

F.A.S. NEWS

FETAL • ALCOHOL • SYNDROME

Spring 2003

A Publication of the Coalition on Alcohol and Pregnancy

Manitoba Addiction Awareness Week Awards: Norway House Round Table on FAS Honoured

Congratulations to the Norway House Round Table on Fetal Alcohol Syndrome on receiving the Manitoba Addictions Awareness Week 2002 Provincial Award of Distinction. The award was presented during the National Addictions Awareness Week Kick-off in Flin Flon in November, 2002.

This provincial award recognizes exceptional work that demonstrates a high level of ongoing commitment, community involvement and support, and a positive, ongoing impact on both the community involved and the province overall.

Each year the Manitoba Addictions Awareness Week (MAAW) committee recognizes, through its "Awards of Distinction," individuals and organizations for their work in raising awareness around substance use/misuse, gambling and other issues related to addictions.

The Norway House Round Table Committee was chosen for playing an important role in raising awareness about the dangers of drinking alcohol, taking drugs and smoking during pregnancy, both in the community of Norway House and in many other places.

In presenting the award, Addictions Foundation of Manitoba C.E.O. **John Borody** noted that since its inception five years ago, the committee has achieved tremendous success.



(Left to right) Walter Spence, Director of Minisewin Child Care Agency, Lia Braun, Special Services Consultant - Frontier School Division, John Borody, C.E.O., Addictions Foundation of Manitoba, Daisy Monias, Vice-Principal, Jack River School - Frontier School Division, and Vic Thordarson, retired Superintendent of Frontier School Division.

"In a recent poll of Norway House high school students, 100% were aware of what FAS meant and how babies were affected."

Committee members have conducted workshops locally and in other communities for pregnant women, teachers, childcare workers and others.

The committee also encouraged and supported the FAS prevention

(cont'd on page 4)

New Screening for Prenatal Alcohol Use

In January, 2003, Manitoba Health modified the BabyFirst Screening form to collect more relevant data on the prevalence of alcohol use during pregnancy. As part of the initial screen process, public health nurses now ask all women who deliver a baby in a Manitoba hospital about their use of alcohol during pregnancy.

If the mother indicates any use of alcohol during pregnancy, further questions are asked to elicit information about amounts and frequency. This process gives all mothers an opportunity to discuss their alcohol consumption during pregnancy and any questions or concerns that they may have.

The information collected through this screen will provide a picture of annual incidence rates on alcohol use during pregnancy; incidence rates on

(cont'd on page 3)

WHAT'S INSIDE...

First Nations & Inuit Health Branch FAS/FAE Projects	2
FAS Community Mobilization Project for Adults	2
New Test Can Reveal Baby's Alcohol Exposure	3
\$320 million for Early Child Development	3
AMC Develops First Nations Response to FAS	3
National Framework for Action of FAS/FAE	3
Update on Fetal Alcohol Family Association of Manitoba	4
Metis Community Development Tool	4
STOP FAS Program - Evaluation Highlights	5
FAS: The Birth Mother's Experience	5
Caldwell to Chair Canada Northwest FASD Partnership	5
Tying the FAS Knot	5
Healthy Child Manitoba Helps to Fund CAP	5
Study looks at Supports for Reserve & Rural Families	6
FAS in Adult Offender Populations	6
Sleep Disorder Study Results	7
WCFS: Working with Families who Misuse Alcohol & Other Drugs	7
FASD - Law Enforcement Training Spreads	7
National Training for Community-Based Practitioners	8
Addictions Foundation of Manitoba Library	8
Come, Walk with Me: A Christian Response to FAS	8
Manitoba Foster Family Network Conference	8

2003 Canada Northwest FASD Conference

(Formerly called the Prairie Northern Pacific FAS Conference)

Winnipeg Convention Centre, November 19-21

"Our Communities...Our Strength" will provide a forum for community partners to hear from experts in the field of FAS and community development. The pre-conference day will provide half-day and full day workshops in focussed subject areas by invited experts.

The focus of the main conference will be to acquire skills in specific best practice prevention/intervention strategies that address the challenges of FAS; to disseminate information on the latest research regarding FAS; to learn about specific community development models to support community efforts to address FAS; and to strengthen regional networks.



Submission guidelines for presenters and information on conference registration will be available at www.fasconference.ca by May, 2003.

The Prairie Northern Pacific FAS Partnership was recently renamed the **Canada Northwest FASD Partnership**. It includes the governments of Alberta, British Columbia, Manitoba, Northwest Territories, Nunavut, Saskatchewan and Yukon.

For more information on the 2003 conference, contact Linda Storoschuk at Planners Plus Inc. at 255-2244 or linda@plannersplus.ca.

Info at www.fasconference.ca by May 2003

First Nations & Inuit Health Branch Projects

In fiscal year 2000-2001, the First Nations and Inuit Health Branch funded 10 FAS/FAE projects across Canada. The projects included training workshops, information and awareness sessions, the development of practical tools, FAS/FAE strategies and publications on the issue, and are briefly described below.

Alberta Treaty 8 Health Council, Edmonton, AB

This project featured awareness training on FAS/FAE within community health centres or school settings in 23 First Nations within the Treaty 8 Alberta territory. It provided the parents of FAS/FAE children with a sense of hope, understanding and inspiration to continue with the challenging job of raising an FAS/FAE child without feeling isolated. It also enabled the communities to develop their own prevention models conducive to their cultural and traditional values.

Contact: Joyce Cardinal at (780) 444-9366 or joyce@at8ha.com.

Anishinaabe Mino Ayaawin Inc., Interlake Reserves Tribal Council Health, Winnipeg, MB

This FAS/FAE Prevention/Community Mobilization Project provided training and mobilization of key frontline workers on FAS/FAE prevention, supporting strong community relations between seven First Nation communities in Manitoba. It was able to reach the identified key target groups and a total of 54 community workers participated in the three-day training session. The development of a community work plan ensured a collaborative and coordinated approach in addressing FAS/FAE. A steering committee was developed from the training session to oversee the community work plans and follow-up on decisions.

Contact Daryl Cote at (204) 659-2094 or hltres@escape.ca.

Battlefords Tribal Council Indian Health Services Inc., North Battleford, SK

The intention of this project was to provide frontline workers with training in the use of storytelling to sensitize and inform the community about FAS/FAE. In partnership with Indian Bands Battlefords and Area Child Development Program and Saskatchewan Literacy Network, this special project was a two-day workshop that involved storytelling/story writing and training of trainers. A total of five communities were served. Besides increasing the knowledge achieved on the issue of FAS/FAE, the stories produced will be used as resource material.

Contact: Janice Kennedy at (306) 937-6700 or btcis@sk.sympatico.ca.

