

The Wisconsin Fetal Alcohol Spectrum Disorders (FASD) Resource Guide

A listing of services and materials for individuals and families affected by fetal alcohol spectrum disorders (FASD) and the providers who serve them.

Updated August 2006

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We hope this directory is useful to you, but please note we do not endorse any specific resources or materials.

The resources and materials listed in this booklet were compiled from a variety of sources including the following:

- o The complete FASD national and state directory prepared by the National Organization on Fetal Alcohol Syndrome (NOFAS) is available online at: <http://www.nofas.org/resource/directory.aspx>
- o The Arc's complete Fetal Alcohol Syndrome Resource Guide is available online at <http://www.thearc.org/misc/fasresources.doc>

Section 1: Overview of FASD

What are fetal alcohol spectrum disorders (FASD)?

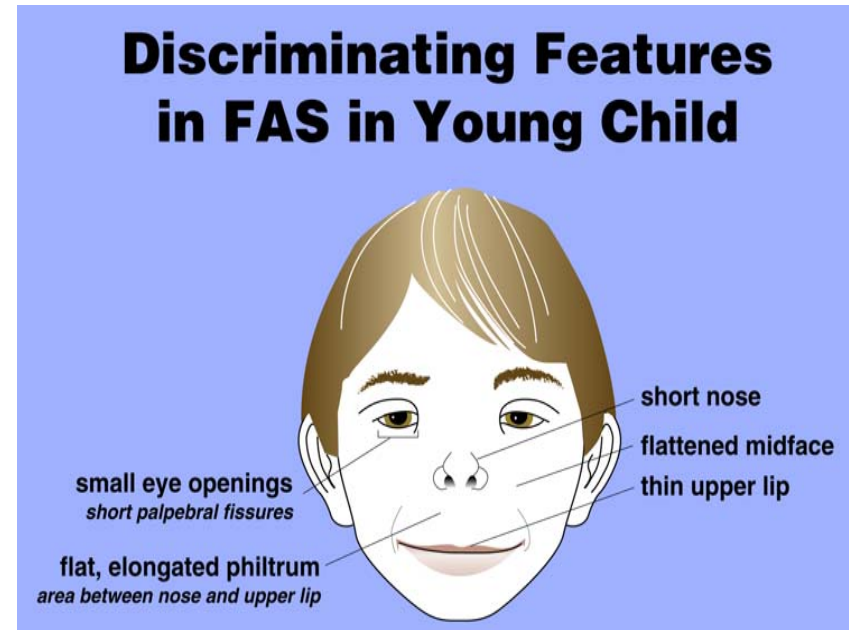
Alcohol use during pregnancy is now considered a leading cause of mental retardation and learning disabilities in the U.S. (Mattson & Riley, 1997). Fetal alcohol spectrum disorders or FASD is an umbrella term used to describe the continuum of effects associated with prenatal alcohol exposure; but is not intended to be used as a diagnosis. A number of factors can contribute to the severity of the effects of prenatal alcohol exposure including the timing and quantity of alcohol exposure during pregnancy, the pattern of drinking (e.g. binges), genetic factors, nutrition, and other environmental factors.

What is fetal alcohol syndrome (FAS)?

Fetal alcohol syndrome (FAS) is a combination of physical features and cognitive impairments that occur in some children who were prenatally exposed to alcohol. Although there is a lot of variability among children with FAS, the three main diagnostic criteria are:

- **Central Nervous System Effects-** the brain is particularly sensitive to alcohol, and prenatal exposure can affect the cerebral cortex, hippocampus, cerebellum, corpus callosum, and basal ganglia resulting in cognitive disabilities; processing, learning, and memory problems; and much more.
- **Growth Retardation-** prenatal alcohol exposure can cause intrauterine and postnatal growth retardation resulting in decreased weight, length/height, and head circumference.

- **Facial Features-** prenatal alcohol exposure can also change the development of a number of facial features resulting in small eye openings (short palpebral fissures), a flat ridge between the upper lip and nose (philtrum), and a thin upper lip (vermillion).



Source: FEN

What are the other effects of prenatal alcohol exposure?

