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Sharing ideas, information, resources, struggles & successes

### HAPPENINGS

## **Annual FASD Conference**

by Lucy Muswagon, Norway House FASD coordinator

We had another successful FASD conference, which took place from February 14 to 15, 2012.

The presentations varied, covering topics from FASD education to life stories. The real-life stories made a big difference, as they were informative, educational and very interesting.

Participants enjoyed the personal stories the most, according to the feedback we received from the evaluation forms. Some of the other feedback included requests to have more conferences throughout the year, although cost is an issue with making that happen.

Throughout the conference, prizes were given away and a silent auction was held. Prizes included a TV, handmade quilts, knitted mitts, hotel accommodations, and more.

I want to thank the participants, the volunteers, the presenters, and most of all, the two mentors, Nancy Apetagon and Madeleine Muskego. I'd also like to give a big thank you to the caterers, Iona Muminawatum and Tamer Crate of 373 Roadhouse, for the delicious meals. Another thank you goes out to our photographer, Val Balfour.

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#### **VOLUME 7** NUMBER 1

disseminate current information about Fetal Alcohol Spectrum

FASD to share ideas, information, regular meetings, special events, the MCAP website and this published newsletter. MCAP receives funding support from Healthy Child

MCAP News Summer 2012 Please share this newsletter with your network

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### HAPPENINGS



Continued from cover

We ended the conference with a Valentine's Day dinner, sponsored by the Maternal Child Health Program. Thank you to Christine Queskekapow, the program's coordinator.

There was also a small fashion show hosted by the Northern Store. Thank you to Melinda York for her assistance with the show.

I also want to thank the Burntwood Parent-Child Centred Coalition Committee for its financial assistance, which offset some of the cost to host this twoday event. As the coordinator, I find each year that a two-day conference seems too short. Maybe with God's will we will host a threeday conference and co-host with internal and external resources in the future.

Once again, thank you to everyone who attended and to all the volunteers.

## Healthy Child Manitoba Office Update

by Eric Friesen, Healthy Child Manitoba Office

The HCMO is committed to moving forward with the provincial FASD strategy and its goals, which include access to support and services for families of individuals with FASD. On March 15, the HCMO hosted a workshop for caregivers of individuals with FASD at the Mennonite Heritage Village in Steinbach, Manitoba, which was attended by 100 caregivers and support workers.

The event featured guest speakers Myles Himmelreich from Alberta and Jaysun from Manitoba, who delivered inspiring and hopeful messages as two adults with FASD. We would also like to thank Cathe, Sue, Dorothy, Anita, Gina, Doug, Leanne, Anne and Bronwen, who formed the planning committee. The

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hard work and wisdom of these caregivers and service providers resulted in a truly magnificent event for all the families that participated.

From April 18 to 21, members of the FASD team from the HCMO had the opportunity to attend the fifth National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder in Vancouver. There were several presentations that focused on the event's theme "It's a Matter of Justice."

Some of the highlights included the Honourable Justice Murray Sinclair and his thoughts on FASD as a legacy of the residential school system, and the young adults with FASD who courageously shared their experiences and feelings about FASD. Manitoba was wellrepresented with presentations from the FASD Youth Justice Program, the CHOICES program, the FASD Centre and the Youth Accommodations Counsel Project. Good job, Manitoba!

On May 2 and 3, the HCMO, with funding from the Public Health Agency of Canada, hosted a second national working meeting to further develop the details of a national FASD prevalence plan. At this meeting, a position paper and video for garnering political and system buy-in were discussed and revised. The goal of this work is to achieve an accurate count of how many people living in Canada and Manitoba have FASD. A report on the meeting will be available in June. This spring, the HCMO was also pleased to assist the Addictions Foundation of Manitoba (AFM) library in updating its special collection on FASD materials.

The AFM loans numerous current resources, including books, articles and videos for Manitobans at no cost (shipping may apply to those outside of Winnipeg). To access the library, please call **1-866-638-2568** or visit the AFM's website at www.afm.mb.ca.

