

A Publication of the Coalition on Alcohol and Pregnancy

INTERNATIONAL FAS DAY

9.99.99 9:09

International FAS Day—Thursday, September 9, 1999—will begin at 9:09 a.m. in New Zealand, just west of the International Dateline, and move westward, wending its way across Canada to Winnipeg.

The goal of International FAS Day is to encourage people everywhere to stop for a "minute of reflection" about Fetal Alcohol Syndrome. During this moment, people are asked to remember the approximately 60 million people throughout the world who are living with brains and bodies damaged by alcohol before they were born. It is also a time to celebrate the successes, achievements and increased awareness of FAS.

Perhaps in that minute each of us can resolve to do everything we can to reduce the number of infants born with this preventable disorder and to help those who are currently struggling with FAS or FAE.

CAP is seeking 99 great ideas to mark International FAS Day. Some of the possible activities that could be presented by you, your agency or organization include:

- host community seminars
- sponsor a poster or essay contest about FAS
- host a "bring a friend" night
- create displays
- undertake local research
- prepare a pamphlet on FAS
- host a speakers series
- consider "wellness" programs
- host an alcohol-free party
- develop an outreach program to assist young parents
- show a video in the schools ("One Drink Won't Hurt My Baby—Will it?" is available from CAP.)

Let CAP know what activities your organization or community is planning. Call Dale Kendel or Diane McMillan at 786-1607.

9 things I will think about in the Minute of Reflection...

- ...the joy that my FAS daughter has brought to me over the years.
- ...my hope that her future, and that of her unborn child, are not as bleak as they sometimes appear.
- ...the precious gifts of friendship that my experience with FAS has brought me.
- ...my hope that we can inform the world about this terrible disorder.
- ...my hope that as a result of our working together, fewer babies will be born with damaged brains and bodies.
- ...my hope that research will find a way to repair some of the damage to our children that alcohol has caused.
- ...all of you.

- Bonnie Buxton, FASWORLD (www.come-over.to/FASWORLD/)

2000 Manitoba:

Prairie Province Conference on FAS

MAY 11-13, 2000 UNIVERSITY OF MANITOBA

The purpose of this interprovincial conference will be to share resources, expertise and experience from across the prairies and to bring together professionals, families and community groups to share and discuss their experiences with each other and with leaders in the FAS field. National and international speakers will present recent initiatives, research and best-practice programs.

Program streams are being planned for professionals and caregivers in areas including: education, health care, mental health, justice, caregiving, prevention, alcohol and drugs, early childhood, First Nations and community initiatives.

The 2000 Manitoba: Prairie Province Conference on Fetal Alcohol Syndrome is the second annual conference sponsored by Manitoba, Saskatchewan and Alberta.

For more information:

Manitoba Children and Youth Secretariat
100-233 Portage Avenue Winnipeg, MB R3B 2A7
Ph: (204) 945-2266 / e-mail: childrenfirst@cys.gov.mb.ca



Discussing the Future of CAP

Why should CAP continue to exist? What accomplishments might be celebrated a year from now and what is the structure required to make these successes happen? These and other questions led to a frequently spirited discussion at the June 14, 1999, meeting of the Coalition on Alcohol and Pregnancy.

to emphasize what participants take away from CAP to their job and workplace as well as how to become more involved.

The conclusion? There's more than enough faith, commitment and interest in CAP continuing forward.

The "Top 10" reasons cited for CAP's continued existence are:

- # 1. To share current and relevant information around FAS.
- # 2. To enhance coordination and prevent duplication of services.
- # 3. To network and problem-solve.
- # 4. To identify gaps in services.
- # 5. To coordinate and publicize activities.
- # 6. To encourage innovative ideas and creativity.
- # 7. To provide a support system and a venue for partnerships.
- # 8. To provide a place of communication.
- # 9. To encourage people to remain interested in the issue of FAS.
- # 10. To provide a place to celebrate successes.

To initiate momentum for the coming year and to attract new people and organizations to CAP, the coalition is staging a fall luncheon on October 1st (see next column).

The event will be a forum to showcase concrete examples of CAP's achievements, such as the creation of the Fetal Alcohol Family Association, and to highlight CAP's goals of education, the sharing of information and resources, and the formation of partnerships.

Specific areas to be highlighted include training, education, daycare, family, child welfare, justice, medical, adult services, rural development, research, media, and women's issues. It will also be an opportunity

The Coalition on Alcohol and Pregnancy invites you to a...