If an individual has some, but not all of the characteristics of FAS—along with a history of prenatal alcohol exposure— he/she may be diagnosed with one of the following conditions:

- Partial FAS
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)

Overview of FASD, Continued

What are the Benefits of a Diagnosis

- o Provides answers and may lead to changed expectations for individuals, families, and providers
- o Creates eligibility for services
- o Facilitates appropriate interventions and support

Why is a diagnosis important?

Although a specialist usually makes the diagnosis of FAS or one of the other FASD, it is important for families, health and human services providers, educators, and others to be aware of the signs and symptoms of FASD. An accurate diagnosis can benefit the individual, family, and service system in a number of ways.

The key to helping individuals with an FASD is to “think younger”. Just because they look and even talk their age, doesn’t mean an individual with FASD can “think” their age. An “external brain” (outside help and support) is the only humane approach in meeting the needs of individuals with FASD.

Patti Cameron
FEN Coordinator

Section 2: FASD Resources

A. Wisconsin Family Support and Advocacy Services

Family Empowerment Network (FEN)

FEN is a program serving families affected by FASD and the providers who work with them. Their mission is to empower families through education, support, and advocacy. FEN provides training, has a toll-free telephone information line, and publishes the *FEN Pen* newsletter.

Staff: Director- Georgiana Wilton, PhD
Coordinator- Patricia Cameron, MS

Address: UW School of Medicine and Public Health
Department of Family Medicine
777 South Mills Street, Room 3807
Madison, WI 53715

Telephone: Toll free- 800-462-5254 Direct- 608-262-6590

Fax: 608-263-5813

Email: fen@fammed.wisc.edu

Website: www.fammed.wisc.edu/fen

FEN-North

FEN-North is housed at the Douglas County Health Department. It’s mission is to raise awareness, provide education, and support families affected by FASD in northern Wisconsin.

Contacts: Judith Walker, Richard Walker

Address: 1901 Baxter Avenue
Superior, WI 54880

Telephone: 715-394-6909 715-395-1300

A. Wisconsin Family Support and Advocacy Services, Cont.

Post-Adoption Online Support Group

The Post-Adoption Online Support Group is an invitation-only group that provides online information, referrals, and support to adoptive, foster, and birth families who have children with FASD and other challenging behaviors. Email for more information or to request permission to join the group.

Contact: Sandy Yaroach
Email: post_adopt@hotmail.com
Website: <http://groups.yahoo.com/group/post-adopt>

Disability Rights Wisconsin (DRW)

DRW (formally the Wisconsin Coalition for Advocacy) is Wisconsin's nonprofit agency chosen to provide protection and advocacy for people with disabilities throughout the state. They are completely independent of state government and direct service providers.

Address: 16 North Carroll Street, Suite 400
Madison, WI 53703
Telephone: Toll free- 800-928-8778 Direct- 608-267-0214
Website: www.w-c-a.org/

Wisconsin Family Ties

Wisconsin Family Ties is a statewide non-profit organization, run by families for families who have children and adolescents with emotional, behavioral, and mental disorders. The group provides information, education, referrals, and support including family advocates and support groups.

Address: 16 North Carroll Street, Suite 640
Madison, WI 53703
Telephone: 608-267-6888
Toll Free: For Parents Only- 800-422-7145
Website: www.wifamilyties.org/

Healthy Choices Project

The Healthy Choices Project raises awareness about the risks of alcohol-exposed pregnancies, promotes prevention, provides education and training, and provides brief alcohol intervention for women of childbearing age. The project provides free awareness materials and has a toll-free telephone information line.

Contact: Kristi Obmascher, Prevention Specialist
Address: UW School of Medicine and Public Health
Department of Family Medicine
777 South Mills Street, Room 3806
Madison, WI 53715
Telephone: Toll free- 800-752-3157 Direct- 608-261-1418
Fax: 608-263-5813
Email: healthy.choices@fammed.wisc.edu
Website: www.fammed.wisc.edu/healthychoices (under construction until fall 2006)

My Baby and Me Program

My Baby and Me is a program to help pregnant women stay alcohol-free, and is a partnership between the Wisconsin Department of Health and Family Services (DHFS) and the Wisconsin Women's Health Foundation. The goal of the program is to increase the number of women who do not drink alcohol during pregnancy by using a strength-based motivational intervention for behavior change and enhancing prenatal care coordination services.