## It's a Matter of Justice Thoughts about the 5th National Biennial Conference on Adolescents and Adults with FASD

by Dee Harvey, coordinator of The Pas Insight Mentoring Program

From April 18 to 21, I, along with other Insight staff members from Manitoba, had the fantastic opportunity to attend this informative and educational conference held in beautiful Vancouver. The conference offered a wide variety of sessions to choose from, and provided different perspectives on the scope and impact of FASD.

There were many highlights, particularly as FASD was

discussed in both a professional and personal context. One that stands out is the panel discussion of individuals with FASD. This Is What We Think was the title of their discussion, and they spoke candidly about how FASD impacts not only their own lives, but also the community. Their honest and open viewpoints about FASD captivated the audience. Each panel member's presence and personality shone through, emphasizing the reality of FASD. I had the privilege of presenting at the conference, along with Noelle Gentes, Insight coordinator at Winnipeg's Aboriginal Health & Wellness Centre. It was an amazing opportunity to share the Insight program with those interested in learning more about what we do and why we do it. We spoke about working with women who live with FASD and how our interactions are shaped by their challenges and successes. A big thank you goes out to Healthy Child Manitoba and our individual workplaces for the support and resources that allowed us to attend the conference. This conference gave so many individuals the chance to network and connect with others about the wide-ranging effects and experiences associated with FASD. The collective experience reflects the event's theme, It's a Matter of Justice.

# Visions and Voices Program Update

by Christina Reinke, program coordinator, Visions and Voices

Operating within the Touchstone FASD Program, and under Initiatives for Just Communities, Visions and Voices is a speakers' bureau comprised of adults who live with FASD. Our speakers share their personal stories with a wide variety of audiences, thereby mobilizing community capacity and creating public awareness of FASD at a grassroots level.

As part of Manitoba's five-year FASD strategy, we are especially pleased that Visions and Voices recently received annualized funding though Healthy Child Manitoba. With this funding, the program has experienced new growth and some exciting opportunities.

As the new program coordinator,

I have had the pleasure of being on the ground level of this expanded initiative.

Since January, three new speakers have been added to the existing six speakers in the bureau. In order to prepare our speakers for future events, we hosted a one-day workshop for the new speakers and their persons of support, followed by a meet-and-greet group gathering with our more experienced participants. These gatherings are a highlight for many of our speakers, and it is neat to see the group rapport that continues to develop within the bureau.

Visions and Voices has also had an

opportunity to present to a wide variety of audiences. Most recently, two of our speakers presented at a training series for camp counsellors, and were able to share possible strategies and accommodations for children and youth living with FASD as they attend camp this summer. Andrew Hayes, Faith Bible Camp program coordinator, says the experience was positive. "We have had excellent feedback from all our attendees, and feel it was a really beneficial time for all involved," he explains.

Heading into the fall season, we are looking forward to seeing our speakers continue to impact more and more audiences, and to grow in their self-knowledge and understanding as adults who live with FASD. I have had the privilege of consistently witnessing how the storytelling experience expands the learning experience for all parties. Not only does the audience learn something new, but the speakers themselves also continue to learn and develop their abilities. As such, Visions and Voices is excited to be a part of Manitoba's FASD initiative.

If you have any questions about the Visions and Voices program, please contact Christina Reinke at by phone at **204-925-2000** or email **creinke.fasd@initiativesjc.org**.

# FASD Events Sponsored by MCAP

by Colleen Tower, MCAP

In February, 2012, MCAP issued a request for proposals to FASD groups and coalitions who work at addressing FASD in their community. Successful applicants have access to one-time funding, which will assist them in hosting an FASD Day event or activity in September.

In their applications, groups were asked to describe how they would meet a short list of criteria. A large part of that criteria involved describing the project or activity the group was planning, who the target audience would be, and how the project or activity would promote FASD awareness.

