Help Groups: Moving from Professional Leadership to Mutual Support

Ontario Health Promotion E-Bulletin, Feb 7, 2003
www.ohpe.ca

Parent-to-Parent Support Manual for Group Leaders

Parents for Children’s Mental Health, 2004
www.parentsforchildrensmentalhealth.org

Tips for Parent Support Groups

Parents for Children’s Mental Health, 2006
www.parentsforchildrensmentalhealth.org

Self-Help Resource Centre

A provincial resource centre with a wide range of workshops, resources and services.
www.selfhelp.on.ca

FASDay 2007 – Events Across Ontario



London: Mocktail Madness

On September 6, Southwest Ontario Aboriginal Health Access Center, Children’s Aid Society and Middlesex London Health Unit participated in the first ever Mocktail Madness event at a local restaurant/bar, Barney’s. A celebrity bartender prepared three different alcohol-free beverages and served to a late afternoon crowd seeking relief from high temperatures and humidity. This activity was planned to create awareness about Sandy’s Law and International FASDay. In addition, on September 9th, a fun filled demonstration was organized at the Western Fair with two half hour stage presentations. Fair goers had the opportunity to enjoy free samples of mocktails and a chance to win assorted prizes. A Candlelight ceremony was held at a London park the evening of September 9.

Wawa: Display, Resources and Discussion

In Wawa, Superior Children’s Centre’s Ontario Early Years Centre recognized September 9 as FASD Awareness Day. A display was created and many resources with facts and information on FASD were made available to the public. The display included videos, DVD’s, books, handouts and FASD awareness ribbons and bracelets. As well, the Pre and Postnatal Drop In Programs made FASD their topic of discussion for the week. Resources and activity sheets were handed out emphasizing the message that no amount of alcohol is safe during pregnancy.



Six Nations: FAScinating FASd MAZE

The Six Nations of the Grand River community had two events including the Annual “Try Hugs Not Drugs Day” and the “September Fall Fair”, where the Degowadihsnye / FASD and Child Nutrition Program set up a Fascinating FASd MAZE event. The maze enabled participants to get a first hand experience of some of the daily challenges a person with FASD might experience. It took participants about 10 - 15 minutes to complete the 12 stations in the maze. Each station offered an activity that might cause frustration, comprehension, memory and recall difficulties, gross and fine motor challenges, as well as sensory overload involving sight and sound and even test anxiety. All of these are repetitive constant hindrances that may aggravate a person living with an FASD. People with FASD are often judged, scolded, punished and shunned, when all the while, unrealistic expectations are placed upon them to function, learn, behave and get along with others. Clearly the sustained brain damage from prenatal alcohol exposure is the contributing cause, along with society’s lack of knowledge about FASD and the need to adjust expectations, provide necessary support and an altered environment. Once participants completed the maze, they were given a brochure explaining the challenges. One of the biggest irritants for the participants was the medical glove that they had to wear on their writing hand.

Kingston: TV and Radio Interviews

The FASD Action Network Committee (service support providers in Kingston) were very busy during the week leading up to International FASD Day 2007. The main focus was television and radio interviews of public health nurse, Nicole Szumlanski and a parent of an adopted FASD child, Marg Palmer who leads the FASD Support Group in the Kingston Area. The interviews were well received and messages about alcohol-free pregnancies and the need for more local FASD diagnostic services were discussed. Displays with FASD resources and an FASD quiz were set up in approximately 15 local organizations. Alcohol-free messages appeared on electronic boards throughout the city.



FASD committee members at Mocktail Event at the Sault Ste. Marie Station Mall Ontario Early Years Centre on September 7 in observance of FASD Day.

Wikwemikong First Nation: Keynote Address by Joseph Cloutier



Wikwemikong First Nation Band Councilor Margaret Manitowabi gives Joseph Cloutier a congratulatory show of support on September 9th, 2007. She is joined by Early Childhood Development Coordinator Rachel Manitowabi (left), who also coordinated International FAS Awareness Day awareness activities held in the community. In a powerful keynote address, Joseph shared his life and struggle with FASD. He also announced his intention to walk from his home community of Sagamok Anishnawbek to the Parliament Buildings in Ottawa, next year. His goal is to arrive in on September 9th, in time to join the International FAS Day March to Parliament which has become an annual event hosted by the Wabano Centre for Aboriginal Health. Joseph plans to dedicate the Awareness Walk to the memory of his mother and hopes that all FASD Programs and services will join him in his bid to raise awareness.



Durham Region Health Department hosted an FASD 101 Lunch and Learn sponsored by FASD Durham Committee on September 6, 2007. Trina Bell from Pinewood Centre and Michelle Michener from Durham Mental Health Services were the presenters.