Contact: Susan E. Gadacz, Women's Alcohol and Other Drug Abuse (AODA) Treatment Coordinator
Fetal Alcohol Spectrum Disorders Project Director
Division of Disability and Elder Services (DDES)
Address: 1 West Wilson Street
Madison, WI 53702
Telephone: 608-267-7704
Email: gadacse@dhfs.state.wi.us

A. Wisconsin Family Support and Advocacy Services, Cont.

The Arc-Wisconsin

The Arc-Wisconsin provides a variety of assistance to people with developmental and related disabilities and their families including advocacy and public policy development, training and information, and guardianship services.

Address: 600 Williamson Street
Madison, WI 53703

Telephone: Toll free- 877-272-8400 Direct- 608-251-9272

Email: arcw@chorus.net

Website: www.arc-wisconsin.org

Wisconsin Council on Children and Families

The Wisconsin Council on Children and Families, Inc. is a nonprofit, multi-issue child and family advocacy agency. The Council's mission is to promote the well-being of children and families in Wisconsin by advocating for effective and efficient health, education, and human service delivery systems.

Address: 16 North Carroll Street, Suite 600
Madison, WI 53703

Telephone: 608-284-0580

Website: www.wccf.org/

Wisconsin Dept of Health and Family Services, Division of Disability and Elder Services (DDES)

DDES focuses on long term support for the elderly and persons with disabilities, mental health and substance abuse issues.

Contact: Susan E. Gadacz
Women's Alcohol and Other Drug Abuse (AODA)
Treatment Coordinator, FASD Project Director

Address: 1 West Wilson Street
Madison, WI 53702

Telephone: 608-267-7704

Email: gadacse@dhfs.state.wi.us

B. Wisconsin Diagnostic Services

FASD Clinic

The FASD Clinic is a collaboration among clinicians at the University of Wisconsin School of Medicine and Public Health Departments of Pediatrics and Family Medicine, the UW Waisman Center, and the UW Hospital and Clinics. The clinic provides assessment and services for children at-risk for fetal alcohol spectrum disorders (FASD) and their families.

Address: 1500 Highland Avenue
Madison, WI 53705

Telephone: Toll free- 800-462-5254
Direct- 608-262-6590

Email: fasdclinic@fammed.wisc.edu

UW-Madison, Clinical Genetics Center

Diagnostician: David Wargowski, MD

Address: 335 Waisman Center
1500 Highland Avenue
Madison, WI 55705

Telephone: 608-263-2507

Outreach Sites: Green Bay, Neenah,
Rhineland, Ashland

Telephone: 608-263-2510

B. WI Diagnostic Services, Cont

Children's Hospital of Wisconsin, Genetics Center

Diagnosticians: William Rhead, MD, PhD
David Bick, MD

Address: PO Box 1997
Mainstation 716
Milwaukee, WI 53201

Telephone: Clinic- 414-266-3347
Scheduling- 414-266-2653

Marshfield Clinic, Genetic & Birth Defects Clinic

Diagnosticians: Philip Giampietro, MD, PhD
Elizabeth McPherson, MD

Address: 1000 N Oak Street
Marshfield, WI 54449

Telephone: Toll free- 877-216-8535
Direct- 715-387-5240

Gunderson Lutheran Medical Center

Diagnostician: Kerry Baldwin Jedele, MD

Address: 1900 South Avenue
LaCrosse, WI 54601

Telephone: Toll free- 800-362-9567
Direct- 608-775-6766

MaMaaawi (Together for Children) Red Cliff Developmental Assessment Clinic

Diagnostician: Grace Heitsch, MD

Address: 88455 Pike Road
Bayfield, WI 54814

Telephone: 715-779-3707

Please note: this program is currently only serving Red Cliff Tribal members.

C. Wisconsin Education and Training Services

Family Empowerment Network (FEN)

The Family Empowerment Network (FEN) provides a variety of educational and training opportunities for families affected by FASD and the health and human services providers who serve them. An annual Training of Trainers (TOT) is held to provide in-depth training for those interested in becoming FASD trainers for their agencies and/or communities.