Successful applicants are required to write an article summarizing the event for MCAP's fall newsletter. Following are the six groups who were chosen to receive the funds and a short description of their plans:

Waywayseecappo Health Centre will host a march/walk on Sept. 20, which will include a drum group, a guest speaker, an information booth focused on healthy choices in pregnancy, and a community lunch.

Burntwood Regional FASD Committee will hold a community barbecue, where attendants will have a chance to spin the "Wheel of FASD" and answer a skill-testing question to win a prize.

Brandon Interagency FAS/FAE Committee will host a walk, barbecue and resource fair. The walking route will have signs with information about FASD posted along the way and participants will have the opportunity to share their ideas about FASD events they would like to see in the future.

**Pinaymootang Health Centre** will host a walk, delivering door-todoor flyers along the way. A talent show will be held to entertain participants and lunch will be provided. There will also be guest speakers and an art contest for young students.

The Portage and Area FASD Coalition will host a one-day seminar called FASD & Justice: Supporting Children at Risk. This presentation by Corey La Berge will be open to the public. The Pas and Area FASD Committee will use Sept. 9 as a day to highlight an ongoing project, which involves encouraging licensed establishments to provide nonalcoholic beverages at no charge to pregnant women.

Everyone who is interested in promoting FASD awareness is encouraged to get out and support their local events to ensure that they are a great success.

Congratulations to all and we look forward to hearing all about your events in the special fall edition of the MCAP newsletter!

# upcoming events

### **SAVE THE DATE!**

### FASD Awareness Day Event

Monday, Sept. 10, 2012 5pm to 7pm

A committee is working to plan an event that will highlight FASD Awareness Day. More information from the Interagency FASD Program will follow regarding the location and activities.

#### Sharing the Knowledge FASD Conference November 6 & 7, 2012 Dauphin, Manitoba

Who should attend: Healthcare providers, foster parents, educators, justice, caregivers, community leaders and advocacy groups.

Registration and more conference information to follow!

The South Parkland FASD Coalition invites new members to join us! Contact Twyla Gilroy at **204-638-3054** Brought to you by the South Parkland FASD Coalition.

### **BEST PRACTICES**

## **Traditional and Western World Views on FASD and Strategies Conference**

by Betsy Kematch, Insight Mentoring Program Supervisor, Portage Friendship Centre

The Portage Friendship Centre hosted the Traditional and Western World Views on FASD and Strategies Conference from November 15 to 17, 2011, at the Canad Inns hotel in Portage La Prairie, Man.

The Portage Friendship Centre's Insight Mentoring Program was able to offer free registration. Approximately 250 people took part.

We had Elder Linda Blomme of Winnipeg do the opening prayer, and she also sang a drum song. Stuart Alcorn, executive director of the Portage Friendship Centre, introduced Jim Rondeau, provincial minister of Healthy Living.

We invited Dr. Chudley from the Health Sciences Centre (HSC) in Winnipeg. He spoke about what FASD is, the common features, and the emerging research on prevention and intervention. Dr. Lori Vitale-Cox, from New Brunswick, spoke about a community approach to FASD using the medicine wheel concept. She addressed maintaining cultural identity in the screening, diagnostic intervention and prevention of FASD. There was also a questionand-answer period from the panel, which consisted of Dr. Chudley and Dr. Vitale-Cox.

The following day, Dorothy Schwab from Winnipeg's FASD Centre did a presentation on FASD strategies for earlier years and youth.

Dr. Sally Longstaffe, from HSC's Children's Hospital, spoke about her FASD research, and worked with Justice Mary Kate Harvie to present about criminal justice in the court system for victims with FASD.

Dr. Lewis Mehl-Madrona, from Brattleboro, Vt., talked about the imbalance of health in those with FASD. Sue Mozden, from Southern First Nations Network of Care in Winnipeg, presented about FASD in the child welfare system. Sue spoke of the medicine wheel concept, which uses four elements to promote a healthy lifestyle.

Dr. Michael Hart, who works at the University of Manitoba, also presented at the event.