FALL LUNCHEON

Friday, Oct. 1, 1999

11 a.m. - 2 pm.

Wildewood Club
(761 North Drive, Winnipeg)

\$10.00 per person

How far have we come?

Join CAP to celebrate the successes. Bring an associate!

Book your spot with Dale Kendel or Diane McMillan at 786-1607.

(Registration will be limited to the first 150 people to confirm.)

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Manitoba Children and Youth Secretariat Takes Action on FAS

The following initiatives are currently underway as part of the Manitoba government's efforts to reduce FAS and alcohol-related birth defects:

STOP FAS

This pilot project is now at three sites including the Nor'west Mentor Program at Nor-west Community Health Co-op, the Fetal Alcohol Syndrome/Fetal Alcohol Effects Prevention Program at the Aboriginal Health & Wellness Centre of Winnipeg, and the Oski-Keesekow Project in Norway House.

The project encourages pregnant substance abusing women to obtain treatment, stay in recovery, care for their children, become less dependent on social services and prevent births of children affected by alcohol and drugs.

Fetal Alcohol Program

This includes short- and long-term initiatives designed to reduce the number of children born with FAS/FAE and to assist caregivers and service providers. Examples are:

- Prairie Province FAS Initiative to share best practices, expertise and resource materials as well as develop joint strategies and initiatives.

- Drug Affected (FAS) Baby Think It Over Dolls introduced as part of a broad program to teach adolescents about the risks of early pregnancy and drinking during pregnancy as a tool for prevention.

- Art therapy classes for preschool children with FAS.

- Tele-diagnostic project to train physicians in diagnosis through FAS clinics in Thompson, linked to the Children's Hospital in Winnipeg.

- Norway House Community FAS Team to develop a community strategy and response to FAS.

- Community outreach program implemented by the Aboriginal Health & Wellness Centre to provide culturally based alcohol awareness information.

- Expanded services and training opportunities for local physicians.

- FAS audio-cassette and CD-ROM for physicians.

- FAS audio-cassette and training manual for educators.

- FAS media campaign involving television and radio public service announcements, posters and brochures to warn women about the risks of drinking during pregnancy.

- Alcohol warning signs produced by the Manitoba Liquor Control Commission to be voluntarily posted in licensed establishments.

- Interprovincial FAS symposium and diagnostics workshop with the Faculty of Medicine to provide physicians and health care professionals with hands-on training on the diagnosis of children with FAS.

- Professional education and training for a broad range of professionals and community members including the development of training modules for community health nurses, professional caregivers and community mentors.

- FAS/E Prevention Curriculum by Frontier School Division with a strong Aboriginal cultural component (funding provided by the Department of Education).

- Research conducted by Manitoba Health on Pregnant Women's Addiction Treatment Services to determine extent of services currently provided and to identify gaps in services (see story on p. 3).

- Community Initiatives Grant Program (see inset box).

First Nations FAS Pilot Projects

In February 1997, the Assembly of Manitoba Chiefs (AMC) mandated an FAS/E working group. This came after hearing a presentation by Dr. Moffatt and Dr. Chudley whose study results indicated that up to 10% of the student population assessed in a Manitoba First Nations community had FAS/E.

Over the past two years, the FAS/E working group has pursued various initiatives, one of which includes setting up projects at 3 pilot sites (locations are yet to be confirmed).

Four funders have been approached including Medical Services Branch (Health and Welfare Canada), the Department of Indian Affairs, Children and Youth Secretariat, and the pilot sites First Nations communities. As of printing, the Department of Indian Affairs had committed to funding 25% of the program.

Projects at the pilot sites will include three components: a school education program including development of a primary prevention curriculum, access to diagnosis and coordination of treatment, and prevention through community development.

In the first component, teachers will receive an in-service program to better teach children with FAS/E or

alcohol-related birth defects. This will include classroom management skills, curriculum modification and one-on-one teaching. It will also include the development of curriculum on an FAS/E prevention program for Grades 3 and 4.

The second component will assist parents and teachers to access diagnosis and coordinate resource support after diagnosis.

The third is a community development component to work with local staff and parents in prevention and resourcing for

FAS. The project will underscore the community development process in which activities will be community-based initiatives.

Implementation of the projects at the pilot sites is contingent on securing the balance of funding. "I'm feeling confident that Medical Services Branch of Health and Welfare Canada will fund the program, but the province has not indicated yet," says Linda Gries, Chairperson, FAS/E Working Group.

Other activities of the AMC FAS/E working group include regular conferencing, advocating for changes in postsecondary institution curriculums to address FAS/E, and raising the issue in the legal system.