Deh Cho Friendship Centre, Fort Simpson, NT

This project provided training workshops for healthcare workers, educators and community members on the causes, prevention and implications of FAS/FAE. It was focussed on training and capacity development for frontline workers in seven different communities of the NWT.

Contact: Gerald Antoine at (867) 697-2577 or friends@cancom.net.

First Nations Education Council, Wendake, QC

This project provided training on FAS/FAE and developed practical tools and methods for special education teachers. It increased the awareness and expertise of frontline workers and promoted the development of resource material.

Contact: Lise Kistabish at (418) 842-7672 or cepnfec@total.net.

Kettle and Stony Point Health Services, Forest, ON

This project provided capacity training for service providers to enable them to develop ongoing, sustainable action plans on FAS/FAE in their respective First Nation communities.

Contact: Janet George at (519) 786-5647 or janetg@ksphs.on.ca

Mamaweswen, The North Shore Tribal Council, Cutler, ON

This FAS/FAE capacity building and prevention project consisted of a five-day workshop and included frontline prevention workers using a train-the-trainer approach to prepare the workers on how to develop and deliver community awareness activities. A series of one-day workshops were also held with educational, health and social work professionals.

Contact: Betty McCullough at (250) 949-8732.

Musgamagw Tsawutaineuk Tribal Council, Alert Bay, BC

This project was intended to inform and train community members and frontline workers about FAS/FAE and provide a mechanism for networking and information sharing between the four communities, three of which are accessible only by seaplane or boat. Participants identified and worked with community members at risk, specifically women ages 12 to 45, and raised community awareness of FAS/FAE by holding culturally appropriate community workshops.

Contact: Fern Assinewe at (705) 865-2171 or mttc@island.net.

Pauktuutit Inuit Women's Association, Ottawa, ON

Pauktuutit's FAS/FAE Prevention/Community Mobilization project reached 53 Inuit communities through resource materials distributed to community health or addiction workers and media coverage. It promoted healthy, alcohol-free pregnancies and encouraged discussion about FAS/FAE. The project produced a culturally and linguistically appropriate radio play called "Before I was Born," which aired on stations throughout the North. Youth were the target audience of the play and were involved in its production and in the direction, acting and filming of the complementary 26 minute video of the same title. The video story is about a young pregnant teenager and her journey through her pregnancy. The complete kit also includes a facilitators' viewing guide and a poster. Approximate cost of the kit is \$50.

Contact: Catherine Carry at (613) 238-3977 or jamviol@pauktuutit.on.ca.

Taku River Tlingit First Nation, Atlin, BC

This project was designed to create a support and respite network for FAS/FAE caregivers while raising awareness of FAS/FAE among potential mothers and community leaders, and encouraging the development of a community mobilized social action justice plan on the issue.

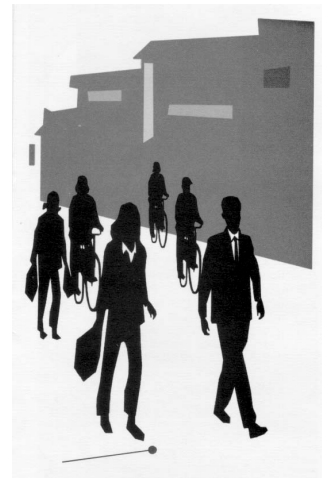
Contact: Ed Anderson at (250) 651-7755 or alternately, Linda McGill at bwood@trtfn.net.

FAS Community Mobilization Project for Adults

In response to the "Think Tank on Adults living with FAS" presented by the Coalition on Alcohol & Pregnancy in March, 2002, the FAS Community Mobilization Project was launched.

The four main focus areas of this project are to:

- (1) Increase the number of service options available to adults living with FASD by assisting those eligible for existing government services to access those services and to assist in the creation of services that will address the gaps as identified by the Think Tank.



- (2) Address the need for general coordination of services for adults living with FASD in Manitoba.
- (3) Address the need for greater access to assessment and diagnosis for adults living with FASD.
- (4) Participate actively in the FAS community.

The FAS Community Mobilization Project is currently funded by the Association for Community Living-Manitoba, Manitoba Marathon Fund, Opportunity Fund, and Health Canada's Population Health Fund. Additional government funding will be essential to increase the services that are available through the project.

FAS Community Mobilization Project

Contact Graham Wyllie at 489-8435 or Brenda Bennett at 786-1607

Existing services being provided in a limited capacity to reach these goals include intake, referral and application to government services; access to assessment and diagnosis; access to community programming; housing assistance; funding for job support programs; support workers; and support to adolescents transitioning to adult services.

A sampling of current activities includes: meeting with individuals who are either formally diagnosed or where there are indications of being alcohol affected; a three month project with Family Services to provide assessment and support services for five individuals; and through the Opportunity Fund, assisting a number of individuals through community programs to provide one-to-one support regarding job search and employment retention.

Summary of Think Tank Goals

- ▶ Address criteria and eligibility for services.
- ▶ Address transition supports from incarceration to community.
- ▶ Address transition from school to community life.
- ▶ Address housing and employment needs.
- ▶ Address the need for alternatives to jail.
- ▶ Address the need for greater support to families.



Screening for prenatal alcohol use (cont'd from page 1)

low dose drinking as well as binge drinking; information at a regional level to help plan and target prevention resources; and a baseline measure with which to compare and determine the impact of prevention work.

"We hope to obtain solid statistics on the incidence of drinking during pregnancy in Manitoba. There have not been any good studies in Canada so far to indicate prevalence. It's very exciting from a research perspective," notes **Jill Swaffer** with Healthy Child Manitoba.

For more information, contact **Jill Swaffer** at Healthy Child Manitoba at 945-8641.

New test can reveal baby's alcohol exposure

An article published on November 5, 2002, in the *Globe & Mail* reported that a new test can reveal a baby's alcohol exposure. **Margaret Philp** reported that doctors at Toronto's Hospital for Sick Children have invented a test that is used on the first bowel movements of newborns to look for chemical clues that their mothers drank alcohol in pregnancy.

Philp explained that the laboratory at Sick Kids' Motherisk clinic analyzed the black, sticky meconium that all newborn babies pass, a result of having digested amniotic fluid in the womb. They look for a chemical that forms when alcohol bonds with fatty acids.

Dr. Julia Klein, director of the Motherisk fetal toxicology laboratory, which developed the meconium test, described how it works: "Meconium is like a trash can. What the fetus experiences in utero accumulates there, and it stays there until the baby is born, so it's a very good medium for measuring what the fetus is exposed to."

Philp reported that only trace amounts of the chemical are likely to be detected in the first bowel movement of a baby born to a woman who sipped an occasional glass of wine in pregnancy. But it will appear in abundance in the meconium of babies born to women who binged or drank regularly.