Contact: Patricia Cameron, MS

Address: UW School of Medicine and Public Health
Department of Family Medicine
777 South Mills Street, Room 3807
Madison, WI 53715

Telephone: Toll free- 800-462-5254 Direct- 608-262-6590

Fax: 608-263-5813

Email: fen@fammed.wisc.edu

Website: www.fammed.wisc.edu/fen

FASD Education Program

The FASD education program at the University of Wisconsin-Madison, Department of Professional Development and Applied Studies (PDAS) provides an array of in-person and online continuing education programs that address FASD and related issues.

Contact: Kristi Obmascher

Address: 313 Lowell Center, 610 Langdon Street
Madison, WI 53703

Telephone: Toll free- 800-442-4617 Direct- 608-262-8971

Email: kobmascher@dcs.wisc.edu

D. National FASD Resources

Centers for Disease Control and Prevention (CDC), Fetal Alcohol Syndrome Prevention Team

The mission of the CDC FAS Prevention team is to prevent FASD and ameliorate these conditions in children already affected. They work with partners across the country to conduct surveillance, and implement and evaluate FASD programs.

Address: National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Road, MS-E86
Atlanta, GA 30333

Telephone: 1-800-CDC-INFO (232-4636)

Email: cdcinfo@cdc.gov

Website: www.cdc.gov/ncbddd/fas/

The FASD Center for Excellence

The FASD Center for Excellence of the Substance Abuse and Mental Health Services Administration (SAMHSA) is a federal initiative devoted to preventing and treating FASD. They provide information, resources, training, and technical assistance.

Address: SAMHSA FASD Center for Excellence
2101 Gaither Road, Suite 600
Rockville, MD 20850

Telephone: 1-866-STOPFAS (786-7327)

Email: fasdcenter@samhsa.hhs.gov

Website: fasdcenter.samhsa.gov

National Organization on Fetal Alcohol Syndrome (NOFAS)

NOFAS is dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and to improving the quality of life for those affected individuals and families.

Address: National Organization on Fetal Alcohol Syndrome
900 17th Street, NW, Suite 910
Washington, DC 20006

Telephone: Toll Free- 800-66NOFAS Direct- 202-785-4585

Website: www.nofas.org/

National Clearinghouse for Alcohol and Drug Information (NCADI)

NCADI is the Nation's one-stop resource for information about substance abuse prevention and addiction treatment; including materials related to FASD.

Address: NCADI
PO Box 2345
Rockville, MD 20847-2345

Telephone: Toll Free- 800-729-6686 Direct- 301-468-2600

Website: www.health.org/

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

NIAAA supports and conducts biomedical and behavioral research on the causes, consequences, treatment, and prevention of alcoholism and alcohol-related problems, including FASD. They also provide free information and publications.

Website: www.niaaa.nih.gov/

Section 3: FASD Materials

A. FASD-Related Videos

“Fetal Alcohol Syndrome and Effect: Stories of Help and Hope” (Hazelden, 1993)

Balanced view of medical and social consequences of fetal alcohol syndrome, including examples of positive outcomes possible for children with FASD. For providers and parents.

Vendor: Hazelden Bookstore
Cost: \$225.00
Telephone: 800-328-9000
Email: customersupport@hazelden.org
Website: www.hazelden.org/

“Recovering Hope: Mothers speak out about fetal alcohol spectrum disorders” (federal Substance Abuse and Mental Health Services Administration)

Video, discussion guide, and brochures sharing intimate look at mothers and families of children affected by FASD.

Vendor: National Clearinghouse for Alcohol and Drug Information (NCADI)
Address: PO Box 2345
Rockville, MD 20847-2345
Telephone: Toll Free- 800-729-6686 Direct- 301-468-2600
Website: www.health.org/

“Worth the Trip”, (Vida Health, 1996)

Video and guide for parents and professionals that includes information regarding the health, development, and learning styles of children affected by maternal drinking. The video was funded by the National Institute of Alcohol Abuse & Alcoholism (NIAAA).