...study results indicated that up to 10% of the student population assessed in a Manitoba First Nations community had FAS/E.

Community Initiative Grants

On May 6, 1999, the Manitoba Government announced one-time funding of \$216,810 for community-based groups to fund programs and activities aimed at reducing the incidence of FAS and alcohol-related birth defects among Manitoba's children. Fifty-three projects were selected.

Through the Community Initiatives Grant Program, non-profit community-based organizations applied for one-time funding of up to \$7,500 per project or group. Applications had to include one or more of the following components: FAS awareness and education; intervention with women at risk of delivering children affected by FAS; and other activities and initiatives that prevent the recurrence of the condition.

Examples of projects which received funding include:

- Brandon and Westman Junior-Senior High School Awareness Project - a prevention initiative sponsored by Salvation Army-Brandon Corps to increase teacher and student awareness
- 2001: Healthy Children Project - a primary prevention initiative of Shamattawa First nation to increase FAS awareness among youth
- FAS/FAE Mobile Resource Centre - an education and awareness outreach program in South Eastman communities sponsored by the Wanipigow School Committee

"It Takes a Community" Fundraiser

The Marsh Bay Farm Experience Camp held a family fun day on August 8, 1999 in support of the Fetal Alcohol Family Association of Manitoba. Recognizing that those with FAS/E have gifts and great potential that often remains unrealized, the event—called "It Takes a Community"—celebrated the gifts and talents of all children.

Special guests at the fundraiser included the former Lt. Gov. Yvon Dumont and his wife Lyla.

The Marsh Bay Farm Experience Camp provided the perfect setting and example of what one young boy is capable of achieving when supported by a loving family and supportive community. At the age of five, Charles was diagnosed with FAS. Now 11 years old, Charles is the creator and owner of the Marsh Bay Farm Experience camp.

The camp, operated by the entire Davidson family, is located on the

family farm near Ashern, Manitoba. It is open to all but gives a special welcome to families of "God's special kids."

Activities at the Marsh Bay Farm Experience Camp provide plenty of opportunities for fun including a playhouse, huge sandbox, trampoline, swings and a play structure. There are also tractor rides, campfires, hiking trails, a small petting zoo, wild berry picking and plenty of birds or wildlife to photograph.

Funds raised at "It Takes a Community" will support the Fetal Alcohol Family Association of Manitoba realize its vision of a community that is not only aware, sensitive and supportive of families and individuals living with FAS/E, but also celebrates all children's gifts.

For more information on the Marsh Bay Farm Experience Camp, e-mail: edavid@escape.ca or call (204) 768-2481.



Best Practices... Environmental Design for Children with FAS

Marlene Waldron and Dorothy Schwab, occupational therapists with School Therapy Services, recognize that the highly charged and stimulating environment of a classroom can be a challenging setting for children with FAS/E. Heightened sensitivity to stimuli due to a compromised Central Nervous System renders these students vulnerable in a highly active setting. The bombardment of sensory information can be difficult for them to process and organize. In turn, these children may appear disorganized, confused, out of control, emotionally upset, and can result in being labelled with behavioural problems.

Drawing from the growing body of FAS research, the two therapists compiled a number of recommendations regarding altered environments, reduced stimulation levels, and structure which provide the best opportunities for children with FAS to thrive in the classroom. A few examples include:

- situating the classroom in a quiet, low traffic area of the school with access to a small self-contained outdoor playground;
- using natural rather than fluorescent lighting;
- painting the walls with muted, soft colours; and
- creating "cozy corners" where the children can go to settle when they are feeling overwhelmed.

For more information, contact Dorothy Schwab in the fall at 452-4311.

Special Education Review Completed

The Manitoba Special Education Review has been completed and includes a section which addresses FAS and FAE. The summary for this section notes:

As knowledge and awareness of FAS/ARBD/ARND [alcohol-related birth defects / alcohol-related neurodevelopmental disorders] has increased, so have the number of diagnoses. While there is great variation in the degree of intellectual impairment, children with FAS/ARBD/ARND often experience difficulties in cognitive functioning, physical, and social functioning. Educational interventions to address the cognitive difficulties... include providing a quiet, distraction-free environment with consistency, brief and concrete activities, and one-to-one assistance. Community-based programs can also contribute to the prevention... and provide vocational training of students... to develop skills for independent living.

Announcements of any program changes are pending from the Department of Education.