Peter Selby, a physician at St. Joseph's Health Centre in Toronto, which is using the testing for babies born to women enrolled in the hospital's program for alcoholic expectant mothers, **cautioned that the test only indicates alcohol was consumed and does not constitute a diagnosis of FAS.**

National Framework for Action on FAS/FAE

On February 12, 2003, Health Canada held a consultation in Winnipeg regarding the development of a National Framework for Action on FAS/FAE. Approximately 40 organizations and government departments were represented by the 41 participants.

The purpose of the working session was to reflect on past experiences and chart out a national framework for action that builds on what has been accomplished to date.

The ultimate goal of the national framework is to develop a broad-based, collaborative effort to prevent FAS/FAE, and to improve the quality of life of people and families affected by FAS/FAE across Canada. The framework document is to be launched in May 2003.

For more information, contact **Lynn Foley** at 983-8028.

\$320 million for Early Childhood Development - First Nations & Other Aboriginal Children

On October 31, 2002, the Government of Canada announced a funding allocation of \$320 million over the next five years for a strategy to improve and expand Early Childhood Development programs and services for First Nations and other Aboriginal children.

This investment will expand the Aboriginal Head Start Program for Aboriginal children living on and off reserve, and will enhance and expand the First Nations and Inuit Child Care Program. The investment also enables the Federal Government to intensify its efforts to address FAS/FAE in First Nations on reserve. Funds will also support a national survey on Aboriginal children and research at the community level.

While conditions are improving, the general health status of Canada's Aboriginal population ranks below the national average. Infant mortality rates are two to three times the national average and anecdotal research suggests growing concerns with respect to FAS/FAE and Sudden Infant Death Syndrome (SIDS).

Initial studies suggest that the rates of FAS/FAE in some Aboriginal communities may be significantly higher than in non-Aboriginal populations. In the 1999 Budget, the existing Canada Prenatal Nutrition Program was expanded to support an increased focus on FAS/FAE and to further improve the health of pregnant women at risk and their babies.

The First Nations and Inuit component of the FAS/FAE Initiative (\$1.7 million annually) has focussed

on training for frontline workers. The training will assist these workers in supporting, identifying and managing those at risk of FAS/FAE. Another objective is the development of public education tools and resources.

With an additional \$10 million in 2002-03 and \$15 million ongoing, the expanded FAS/FAE Initiative will include a stronger focus on First Nations children and families to increase efforts in raising awareness of this important health issue and will assist in the prevention of FAS/FAE and in providing supports for those affected.

Initiatives will be put in place to help mobilize community action and contribute to enhancing the quality of life for affected individuals and families, including the improvement of family and parent supports in federal community-based programs.

Current efforts will be expanded to enhance professional training and to develop practical screening tools for physicians and health care providers working with First Nations children and families on reserve.

The expansion will also support the development of new programming through demonstration projects in First Nations communities.

Working collaboratively with other federal departments, provincial/territorial governments, professional associations and non-governmental organizations, Health Canada will continue to play a key role in the overall strategy to prevent FAS/FAE.

AMC Develops First Nations Response to FAS

The Assembly of Manitoba Chiefs (AMC) FAS Working Group is working towards developing a First Nations strategy in the area of FAS. This year's strategy is to increase education while next year's goal is intended to include a number of strategic projects, says committee member **Kathy Jones** of West Region Child and Family Services.

Funding to develop the First Nations strategy is provided by Health Canada through the First Nations and Inuit Health Branch as part of a national FAS strategy.

"The committee has been meeting for two years and is really interested in developing a customized Manitoba First Nations response and not try to fit someone else's ideas into ours," says Jones who notes that the needs of a First Nations community are very different.

"There are no professional supports to speak of, few recreational opportunities, and no children's programs. There is a combination of high levels of FAS but also high levels of emotional difficulties, including high suicide rates."

Recognizing this, the committee is starting with a community response. The intent is to heal a community first and then the children.

This year, to meet their goal of increasing education, two on-reserve FAS conferences took place in March, one in the north and one in the south. **Kathy Jones** was the contact person for the southern conference and **Freda Lepine** was the contact for the northern gathering.

"What we tried to do at these conferences is give people ideas on how to do community-based interventions in the area of FAS," says Jones.

A third FAS conference is planned that will focus on best practices in daycares in First Nation communities. It will include funding for retrofitting First Nation daycares to support kids with FAS.

Jones notes that the FAS working group is excited about where they are and are looking forward to some really innovative programs next year.

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Improving the Quality of Education for First Nations Students

Improving the Quality of Education for First Nations Students

Update on Fetal Alcohol Family Association

The Fetal Alcohol Family Association of Manitoba (FAFAM) is dedicated to providing advocacy, support and education to families caring for and professionals working with children and adults prenatally exposed to alcohol/drugs.

Donations needed

The Family Association is a charitable, not-for-profit organization. Should you wish to make a charitable donation, a tax receipt will be issued for all donations over five dollars.



After a meeting with **Drew Caldwell**, Minister of Family Services and Housing, regarding ongoing operating funding for the Association, the Board of Directors is hopeful that additional dollars will be included in the next provincial budget. The Board was particularly appreciative of the many letters of support they received from families, agencies, organizations and community groups whom the Association has served and partnered with over the last two years.

Parent Information Series: Fostering Awareness and Strength

The FAFAM began its sixth Parent Information Series on March 3 at the Family Community Centre (100-475 Sargent Ave). The series runs until April 28 and is titled "Fostering Awareness and Strength".

Topics and speakers in the series include: "What is Fetal Alcohol Spectrum Disorder" with **Leilani Buschau** (Executive Director, FAFAM); "Talk to the Doc" with **Dr. Sally Longstaff** (Clinic for Alcohol and Drug Exposed Children); "Adolescence or FAS" with **Susan Opie** (Interagency FAS Program); "Ahh, How Come You Don't Listen? Managing Behaviours" with **Lisa Hurl** and **Karen Johnston** (FAS Outreach Team); "IEPs and Team Meetings - Where do Parents Fit?" with **Deb Thordarson** (FAFAM); and "What is the Behaviour Communicating" with **Anita Posaluko** and **Dan Neault**.

Community workshops & presentations

Over the past fall, the Family Association delivered numerous work-

shops in communities across the province. For example, FAFAM president Deb Thordarson spoke to numerous families considering adoption through Winnipeg Child and Family Services about the effects of prenatal exposure to alcohol. FAFAM Executive Director Leilani Buschau presented to Winnipeg librarians about making library programs more inclusive. Two full-day workshops were held in St. Martin for foster parents working for Anishinaabe Child and Family Services and a half-day workshop was

held in Eriksdale for foster families working for New Directions for Children, Youth and Families.