From Healthy Child Manitoba, Jill Isbister presented the Insight Mentoring Program. The program is a three-year, intensive service for women 18 years of age and older who are pregnant or who have recently given birth, and who have used alcohol or drugs throughout their pregnancy. This program uses an approach that reduces the harm associated with alcohol and other drugs and substances. The program supports and empowers women to achieve their goals.

On the last day of the event, Belinda

VandenBroeck spoke about the impacts of residential schools and colonization.

During the conference, break-out room sessions were held on the main floor of the hotel. There was an elder panel each day, with First Nations elders discussing lifestyle and parenting. Visions and Voices shared the stories of youth and young adults living with FASD. Angela Roulette, an Insight mentor, spoke to the audience as well.

We received good feedback and suggestions for the next conference. Most folks wanted to hear life stories of FASD-affected individuals.

Thank you to everyone who participated in this event.

# Manitoba Announces Province-wide Expansion of FASD Services by Eric Friesen, Healthy Child Manitoba Office

Manitoba will double the capacity of a respected FASD support program and expand FASD diagnostic capacity in northern and rural communities with new funding for its five-year FASD strategy, Children and Youth Opportunities Minister Kevin Chief announced. "Manitoba is recognized as a leader in the area of FASD diagnosis and treatment across Canada," said Chief. "Our continuing investments will help ensure that people living with FASD and their families have the supports they need to succeed in their communities, wherever they live in the province." Manitoba's five-year FASD strategy is now in its fifth year and the 2012 budget will add nearly \$500,000 to the strategy for a total investment of \$13.3 million.

Part of the new funding will go to doubling to the capacity of Stepping Out on Saturdays, a respite and socialization program for children and families affected by FASD that are involved with Manitoba Child and Family Services. The funding will also be used to expand multi-disciplinary FASD diagnostic capacity within rural

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## **BEST PRACTICES**

Continued from page 5

Increased capacity will provide more access to diagnostic services and peer support, says Chief

and northern areas of Manitoba. Multi-disciplinary diagnostics is a proven approach that ensures children affected by FASD have early support services tailored to their specific needs.

"Manitoba FASD Centre staff members are profoundly grateful and enthusiastic for the opportunities of expanding FASD diagnosis in Manitoba," said Dr. Sally Longstaffe, medical director of the Manitoba FASD Centre and the Manitoba FASD Network. "We are equally eager to work collaboratively in enhancing diagnostic capacity both here at the Manitoba FASD Centre and within the rural and northern communities. This will be greatly beneficial for families across the province."

There will also be new funding for projects that address awareness and prevention, diagnosis, intervention and support, community engagement, research and training, such as:

- Support for Visions and Voices, a public speaking program for adults with FASD.
- Services for youth and adults with FASD in rural and northern areas.
- Support for The Mothering Project, a new drop-in program launching in 2013 that will offer a variety of supports for women who use substances and are

pregnant or have young children.

- Expansion of the Youth Justice Program.
- Additional direct service support for children, youth and families in Winnipeg.
- A new FASD Parent Support Program to help families and service providers outside Winnipeg understand FASD and connect effectively with local supports and services.
- Funding for community coalitions across Manitoba to network, share ideas and successes, and learn about current FASD research and best practices.
- Expansion of research capacity.
- More training opportunities for a variety of direct service providers.

In April 2007, the Government of Manitoba announced a FASD strategy developed by an interdepartmental committee in consultation with experts and community stakeholders. "The strategy builds upon existing multidepartmental, multi-million-dollar prevention activities and service supports available for individuals with FASD throughout their lives," said Minister Chief.

# **Conflicting Messages About Drinking During Pregnancy**

by Colleen Tower, Insight Program Co-ordinator Flin Flon Primary Health Care Centre

Canada's low-risk alcohol drinking guidelines read, "the safest option during pregnancy, when planning to become pregnant or before breastfeeding, is to not drink alcohol at all." However, you may hear some say they were told a drink a day or a few drinks a week are fine. A recent Danish study even declared that a pregnant woman could drink up to eight alcoholic beverages a week without affecting her child's intelligence or activity

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levels. While most women will still choose to quit drinking alcohol while pregnant, these conflicting messages might influence the choices some make.