Opportunities for FASD Prevention Activities

- January – New Years
- February – Valentines Day
- March 8 – International Women's Day
- April 7 – World Health Day
- May – Mothers Day
- May 15 – International Day of Families
- June 26 – International Day Against Drug Abuse
- August 12 – International Youth Day
- September 9 – International FASD Day
- October 10 – World Mental Health Day
- November 20 – Universal Children's Day
- December 3 – International Day of Disabled Persons
- December 10 – Human Rights Day
- December – Holiday Season

FASD Newsletters

Network News

FASD Support Network
of Saskatchewan Inc
www.skfasnetwork.ca

Frontline: FASD newsletter

Region 6 FASD, Alberta
[www.region6fasd.ca/
newsletter.php](http://www.region6fasd.ca/newsletter.php)

Iceberg

FAS Information Service, USA
www.fasiceberg.org

FAS Times

FAS Family Resource
Institute, USA
[http://fetalalcoholysndrome.
org/times.htm](http://fetalalcoholysndrome.org/times.htm)

SAMSA News

Substance Abuse and Mental
Health Services, USA
[www.samhsa.gov/
SAMHSA_News/index.htm](http://www.samhsa.gov/SAMHSA_News/index.htm)

Feedback about FASD Ontario News

If you have any comments
about this newsletter, or
suggestions for future editions,
please contact:

w.burgoyne@beststart.org

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Public Health Agency of Canada. The
opinions expressed in this publication
are those of the authors and do not
necessarily reflect the views of the
Public Health Agency of Canada or the
government of Ontario. Resources and
services mentioned in this publication
are not necessarily approved or endorsed
by the Public Health Agency of Canada
or by the Best Start Resource Centre.

Also available in French

NEW FASD RESOURCES

Breaking the Cycle, Measures of Progress 1995-2005

Mothercraft
[www.motherisk.org/JFAS_documents/
BTC_JFAS_ReportFINAL.pdf](http://www.motherisk.org/JFAS_documents/
BTC_JFAS_ReportFINAL.pdf)

Mocktails for 2 pamphlet

Distributed by
Timiskaming
Health Unit
French/
English [www.
timiskaminghu.com](http://www.timiskaminghu.com)



“It’s Just Not Worth the Risk” Campaign

Bookmarks, Posters,
Banner, Table Tents
Porcupine Health Unit
Contact: [normac@
porcupinehu.on.ca](mailto:normac@porcupinehu.on.ca)

Highs & Lows

Canadian Perspectives on Women and Substance Use

Nancy Poole and Lorraine Greaves, Ed
B.C. Centre of Excellence for
Women’s Health & Centre for
Addiction and Mental Health
[www.camh.net/Publications/
CAMH_Publications/highs_lows.html](http://www.camh.net/Publications/
CAMH_Publications/highs_lows.html)

This is Me: New Tool For Learning About and Working with People Affected by FASD

Printed guide and interactive CD
Manitoba Interdisciplinary
Development Team
www.mefasd.com

Enhancing Patient Care: Clinical Approaches to Addressing Alcohol Use During Pregnancy

Saskatchewan Prevention Institute
Contact: info@preventioninstitute.sk.ca

FASD TRAINING

TRAINING EVENTS IN ONTARIO:

FASD in our Schools, FASAT
October 25 - 26, 2007, Guelph, ON
www.fasat.ca

Can’t Not Won’t
FASD Coalition of York Region
October 30, 2007, Newmarket, ON
alewis@bluehillsschildandfamily.ca

Caregivers of FASD Mini-Conference
The Hamilton Task Force on FASD
November 9, 2007, Stoney Creek, ON
Contact: agrom@ascy.ca

**Recognizing Personal Losses While
Caring for Those Affected by FASD**
November 10, 2007, Toronto, ON
Contact: stadeb@smh.toronto.on.ca

Canadian Congenital Anomalies
Surveillance Network Scientific Meeting
November 18-20, 2007, Ottawa, ON
[www.phac-aspc.gc.ca/
ccasn-rscac/index.html](http://www.phac-aspc.gc.ca/ccasn-rscac/index.html)

KEY TRAINING EVENTS OUTSIDE ONTARIO:

**Third National Biennial Conference
on Adolescents and Adults with FASD
FASD and Mental Health:
The Wisdom of Practice**
April 10-12th, 2008
Vancouver, BC
[www.interprofessional.ubc.ca/
Adults.html](http://www.interprofessional.ubc.ca/Adults.html)

**Canada Northwest FASD
Partnership Conference
Building on our Strengths:
Stone by Stone**
May 21 - 24, 2008
Banff, Alberta
www.cnfasdpartnership.ca/index.cfm

ONLINE:

**FASD Module 1: Preventing and
Addressing Alcohol Use in Pregnancy**
www.mdcme.ca