On the request of the national Native Alcohol and Drug Addiction program in Little Saskatchewan First Nation, the Family Association made a presentation to students from grades 7-12 during Alcohol and Drug Awareness Week on the prevention of FASD. In Winnipeg, students at the Arthur E. Wright School heard a presentation on the effects of prenatal exposure to alcohol.

New FAFAM brochure being developed

Buschau notes they are working hard at developing ways to let people in the community know what the Family Association can offer to families and professionals. One method is a new FAFAM brochure that will soon be available.

Care for the Caregivers: Parent Support Group

In partnership with the Interagency FAS Program, the Family Association offers the "Care for the Caregiver" project—a closed support group for parents of children who have been prenatally exposed to alcohol.

The parent support group meets weekly to celebrate accomplishments and discuss issues of concern. Topics for discussion are decided in collaboration with group participants.

The group meets Wednesday evenings from 5:30 to 7:30 p.m. at the Family Community Centre (100-475 Sargent Ave). For more information this or on any FAFAM programs, contact Leilani Buschau at 786-1847.

Fetal Alcohol Family Association of Manitoba

Annual General Meeting
May 21, 2003

Call the Family Association at
(204) 786-1847 for details.

Metis Community Development FAS Tool

This past year, The Pas Family Resource Centre partnered with the Manitoba Metis Federation (MMF) to prepare and deliver a community development tool to representatives from the 23 Metis communities in the NOR-MAN region.

Funded through the Health Canada Rural and Remote Innovations Fund, the project involved a "train-the-trainer" approach. Each community was invited to send two representatives to a three-day training workshop.

Representatives took away a presentation package that could be shown in their community using either overhead slides or a Powerpoint version.

Also included in the package were two types of the "Baby Think It Over" dolls, one of which is an FAS model, that they can use in their community, public health and school presentations.

"In this way we are leaving the expertise and training in the community so they don't have to keep

coming out and asking others for resources," explains **Terralyn McKee**, Executive Director of The Pas Family Resource Centre.

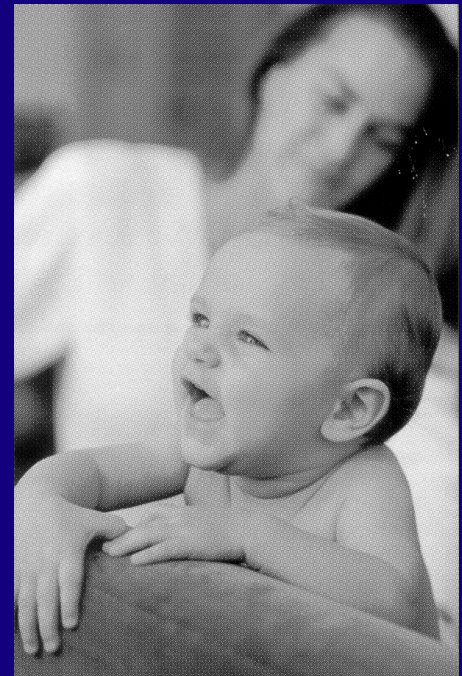
The training tool is currently under revision with a consultant, **Caroline Chartrand**, who has done extensive work with Manitoba Metis organizations.

The goal, says McKee, is to produce a tool that can be used in other communities and provinces to address FAS in a respectful and empowering manner. The final version should be available by September, 2003.

Another avenue to support community development and FAS awareness activities is the submission of an electronic version of the tool to a Health Canada web site.

"The idea is that people could either download it for free from the web site or they could purchase a hard copy for which they would pay the production cost," explains McKee.

Fetal Alcohol Syndrome: A resource for professionals



Let's Find A Solution

Saskatchewan Institute on Prevention of Handicaps
Tel: (306) 655-2512 / Fax: (306) 2511
skiph@sk.sympatico.ca
www.PreventionInstitute.sk.ca

Manitoba Addictions Awareness Week (cont'd from page 1)

curriculum document, "Making the Right Choices," published by the Frontier School Division. In addition, the committee has been involved in the development of a diagnostic protocol in collaboration with Norway House Hospital and the Northern Medical Unit. At the time of the award presentation, the protocol had resulted in the diagnosis of 27 children.

In addition to the awards, the Manitoba Addictions Awareness Week (MAAW) committee is involved in several other activities to raise awareness.

"Manitoba really is a leader in this area, undertaking the awards program, funding community initiatives and developing and distributing MAAW Resource Kits each year," notes committee member **Sheila Duprey** and AFM librarian.



The kit, available in English and French, goes out to all schools in the province as well as various community groups, such as Girl Guides, 4H, church groups, and selected work places. This year, around 2,000 kits were produced, 1800 in English and 250 in French.

"They were gone in a flash," says Duprey. "We ended up having the RCMP photocopy another 90 English kits and there are only about 10 left of the French version."

Included in the resource kit distributed annually is a Fast Facts sheet on FAS plus learning activities for students appropriate for kindergarten through secondary school.

The MAAW resource kit is updated each year with new statistics, topics and activities being added. The 2003/04 kit will be ready for distribution at the beginning of September, 2003. Manitoba Addictions Awareness Week runs this year from November 16-22.

To add your organization's name to the mailing list for the resource kit or for more information, contact Sheila Duprey at 944-6367.

STOP FAS Program Evaluation Highlights

The STOP FAS Program is a paraprofessional mentorship model of enhanced case management. The mission of the program is to work with high-risk mothers who use alcohol and drugs heavily and who are currently pregnant or have just had a child, to avoid the birth of other children affected by alcohol and drug use.

Each participant is assigned a mentor who works intensively on a one-to-one basis with her and her family for up to three years.

The typical client is approximately 26 years old, has had four children, has lost three children to the child welfare system, has not planned her pregnancies, has completed a Grade 8 education, is in an abusive relationship, began drinking early in youth, uses other substances in addition to alcohol, was raised in a family with addiction issues, moves frequently or is homeless, and has a history of trouble with the law.

After completing three years in the STOP FAS program:

- ▶ 84% of the clients are no longer at risk of having a child with FAS; they have stopped using alcohol or drugs, or are using birth control
- ▶ 65% have completed an addictions treatment program
- ▶ 49% have stopped using alcohol; of those more than half have abstained for 6 months or more
- ▶ 49% use birth control
- ▶ 28% have completed an educational/training program
- ▶ 63% of children are living with their own families
- ▶ 100% of the target children are fully immunized

Healthy Child Manitoba Helps to Fund CAP

The Healthy Child Committee of Cabinet approved \$7,500 in funding to help support the continued activities of the Coalition on Alcohol and Pregnancy (CAP) in 2003.