An article by Susan Astley, PhD., and Therese Grant, PhD, explains why the message should still be that the way to have the healthiest baby possible is by not drinking alcohol while pregnant or trying to become pregnant. They explain the Danish

#### study this way in their article:

Mothers were interviewed during pregnancy about their alcohol use, and about half of them agreed to participate in the follow-up study five years later. The researchers studied 870 preschool children whose mothers reported drinking during pregnancy and compared them to 758 preschool children whose mothers reported not drinking during pregnancy. They measured the children's IQs and attention levels at age five. Children exposed prenatally to one to eight drinks per week had the same IQs and attention levels as children with no exposure to alcohol.

The reason the children in this study did not appear to be harmed by the alcohol is because the children were too young to measure the full impact alcohol may have had on their brains.

### **BEST PRACTICES**

"At five years of age, the brain is still developing. A five-year-old's brain is not developed enough to perform complex tasks like remembering and following multiple instructions, writing an essay, communicating abstract ideas effectively, (or) exercising good judgment.

Over thirty years of research on fetal alcohol syndrome (FAS) confirms that alcohol has its greatest impact on complex brain functions. This is why children exposed to and damaged by prenatal alcohol exposure look deceptively good in the preschool years. The full *impact of their alcohol exposure will not be evident until their adolescent years.*"

The statistics Astley and Grant provide from the Washington State FAS Diagnostic & Prevention Network further show what the Danish study was missing. "One out of every seven children diagnosed with FAS (the most severe outcome caused by prenatal alcohol exposure) had a reported exposure of one to eight drinks per week," the report explains.

> "Half of the children with FAS had developmental scores in the normal range as preschoolers;

however, all had severe brain dysfunction confirmed by age ten."

Only ten percent of the children with FAS had attention problems by age five, while sixty percent had attention problems by the age of ten.

Only thirty percent of the children with FAS have an IQ that is below normal, but one hundred percent had severe dysfunction in other areas like language, memory and activity level.

The Danish study did not conduct FAS diagnostic evaluations on the

children in its study. It only assessed preschoolers, and only looked at attention problems at age five—it did not assess attention at a later age, nor did it look at dysfunction in other areas such as language, memory or activity level.

So, while the messages women get may sometimes be confusing, the reality is that the only way we know right now to have a healthy pregnancy—free from the effects of FASD—is to stick with the Canadian guidelines and not use alcohol during pregnancy. *source: fasdprevention.wordpress.com* 



## **Recommended Websites**

The following are FASD-related websites that are recommended by members of MCAP.

## *Girls, Women, Alcohol and Pregnancy* www.fasdprevention.wordpress.com

This website is sponsored by the Canada FASD Research Network. It features at least one new post a week on what is happening with FASD prevention in Canada and around the world, including the latest research, new campaigns, successful programs and what celebrities and the media are saying. It also has two years of archived posts to refer to.

This site is for service providers, students, researchers, policy makers and advocates. It is my go-to website to keep current on what is happening in the world of FASD—and Manitoba has been featured a few times!

-Jill

#### Provincial Outreach Program for Fetal Alcohol Spectrum Disorder www.fasdoutreach.ca

Based in Prince George, B.C., this site has some excellent short educational videos as well as a multitude of resources for teachers. Many of the resources can be downloaded at no charge.

-Rodney

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## *The National Adult Literacy Database (NALD)* www.nald.ca

This website offers information and resources for adult educators and employers. It has an online library, which houses some FASD-related resources. It also provides several resources on strategies and building success around employment. I like the site because it allows me to see what ideas and resources are coming out across Canada, and I can download the resources for free.