Mapping an Interagency Model

When the Interagency FAS/E Program began in Winnipeg, the participants—New Directions, Mount Carmel Clinic, Pregnancy Distress Family Support Services, and Child and Family Services—saw an opportunity to aid other communities considering a similar initiative. "It was a new model," notes Rosemary Craig-Shariff, Senior Family Counsellor at Pregnancy Distress Family Support Services and chair of the steering committee for the Interagency FAS/E Program. "There was a certain excitement generated by the opportunity to develop and implement the model."

This recognition led to a project to document the interagency model in the form of a manual or guidebook. Beyond a working description of the Interagency FAS/E Program, the manual includes a series of articles by people working in the FAS field as well as professionals associated with the interagency program. Also included are personal stories such as an article about a young woman with FAS living in Winnipeg and two others about young mothers who have children with FAS.

Professional contributions to the manual represent a variety of perspectives including those from a daycare provider, a speech therapist, an occupational therapist, and a social worker who works with birth families as well as foster and adoptive families. Concluding the compilation is a final article from the steering committee's perspective on what it was like to start a program from scratch and to run it as a multi-agency committee.

While the manual is being compiled mainly for the benefit of health professionals involved in the FAS/E field, it may also be of interest to parents of children with FAS due to the wide variety of perspectives included. The final draft of the program model is expected to be ready for publication in fall 1999.

For more information, contact Rosemary Craig-Shariff at 772-9091.

Manitoba Study of the Service Needs of Pregnant Addicted Women

The Manitoba Study of the Service Needs of Pregnant Addicted Women is funded by Manitoba Health through the Prairie Women's Health Centre for Excellence. Caroline Tait is the researcher conducting the study.

This study—to determine the service needs of pregnant addicted women in Manitoba—is framed by the following research questions:

- What are the experiences of pregnant addicted women in seeking, participating in, and completing treatment for addiction and in maintaining recovery?
- What range of programs and services currently exist in Manitoba for pregnant addicted women?
- What are the particular challenges in meeting the needs of Aboriginal pregnant addicted women given that programs and services are delivered both on- and off-reserve?
- Are existing programs and services meeting the needs of pregnant addicted women? If not, what barriers, gaps or duplications exist? What programs and services should be in place?
- What are the characteristics of effective programs and services for pregnant addicted women?

West Region Child and Family Services
Presents:

RECLAIMING OUR VOICE: A GATHERING OF MOTHERS

A Two Day Journey for Mothers
who Drank Alcohol or
Used Drugs While Pregnant



November 18-19, 1999
Russell, Manitoba

For details, call Kathy Jones at 985-4050.



20 Ways to Have a Healthy Baby

- Smile and laugh every day.
- Sing children's songs in the shower.
- Recite nursery rhymes to your belly.
- Have an afternoon nap.
- Drink juice, not pop.
- Hug your kids, pets, partner and yourself.
- Rub your tummy with oil, cream or lotion.
- Stay alcohol free.
- Live in a smoke-free home.
- Pick your future babysitters.
- Share your fears and joys about having a baby.
- Meet with your future health nurse.
- Get plenty of fresh air and sunshine.
- Plan to breastfeed.
- Stay drug free.
- Keep at least 10 prenatal visits.
- Soak your feet.
- Make the break — be smoke free.
- Take a stroll.
- Nurture your spirit. Be kind to yourself.

(Reprinted from "101 Ways to have a Healthy Baby" published by the Alberta Alcohol and Drug Abuse Commission.)

COALITION ON ALCOHOL AND PREGNANCY (CAP)

CAP represents 60 organizations interested in FAS/FAE issues in Manitoba. The six working committees include: Research/Communications, Family Support, Education, Service Coordination, Prevention and Justice. CAP's members represent a diverse cross-section of individuals, groups and communities. They participate on behalf of parents (including birth, adoptive and foster) and professionals in the health, education, social service and correctional sectors.

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RESOURCES & TRAINING

PROFESSIONAL

"What Doctors Need to Know About Fetal Alcohol Syndrome" (CD-ROM format)

Produced by The College of Physicians & Surgeons of Manitoba and the Manitoba Children and Youth Secretariat.

Topics include the birth defects associated with FAS, the frequency of FAS, causes of and how to diagnose FAS, and the importance of peer support groups for parents.

"What Educators Need to Know About Fetal Alcohol Syndrome" (audio-cassette tape)

Produced by Manitoba Education and Training and the Manitoba Children and Youth Secretariat.