As noted by Minister **Tim Sale**, Chair of Healthy Child: "We know that addressing Fetal Alcohol Syndrome cannot come from government action alone; it requires a collaborative effort between government and its community partners. I would like to take this opportunity to commend CAP for providing a forum for this partnership and playing an integral role in supporting those whose lives are affected by a fetal alcohol syndrome disorder (FASD)."

FAS: The Birth Mother's Experience

(In her masters' thesis, **Jessica Neville** looked at FAS from the birth mother's experience. She summarizes her study and results below.)

Research data was collected through two primary sources: interviews and field notes. Given the blame and stigma often associated with being a birth mother, several women were reluctant to participate. Further, given that many lived in situations that were often chaotic, they were not always easy to locate, even once they had agreed to participate.

Fortunately, with the assistance of the *Interagency FAS Program* in Winnipeg, and the *FAS/E Support Network of BC*, two women from Winnipeg and six from British Columbia ultimately agreed to participate. They ranged in age from 22 to 45 years.

Interviews were the main method of collecting data. The objective in meeting and working with the women was to generate information of benefit to each participant, and to the community at large.

Main themes of findings

Several main themes emerged through the interviews. The first, **broken trust**, describes experiences of abandonment and disappointment during the participants' lives. Participants spoke of abuse as children, of often-painful relationships with parents, and of patterns of difficulty subsequently experienced in relationships with men.

Each participant described having been repeatedly **failed by the system**, a failure that had continued into the lives of their children. The women explored their own difficult experiences with various systems as children. They further described the obstacles they had encountered while trying to obtain a diagnosis for their children and the ensuing struggle that followed diagnosis, stemming largely from the lack of supports available for their children.

Experiences with alcohol, the third theme, involved participants' relationships with alcohol and drugs, about which they spoke emotionally. Most had had early experiences with alcohol and in many cases, immediate addiction. They described their histories with treatment and what had worked for them in creating lives without alcohol.

Bonnie Buxton and husband **Brian Philcox** of FASWorld are founding coordinators of International FAS Day along with **Teresa Kellerman** in Tucson, Arizona.

One of the symbols created by Buxton and Philcox to mark International FAS Day (September 9) is the "FAS Knot." In their words, this piece of knitted cord was designed in memory of **Abel Dorris**, 1968-1991, whose brief and poignant life resulted in the groundbreaking 1989 book about FAS, "The Broken Cord," written by his father, Michael Dorris, 1945-1997.

The fourth theme explored the toll taken on their **emotional and physical well-being**. All had accessed mental health support during their lives, predominantly to combat depression. Two revealed they, like their children, were living with the effect of their mothers' alcohol use during pregnancy. One had herself been diagnosed with FAE and another was awaiting a diagnosis.

Discovery and reclamation also emerged as an important theme. Several spoke of the self-loathing that accompanied the way they had lived, and the impact their lifestyles had on their children. They spoke extensively of how they came to make incredible changes in their lives, discovering not only who they were as women, but reclaiming their strength and dignity.

Significance of the Study

This study is significant for several reasons. First, it gives a voice to the women, who in their self-described experience, have been without it. They had felt silenced by the guilt and shame associated with being both alcohol dependent and birth mothers of children affected by alcohol. Many of the women also believed that they were not represented in either the literature or the media in portrayals of birth mothers of children with FAS or FAE. For many of them, participating in this study was their first experience speaking "publicly" about their experiences.

Second, it provides a frame of reference for those who are currently working, and those planning on working, with mothers and children who have been identified as high-risk. Participants were able to identify what services and interventions would have made a difference for them and their children. This study may assist in identifying which services and approaches are effective and which are not.

Finally, FAS and FAE are issues attracting increased attention by researchers, the media and policy makers alike. As previously mentioned, the literature that speaks to the experiences of birth mothers is limited, particularly that from a qualitative perspective. This study adds to the growing body of literature that seeks to provide greater depth to what is presently known about birth mothers of children with FAS and FAE, offering insight into the life experiences of these women. (Contact *Jessica Neville* at jessmneville@hotmail.com)

Caldwell to Chair Canada Northwest FASD Partnership

Manitoba's Minister of Family Services and Housing, **Drew Caldwell**, is the 2002-03 chair of the Canada Northwest FASD Partnership, formerly known as the Prairie Northern Pacific FAS Partnership.

The partnership is an ongoing collaboration of the four western provinces and three territories designed to maximize the use of existing expertise and resources in the development of joint strategies and initiatives to address Fetal Alcohol Spectrum Disorder (FASD). The Ministers' Committee is supported by a multi-disciplinary steering committee of officials.

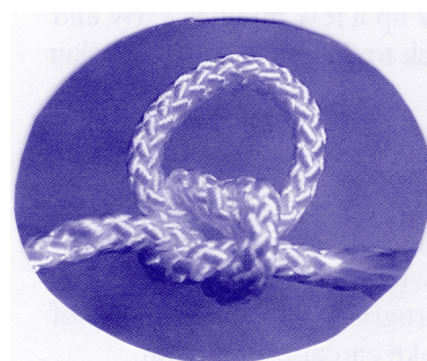
The Ministers agreed to change the partnership's name to reference Canada as the country of origin of the partnership. They also agreed to use the more current, accurate and inclusive term of FASD in all partnership business.

Another significant change Ministers agreed to was altering the frequency of partnership conferences and symposia from annual to bi-annual events, with the partnership-sponsored conference occurring in the years opposite to British Columbia's bi-annual FAS conference. The Ministers also approved expanding the focus of symposia to target a range of professional designations with an interest in education and professional development opportunities around FAS. Previously, the symposia have been directed primarily at physicians and allied health professionals.

Other partnership-sponsored events include: the **FASD Symposium Inuuqatigiiani** (Community Kinship), March 21-24, 2003, in Iqaluit, Nunavut; the **Medical Education Symposium**, September 27-29, 2003, in Burns Lake, B.C.; and the next major FASD conference, **Our Communities ...Our Strength**, November 19-21, 2003, in Winnipeg.

Ministers also agreed to explore sponsoring FASD activities and initiatives beyond conferences and symposia, which could potentially include such initiatives as a national forum, the publication of a document, or a project selected through a Request for Proposals.

Tying the FAS Knot



"The circle symbolizes the womb, a baby's head, the human brain, the earth. And we, a planet-size network of people who care about people living with FAS, are the knot that will make them whole. If women did not drink in pregnancy, FAS would be eliminated. Our long-range goal is to rename this small piece of cord 'The FAS Not!'"

Step-by-step photos showing how to make the FAS Knot can be found at:

www.fasworld.com/symbol.ihtml

To contact **Brian Philcox** at FASWorld, call (416) 264-8000.

Study Looks at Supports for Rural & Reserve Families

Drawing from her work with West Region Child and Family Services, **Kathy Jones** recently defended her PhD thesis, which looked at the kind of supports individuals from rural and reserve families need to support their children affected by FAS.