Vendor: Vida Health Communications, Inc
Cost: \$150.00 Classroom License
\$24.95 Home Edition
Address: 6 Bigelow Street
Cambridge, MA 02139
Telephone: Toll Free- 800-550-7047 Direct- 617-864-4334
Website: www.vida-health.com/

“Students Like Me”, (Vida Health, 2000)

Video and guide for elementary and special educators who work with children affected by FASD, including recommended teaching methods and classroom modifications.

Vendor: Vida Health Communications, Inc
Cost: \$195.00 Classroom License
\$24.95 Home Edition
Address: 6 Bigelow Street
Cambridge, MA 02139
Telephone: Toll Free- 800-550-7047 Direct- 617-864-4334
Website: www.vida-health.com/

B. FASD-Related Print Materials

“Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome” (Kleinfield & Wescott, Editors; 1993)

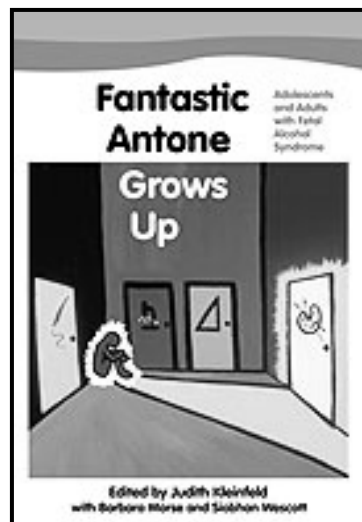
Compilation of promising strategies used by parents, educators, and others who work with children with FASD.

Vendor: University of Alaska Press
Cost: \$21.95 (paperback)
Address: PO Box 756240- UAF
 Fairbanks, AK 99775
Telephone: Toll Free- 888-252-6657 Direct- 907-474-5831
Email: fypress@uaf.edu
Website: www.uaf.edu/uapress

“Fantastic Antone Grows Up” (Kleinfield, Morse, and Wescott, Editors; 2000)

Sequel to “Fantastic Antone Succeeds”, the book provides a guide to raising adolescents and adults with FASD.

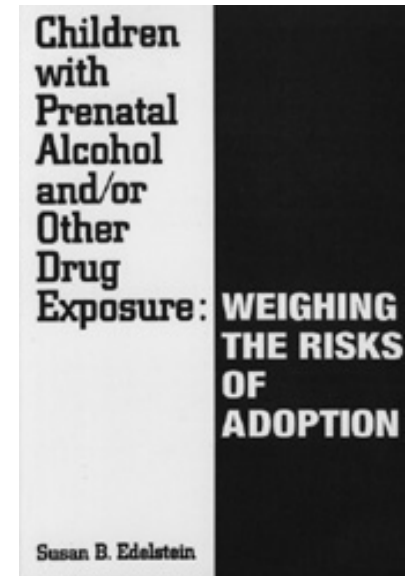
Vendor: University of Alaska Press
Cost: \$23.95 (paperback)
Address: PO Box 756240- UAF
 Fairbanks, AK 99775
Telephone: Toll Free- 888-252-6657
 Direct- 907-474-5831
Email: fypress@uaf.edu
Website: www.uaf.edu/uapress/



“Children with Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption” (Susan Edelstien, 1995)

Practical suggestions, recommendations and ideas for families adopting children with FASD.

Vendor: CWLA Press
Cost: \$12.95 (paperback)
Address: 440 First Street, NW
 Third Floor
 Washington, DC 20001
Telephone: 202-638-2952
Website: www.cwla.org/pubs/



“Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook” (Brenda McCreight, 1997)

Guide offers a developmental approach to specific behavioral techniques for children with FASD from infancy through late adolescence.

Vendor: CWLA Press
Cost: \$16.95 (paperback)
Address: 440 First Street, NW
 Third Floor
 Washington, DC 20001-2085
Telephone: 202-638-2952
Website: www.cwla.org/pubs/

B. FASD Print Materials, Cont.

“Fetal Alcohol Syndrome, Fetal Alcohol Effects: Strategies for Professionals” (Diane Malbin, 1993)

Guide for substance abuse counselors and othes; includes information and suggestions for talking with women about FASD.