Speakers include John McCaig (Consultant in Mental Health, Clinical Management Group), Lois Friesen (Special Education Teacher, Laura Secord School), Julia Wellwood (Child Development Specialist, FAS Outreach Team, Children's Special Services), and Val Surbey (parent of children with FAS and paraprofessional).

MMA Training Session

The Manitoba Medical Association (MMA) is holding a workshop/training session for physicians on November 13, 1999.

GENERAL/PUBLIC

FAS/FAE Information Service

For bilingual information on Fetal Alcohol Syndrome/Fetal Alcohol Effects, call TOLL FREE:

1-800-559-4514

The FAS/FAE Information Service is provided by the Canadian Centre on Substance Abuse (CCSA).

Alcohol Substance Use in Pregnancy Helpline

Toll free within Canada

Monday to Friday, 9 a.m. to 5 p.m. (in each time zone)



The Hospital for Sick Children

The Motherisk Alcohol and Substance Use Helpline provides information about alcohol and social drug use during pregnancy and breastfeeding.

Motherisk provides information and nonjudgmental counselling to pregnant and breastfeeding women, their families, and health-care providers.

New RRC certificate program...

FAS/FAE Support Worker

Parents often need a break from the demanding role of parenting. For those who have children with FAS or FAE, that need is particularly critical.

"Research has clearly shown that the most important factor for kids to reach their potential is to have a stable home," says Diane McMillan, Executive Director of the Fetal Alcohol Family Association of Manitoba. "Families break down if there is no respite available for the parents."

Due to the complexity of care required, a qualified respite worker with a sound understanding of FAS/FAE is essential. Babysitters are often unable to cope resulting in a frustrating and traumatic experience for the entire family. The need for structured, repetitive support means a support worker must be able to step in and take over the duties and routines already established in the household.

To develop a pool of trained support workers, a partnership was formed between the Fetal Alcohol Family Association, the Association for Community Living, the Addictions Foundation of Manitoba and Red River College.

The FAS/FAE Support Worker Certificate Program will train participants to work with families who have children with alcohol-related birth defects. The program content is based on issues of safety, consistency, flexibility, unpredictability and reinforcement.

Administered by the Fetal Alcohol Family Association, the program is being expanded to a full-time program during the day from its start as a few continuing education courses offered in the evenings. Funding from the Department of Education and Training is expected to allow 20 full-time

day students to take the first offering of the FAS/FAE Support Worker Certificate Program this fall. It will take students approximately 12 to 14 weeks, including 3 practicums of one week each, to complete the 370-hour program.

McMillan notes there is good potential of employment for graduates. Interested employers would include families, schools, child welfare agencies, daycares, and youth corrections services.

Advertisements to promote the 20 funded full-time openings to potential participants are scheduled to appear in late August and early September.

For more information, call Diane McMillan at 786-1847.

AFM Adult Education Services

General and advanced courses being offered by the Addictions Foundation of Manitoba in 1999-2000 include:

Alcohol Related Birth Defects (FAS/FAE) - this course is appropriate for professional caregivers such as physicians nurses, child care workers and clinicians.
Dates: September 16 & 17, 1999
Fee: \$115.00

Chemical Dependency Intervention Course - This course is appropriate for professionals, para-professionals and other resource people, students and the general public.
Dates: September 20-24, 1999 (1 week block - 9 a.m. to 4:30 p.m.)
Fee: \$175.00

For more information, contact the Community Prevention Programs Unit at 944-6260.

Fetal Alcohol Family Association

The Fetal Alcohol Family Association of Manitoba (FAFA) is a provincial advocacy and support network for families affected by FAS or FAE. The goals of FAFA are to provide support, education and training to families affected by FAS/E; to network with families, family support groups and professionals on

a provincial level; and to advocate for improvement in services.

For information on FAFA activities and services, contact Diane McMillan at 786-1847. For information on the parent support group in Brandon, call group leader Melody Brooks at (204) 725-4892.



THIS IS YOUR LAST ISSUE OF MANITOBA F.A.S. NEWS...

We need to hear from you!

We do not want to send unwanted material. Let us know that you want to continue receiving Manitoba F.A.S. News and show your support by purchasing an annual subscription for \$15.00.

Specific areas of interest (check as many as applicable):

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Name: _____

Organization: _____

Address: _____

Ph: _____ Fax: _____ E-mail: _____

Send the completed form and a \$15.00 cheque payable to the Association for Community Living Manitoba and mail to:

Coalition on Alcohol and Pregnancy (CAP)
c/o Association for Community Living Manitoba
210-500 Portage Avenue Winnipeg, MB R3C 3X1