-Kim

Other Helpful FASD Resources

#### DVD FASD and the Criminal Legal System—Are We Criminalizing Disability?

Available for \$40 on the Minga Marketplace website (www.mingamarketplace.com), this DVD was made by the University of Victoria School of Social Work.

The DVD discusses key issues that relate to FASD and the legal system. It focuses on the need for diagnosis, long-term support and accommodation for those living with FASD.

Online Video *The Circle of Hope Birth Mothers Network* 

This video can be found on the National Organization on Fetal Alcohol Syndrome's (NOFAS) website at www.nofas.org/Circle\_ of\_Hope\_Videos.aspx.

## The *Hidden Disability* Brochure

The Interagency FASD Program of New Directions for Children, Youth, Adults & Families has developed a new FASD resource for caregivers, service providers and the community.

The brochure, called *The Hidden Disability*, is meant to be a userfriendly, concise overview of FASD. It includes information about FASD, alcohol and pregnancy, strategies for success, a story of hope and a list of resources.

For copies of this brochure, please contact the Interagency FASD Program by calling **204-582-8658** or emailing **IFASD@newdirections.mb.ca.** 

A minimal fee may be added for large orders and out-of-province orders to cover costs for re-printing.

## **FASD Prevention Website**

#### Check out this website! www.fasdprevention.wordpress.com

This site, called Girls, Women, Alcohol and Pregnancy—Perspectives on FASD Prevention, is an initiative supported by the Network Action Team (NAT) on FASD Prevention from a Women's Health Determinants Perspective. It features posts about what is going on in the world of FASD prevention from NAT members across Canada.

The site is updated frequently, with information about the effects of alcohol and pregnancy, international campaigns and upcoming educational opportunities, as well as links to many other interesting and informative resources on FASD.

### Manitoba Coalition on Alcohol and Pregnancy (MCAP) – Membership Form

Thank you for your interest in the Manitoba Coalition on Alcohol and Pregnancy (MCAP). MCAP membership is open to all Manitobans with an interest in fetal alcohol spectrum disorder (FASD). MCAP will facilitate representation from across the province through the use of teleconferencing technology. Anyone may attend a MCAP meeting, however only voting members may participate in making decisions for MCAP. There are no membership fees or dues. Members must complete and submit annually a membership form confirming their intention. The type of membership chosen reflects the level of commitment to MCAP. Voting members are encouraged to attend meetings regularly to ensure quorum can be established at each meeting. Voting members are asked to let the MCAP administrative co-ordinator know when they are unable to attend a meeting.

Name:		Date:
Organization (if applic	able):	
Mailing address:		
Tel:	Fax:	Email:

#### Please indicate the type of member you wish to be:

**Individual Voting Member:** An individual voting member is a person with an interest in FASD, who is not representing an organization. Voting members are committed to attending meetings on a regular basis and are engaged in MCAP activities.

**Organizational Voting Member:** An organizational voting member is a person representing an organization. The membership will be held by the organization who will appoint a representative to vote at MCAP meetings, participate in MCAP events and receive minutes and correspondence. Each organization will have one vote. An alternate may attend meetings to represent the organization. The organization is committed to providing a representative to attend meetings on a regular basis and engage in MCAP activities.

**Individual Non-Voting Member:** An individual non-voting member is a person not representing an organization, interested in receiving the FASD News and invitations to MCAP events but does not wish to participate in the operation of MCAP. Individual non-voting members are encouraged to attend MCAP meetings, however if they wish to participate in the administration of MCAP they must change their membership to a voting member.

**Organizational Non-Voting Member:** An organizational non-voting member is an organization with an interest in receiving the FASD News and invitations to MCAP events but does not wish to participate in the operation of the MCAP. The organization will identify a contact person to receive information. The organization is encouraged to send a representative to attend MCAP meetings, however if they wish to participate in the administration of the MCAP they must change their membership to a voting member.

Ex officio non-voting member: MCAP funders.

Please mail the completed form to: Kerri Hiebert, MCAP Administrative Coordinator 299 Truro Street, Winnipeg, MB R3J 2A2