Vendor: Hazelden Bookstore
Cost: \$5.35 (booklet)
Telephone: 800-328-9000
Email: customersupport@hazelden.org
Website: www.hazelden.org/

“Trying Differently Rather Than Harder” (Diane Malbin, 2002)

A sequel to “Fetal Alcohol Syndrome, Fetal Alcohol Effects”, this booklet provides a model for working effectively with children, adolescents, and adults with FASD.

Publisher: Tectrice Northwest
Vendor: FASCETS, Inc
Cost: \$15.00 (booklet)
Email: dmalbin@fascets.org
Website: www.fascets.org

A very different picture of people with FAS... is now emerging... one of hope and potential...Although the damaging effects are very real...there is increasing evidence... that with identification and supportive intervention people with FAS... are living healthy, successful lives.

Diane Malbin
“FAS/FAE: Strategies for Professionals”

“Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment” (Stratton, Howe & Battaglia, Editors; 1996)

The U.S. Congress mandated report on FAS by the Institute of Medicine (IOM) that discusses diagnosis and surveillance, as well as prevention and treatment of FASD.

Vendor: National Academies Press
Cost: \$42.08 (paperback)
\$32.00 (PDF version)
Telephone: 888-624-8373
Website: www.nap.edu/

“Fetal Alcohol Syndrome: A Guide for Families and Communities” (Ann Streissguth, 1997)

Provides an overview of medical and social issues related to FASD for families and others.

Vendor: Paul H Brooks Publishing Co, Inc
Cost: \$24.95 (paperback)
Telephone: 800-683-3775
Website: www.brookespublishing.com

“The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction” (Carol Stock Kranowitz, 1998)

Clearly written guide to sensory integration dysfunction, including strategies for parents.

Publisher: Berkley Publishing Group
Vendor: Available from Amazon.com
Cost: from \$19.99 (new paperback)

C. FASD-Related Websites

The Family Empowerment Network (FEN)

Web Address: www.fammed.wisc.edu/fen

The Centers for Disease Control & Prevention (CDC)

Web Address: www.cdc.gov/ncbddd/fas/default.htm

The FASD Center for Excellence

Web Address: fasdcenter.samhsa.gov/

The National Organization on Fetal Alcohol Syndrome (NOFAS)

Web Address: www.nofas.org

The Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)

Web Address: www.mofas.org/

The University of Washington, Fetal Alcohol and Drug Unit

Web Address: <http://depts.washington.edu/fadu/>

Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc (FASCETS)

Web Address: <http://www.fascets.org/>

FAS Community Resource Center

Web Address: <http://www.come-over.to/FASCRC/>

D. FASD-Related Online Curriculum

“Fetal Alcohol and Women”

This two-hour online course provides an overview of FASD for health care providers and others. Learning objectives include: increasing detection and treatment of women affected by alcohol; and minimizing fetal damage due to alcohol use during pregnancy.

Vendor: University of Wisconsin

Web Address: <http://www.cme.uwisc.org/>

Course #: 6049

Instructor: Mike Fleming, MD

Cost: Free until 12/10/06

“Fetal Alcohol Syndrome”

This online lecture was originally given as a 50 minute presentation at a Research Society on Alcoholism meeting. It provides a basic overview of what we know about the effects of prenatal alcohol exposure

Vendor: Research Society on Alcoholism (RSA)

Web Address: <http://rsoa.org/lectures/07/index.html>

Instructor: Ed Riley, PhD

Cost: Free

Notes...

Directory Provided By:

The Family Empowerment Network (FEN) and Wisconsin Treatment Outreach Project (WTOP) at the University of Wisconsin, Dept of Family Medicine— with funding from the Wisconsin Bureau of Mental Health and Substance Abuse Services (BMHSAS); and the Healthy Choices Project at the University of Wisconsin, Dept of Family Medicine— with funding from the Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), Cooperative Agreement # U84/CCU524082-01.

For more information about fetal alcohol spectrum disorders (FASD) contact the Family Empowerment Network (FEN): 1-800-462-5254

For more information about alcohol and pregnancy contact the Healthy Choices Project: 1-800-752-3157