"As a child welfare agency we know that 70% of children with FAS are in care and that children with FAS are the most transient," says Jones. "And we know that children in long-term foster home placements are healthier, emotionally and physically. So I was looking at what we at the agency can do to ensure children stay there."

For example, the Streissguth study on secondary disabilities concluded that children who stay in the same home for 72% of their life are healthier.

"The Manitoba FAS study showed that 20% of children with FAS had more than 5 foster home placements in their childhood. The question was what did child welfare need to put into the mix to make these foster homes more stable and more long-term."

Jones interviewed eight families representing 22 children from rural and reserve areas in West Region. She found that the issues were not around supporting the family but around creating what Jones calls a circle or network of support for each child.

"I found that foster families were very able to support their children as long as they were the principal means of support. It was community demands that were crumbling the families. The moment the children went to school or to recreational activities where there were no supports, things started to fall apart."

Jones found families were able to make astounding accommodations for their children and were good case managers of the children in the home. The problems for the family arose with outside systems that had problems with the children.

In her research, Jones also looked at resiliency of the children in the study, specifically what was going on with children that was making their outcome more successful.

She found that children who were able to show emotion were actually healthier as teenagers. Those who seemed to be the most unhealthy in their teenage years were described as children who could not make emotional connections.

"This was very interesting because as a system we tend to lump all children with FAS into the same pot, thinking that all children with FAS need certain things. What this might suggest is that a particular subset of children with FAS are at a higher risk. The subset of children who have difficulty with

emotional relationship had a harder time maintaining a family."

Jones found that the families did not mind the child's difficulty with emotional reciprocity, but the child had a much harder time at school, with friends or in a recreational setting.

"I would argue that not being able to join in an emotional way with people is the damage of FAS, not a bonding issue," she notes, who adds that as someone who has worked in this area for a long time, she had always assumed that it was about bonding when a child could not show emotional reciprocity. Now she believes that is a physical disability.

Jones hopes that research will be done to look at this subset of children to determine whether it is about bonding or another facet of FAS.

Based on the results of her study, West Region CFS will work to look more carefully at children who have issues with emotional reciprocity to determine whether they have enough services in place.

"Instead of saying we're going to help teach this child how to feel emotions, we might have to realize that certain children can't," says Jones,

noting that the real need is to develop a network of support for every child and particularly for the children who have problems with emotional reciprocity.

"In child welfare, we need to look really carefully at the model of support for children with FAS because they are at the highest risk in the system for multiple placements and at highest risk for never returning to their families."

Jones also believes that we need to think carefully about where child welfare fits into the FAS field.

"Child welfare has not been active at the table. We have all the children but we've never talked about a different way of dealing with children with FAS. There needs to be a focus on how child welfare needs to work differently."

The role of foster fathers

Jones was intrigued to see the amount of work being done by foster fathers. She found their role was quite different and yet there is very little research in this area. As such, she plans to look next at the role of foster fathering.

"The foster fathers really were the parent who supported the mother and child," she says. "They did a ton of work maintaining the mother and child connection and giving emotional and physical respite to mom. We don't often see foster fathers as an important component of the support program so I'm particularly interested in looking more carefully at where fathers fit into the picture."

FAS in Adult Offender Populations

*The following is excerpted from a paper titled "The Challenge of FAS in Adult Offender Populations" co-authored by **Fred Boland** (Addictions Research Centre, Correctional Service of Canada), **Dr. Ab Chudley** (University of Manitoba), and **Brian Grant** (Addictions Research Centre, Correctional Services of Canada), which appeared in the September 2002 issue of *Forum on Corrections Research* (Vol. 14, No. 3).*

Offenders suffering from Fetal Alcohol Syndrome (FAS) and its related disorders present a significant challenge within correctional settings. The behavioural and learning characteristics associated with these disorders make it difficult for affected individuals to function effectively in the aggressive and often uncertain environment of a prison. The presence of affected individuals creates issues for institutional staff, program deliverers, parole boards, and those involved in community supervision. How we address these issues is dependent on the number of affected individuals within the correctional system. Unfortunately, to date, no study has been undertaken to estimate the incidence/prevalence of affected individuals within the offender population.

Collecting incidence/prevalence data is not a simple task. No screening instrument with known reliability and validity is currently available.

Since one of the key principles of good correctional planning and intervention is the assessment of offender criminogenic needs and risk levels, it is important to identify this sub-population so their needs can be addressed.

Diagnosing FAS/FAE: The challenge with adults

There are many difficulties diagnosing adults. Official records from pregnancy, early childhood and school are often unavailable, and older records may not be complete. Memory related to prenatal alcohol use may be inaccurate and self and collateral information may be limited or unavailable. Facial structures change with age and the characteristic features may be lost. Most research on developing diagnostic criteria have been based on children and there are few experts available who are experienced in adult diagnosis.

FASD: a definition

Fetal Alcohol Syndrome (FAS) and related disorders, such as Fetal Alcohol Effects (FAE), are conditions now commonly referred to by the non-diagnostic umbrella term **Fetal Alcohol Spectrum Disorders (FASD)**, where prenatal exposure to alcohol is an important factor in problems an individual exhibits throughout development.

Theoretically, one way to identify offenders with FASD is to do a full diagnostic assessment on all incoming offenders. However, this would be prohibitively expensive and neither the expert personnel nor financial resources could possibly be found. The alternative is to develop a reliable and valid screening tool that would identify the much smaller subgroup at "high risk" for FASD who could then be sent for a diagnostic assessment.

The authors have initiated a research project to develop a potential screening instrument that could be used with adult offenders. It is anticipated that final planning for the project will be completed in the fall of 2002 with data collection to commence as soon as possible.

In child welfare, we need to look really carefully at the model of support for children with FAS because they are at the highest risk in the system for multiple placements and at highest risk for never returning to their families.



Trying Differently

A Guide for Daily Living and Working with FAS and Other Brain Differences ~ 2nd Edition

Produced by Fetal Alcohol Syndrome Society Yukon, 2002
Edited by Debbie Trudeau

To contact FASSY:

Box 31396, Whitehorse, Yukon Y1A 6K8
Phone: (867) 393-4948 / Fax: (867) 393-4950
Email: fascalp@yknnet.ca

Sleep Disorders Study Results

Anecdotes from parents and other caregivers of children affected by FAS describing a variety of sleep problems has been confirmed and quantified in a study by **Dr. Ana Hanlon-Dearman** at Children's Hospital.

"Parents frequently tell us their child sleeps terribly, that they may chew on their bed clothes or bang their heads," says Dr. Hanlon-Dearman. "We have heard that these kids are awakeful, that they're up often, restless, moving."

The parents would ask her if the sleep problems were connected with FAS or if it was something else. This became the focus of the research.



The objective of the study was to quantitatively describe the sleep characteristics of children with FASD and qualitatively describe the effects of sleep disruption on the affected child and family. The results could then be used to develop appropriate sleep management strategies for these children.

Families were recruited to the study through the Clinic for Drug and Alcohol Affected Children. Dr. Hanlon-Dearman looked for families who had a child affected by prenatal exposure to alcohol and a second child around the same age who was not affected. The non-affected child acted as the control in the study.

"By including the second, non-affected child of roughly the same age in the same household, we could say these parents are doing the same thing for both kids so it's not about the parenting, it's intrinsic to the child."

In the quantitative part of the study, both children wore a watch-like motion detector called an Actigraph that could be worn on the wrist or ankle. It picked up restlessness and movement in sleep, and identified how long it takes the child to fall asleep, what time they get up in the morning and how many times they get up in the night.

This information was correlated with a sleep log kept by the parents, who would record when they believed the child fell asleep and woke up. The parents also filled out a questionnaire describing the child's sleep habits.

The qualitative segment of the study followed in which most of the parents

(continued on page 8)

Winnipeg CFS: Working with Families who Misuse Alcohol and Other Drugs in Child Welfare

Winnipeg Child and Family Services (WCFS) recently offered training to its 500 social workers around working with families who are experiencing problems with substance abuse.

The training evolved from two factors: agreement by frontline staff that substance abuse training geared specifically toward child welfare/protection was needed and secondly, the results of a study completed by **Valerie Bimm** and **Kim Thomas**, project coordinators with Quality Assurance and Research and Planning at WCFS.

"The study looked at families who return to the agency for service to gain a better understanding of the factors that contribute to this phenomenon," explains Bimm.

In the study they discovered that substance abuse was one of the most significant drivers for families who returned to the agency in a relatively short time. Since this is not unique to Winnipeg, they started to explore what other agencies are doing across North America.

"We learned that agencies are collaborating with addictions treatment programs in a more integrated way than in the past."

While it is standard practice to refer individuals to an outside source for addictions treatment, they realized there were additional ways in which they could collaborate.

The training content was based on the harm reduction model, stages of change model, and the use of motivational interviewing techniques. Motivational interviewing uses a set of techniques and tools that a worker can apply depending on what stage of change the family is at.

"Many clients are not at a stage where they're ready to address the substance abuse issues. The training offers techniques that can be used in discussion with clients that can potentially motivate them toward taking action to address their substance misuse," explains Bimm.

A two-day training session focussing specifically on substance using mothers and their families was offered to all WCFS social workers. Two separate sessions were held, one in January and the other in February, with approximately 140 workers attending each.

The training built on the existing counselling and support skills of WCFS workers, and promoted discussion and action on policies and practices that support workers can use in responding to the needs of mothers with substance use problems.

The keynote speaker was **Nancy Poole**, a provincial research consultant on women and substance use issues with the Aurora Centre, a provincial women's alcohol and drug treatment program based at B.C. Women's Hospital in Vancouver.

Representatives from the major addictions programs in Winnipeg participated in a panel session, including Tamarack Rehabilitation, Native Addictions Council, Behavioural Health Foundation, Main Street Project, Addictions Foundation of Manitoba, Laurel Centre, Salvation Army, and Nor'west Co-op Mentor Program.

These and other agencies were invited to put up display booths. Examples of other agencies included Alcoholics Anonymous, Narcotics Anonymous, Health Sciences Centre detox program, and Union Gospel Mission.

Additional individuals from five key outside addictions agencies also attended the training, allowing the addictions workers and social workers to intermingle and share ideas.

In addition to this training, WCFS is developing an initiative to provide enhanced service to families who present substance abuse issues at intake. The Addictions Foundation of Manitoba is helping intake workers with more intense, specialized training to provide this service.

"This continues our collaborative approach with outside addictions agencies," notes Bimm. "We are all trying to help the same families so it makes sense that we work together in our efforts to do so."

For more information, contact Valerie Bimm at 944-2041 or VBimm@gov.mb.ca.

FASD - Law Enforcement Training Spreads

The FASD training program developed for police officers by **Constable Annette Laporte** of "D" Division, RCMP, and **Terralyn McKee**, Executive Director of The Pas Family Resource Centre, is spreading across the country and across borders.

Over 80 Western Canada court workers were presented with an overview of the program last March, organized by **Sandra Delaronde** with the Department of Justice. This led to a two-day workshop being presented to more than 50 participants of the Aboriginal Federation of Court Workers in Ontario in June, 2002.

In September, 2002, Laporte and McKee presented at the World Forum on Drugs held in Montreal and co-hosted by the Canadian Centre on Substance Abuse. The purpose of the Forum was to engage addictions professionals and those affected by drug use. Participants represented a wide range of interests, including public policy, social services, academia, the justice system, law enforcement, community services, education, and health.

"There was a mix of people from around the world in our session. A doctor from a large research hospital in Toronto really applauded the fact there was finally something in place where there had been a gaping hole," says McKee.

Laporte and McKee followed up in October with another presentation at an FAS conference held in Hamilton, Ontario.

Most recently, in January, 2003, they presented to the Winnipeg City Police Department along with invited Manitoba judges.

"They were an exceptionally receptive crowd. My understanding is that two of the officers will be working internally to implement a program around FAS."

Judge Giesbrecht was one of the judges who attended the training session. He sits on a national committee for the Judges' Association of Canada, which looks at professional development for judges. McKee is excited that the committee is considering adopting the Manitoba-initiated training program with a few additions around alternate sentencing options and more case law. McKee and Laporte have submitted a proposal to present nationally to judges in September, 2003.

For more information, call Terralyn McKee at (204) 623-4841.

COALITION ON ALCOHOL AND PREGNANCY (CAP)

CAP represents over 160 organizations interested in FAS/FAE issues in Manitoba. Six focus areas include: Family Support, Education (including early years), Service Co-ordination/Development, Justice, Research, Communication and Information Dissemination. Special task forces are formed around specific issues. CAP's members represent a diverse cross-section of individuals, groups and communities throughout Manitoba. We bring together the needs of parents (including birth, adoptive and foster) and professionals.

Manitoba F.A.S. News

is published by the Coalition on Alcohol and Pregnancy (CAP).

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Manitoba R3C 3X1
(204) 786-1607 (Fax) 789-9850

CAP receives funding support from Healthy Child Manitoba.

TRAINING

National training for community-based practitioners working in prenatal and early childhood settings

Taking advantage of knowledge gained through several years of work with CAPC/CPNP agencies on this topic, the Canadian Centre on Substance Abuse (CCSA) and Breaking the Cycle have partnered and assembled a team to develop and present a two-day workshop. Day 1 will focus on working effectively with women who have substance use issues to prevent FAS, and Day 2 will address ways to effectively support a child affected by prenatal alcohol exposure.

Intended participants: CAPC/CPNP/AHS workers and others who work with pregnant women, mothers and young children in a community agency setting who've received previous awareness and education on this issue.

When: The team is available to conduct 8 sessions during the months of June and September through December of 2003.

Subject to interest and scheduling, the team aims to conduct at least one workshop in each Health Canada region. They will set up and work at a venue arranged by a host team. The host team will secure a minimum of 20 participants and receive registration fees, arrange for an appropriate venue, and breaks and lunch.

Registration fee: for the two-day workshop is \$100, payable to CCSA, 75 Albert St., Ottawa, ON, K1P 5E7.

Contact: Gary Roberts at the Canadian Centre on Substance Abuse at (613) 235-4048 or GRoberts@CCSA.ca.

Sleep study results cont'd...

participated in an in-depth interview discussing sleep habits, how they coped with the sleep patterns, and their recommendations to others.

When the data was compared, Dr. Hanlon-Dearman found the differences that were significant were the amount of wake episodes as well as the number of sleep episodes, reflecting wakefulness or restlessness in their sleep.

"This tells us that these children are up and down a lot. The number of these episodes increased in children who are alcohol-affected, which means they are constantly awake and asleep through the night. This was the strongest trend in the data."

They also saw trends indicating that the sleep episodes of the children who are alcohol affected were somewhat shorter and the wake episodes were somewhat longer, but not quite enough to reach significance.

"We were just coming close to it and it likely would have with more participants in the study," she notes.

FAS/FAE RESOURCES

Addictions Foundation of Manitoba Library

The William Potoroka Memorial Library at AFM (1031 Portage Ave, Tel: 944-6233) contains a large collection of FAS/FAE materials. Library membership is free and resources can be shipped anywhere in the province.

To receive a bibliography listing the wide range of print and video titles available through AFM Library on:

- ◀ Fetal Alcohol Spectrum Disorder - Parenting, Caregiving and Educational Strategies
- ◀ Prevention of Substance Abuse During Pregnancy

Please contact the Library at 944-6279 or library@afm.mb.ca.

Recent additions to the library include:

FETAL ALCOHOL SPECTRUM

Letters to our children, letters from our children: living with Fetal Alcohol Syndrome and alcohol related effects.

Corp. Author: Alberta Association for Community Living

FETAL ALCOHOL SPECTRUM DISORDER-DIRECTORIES

Directory of FAS/FAE information and support services in Canada (2002)

Corp. Author: Canadian Centre on Substance Abuse

Come, Walk with Me

A Christian response to fetal alcohol-related disabilities

The Mennonite Central Committee (MCC) has produced an informational brochure that briefly explains fetal alcohol-related disabilities, describes symptoms and secondary disabilities, and provides ideas on how a church community can respond and support the family.



Brochure cover photo by Bruce Ritchie

Suggestions for how a church community can respond include:

- Be a loving, caring and appreciate community for all people and their abilities and contributions.
- Work at prevention.
- Respond to individuals who live with the disability.

Copies of the brochure are available from:

Mennonite Central Committee

134 Plaza Drive, Winnipeg, MB, R3T 5K9
Tel: (204) 261-6387 Toll-free 1-888-6337
Online at: www.mcc.org/canada/health/resources.html

Notably, both children were able to wear the sleep watch for basically the same amount of time and in total, the amount of time that the children spent in bed was comparable.

"This is of interest to parents because they may have the sense that the amount of sleep that a child affected by alcohol needs is less, but the study didn't show that," says Dr. Hanlon-Dearman. "This tells us that these kids need their sleep but they're not able to get it, which is why they're tired during the day. They show being tired by being hyperactive."

Results from the sleep questionnaire confirmed significantly more sleep concerns in the children affected by alcohol—they were significantly more tired and more hyperactive during the day. Dr. Hanlon-Dearman thinks these two are interrelated.

"The one thing that surprised us was not seeing a difference in the amount of sleep in total. We may need larger numbers to show that."

The challenge of including a non-affected control child of roughly the same age in the same household turned out to be a limiting factor in

recruiting as many study participants as desired.

Perhaps not surprisingly, parents who were very scheduled and routine oriented were found to be dealing with the sleep problems the best.

They prepared for sleep and set firm limits, such as putting a child to bed with the expectation they would sleep until morning. Although these children would wake during the night, they weren't disruptive.

"Parenting and environment have an impact on a child but I think there are some inherent differences related to being alcohol-affected. I hope that this has been confirmed and that this will be helpful to parents who intuitively recognize this. This study will be used to do more research in this area."

Next steps for Dr. Hanlon-Dearman will be to study more families, and to collaborate with colleagues to look at medical treatment.

"Parents need to understand that the kids are more wakeful and focus on setting routines and firm limit-setting. But I also think we need to look at medical treatment," she notes.

CONFERENCES

Manitoba Foster Family Network Conference

This gathering is a time for foster parents from across Manitoba to get together and learn from guest speakers and each other. The keynote speaker will be **Karen Emilson**, author of *Where Children Run* and *When Memories Remain*. Joining Karen will be the subjects of her books – **David and Dennis Pischke**. Recording artist "Shingoose" (**Curtis Johnnie**) is the closing speaker and will perform his address.

April 25-26, 2003

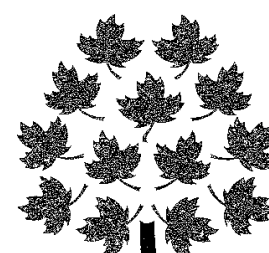
Friday, April 25: 9 a.m.-4 p.m.
plus wine & cheese from 4-6 p.m.
Saturday, April 26: 9 a.m.-3 p.m.

**Canad Inn, Fort Garry
(1824 Pembina Hwy)
Winnipeg, Manitoba**

For more information on conference sessions and registration, contact:

**Manitoba Foster Family Network
Tel: (204) 940-1280
Toll-free: 1-866-458-5650**

FASWorld is an international alliance of parents and professionals who do not want to see any more children, teenagers and adults struggle with birth defects caused when their mothers drank alcohol in pregnancy. For more information, visit www.fasworld.com. To join the FASDay list, subscribe to FASDAY-subscribe@egroups.com.



CHN RCS
canadian-health-network.ca
reseau-canadien-sante.ca

The Canadian Health Network is a national, bilingual, Internet-based health information service. FAS/FAE information can be found under the topic area of Substance Use/Addictions.

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ALCOHOL AND
SUBSTANCE USE
IN PREGNANCY**

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1 (877) FAS-INFO
Toll-free 1-877-327-4636