Wisconsin Fetal Alcohol Spectrum Disorders (FASD) Resource Guide

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

FASD Education and Outreach Projects
University of Wisconsin Department of Family Medicine and Community Health
1100 Delaplaine Court
Madison, WI 53715
Phone: 608-262-6590
Email: WTOP@fammed.wisc.edu
www.pregnancyandalcohol.org
The Wisconsin FASD Resource Guide

This booklet is designed to share an array of valuable resources that address fetal alcohol spectrum disorders (FASD) and related issues.

It is comprised of three sections:

2. Wisconsin and national resources for individuals and families affected by FASD, and the providers who work with them.
3. Listing of state-wide and nationally available information and awareness materials.
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We hope this directory is useful to you, and please note we do not endorse specific resources or materials. The resources and materials listed in this booklet were compiled from a variety of sources including the following:

National Organization on Fetal Alcohol Syndrome (NOFAS)
http://www.nofas.org/resource/directory.aspx

The Arc’s Fetal Alcohol Syndrome Resource Guide
http://www.thearc.org/misc/fasresources/doc
Section 1: Overview of FASD

What are fetal alcohol spectrum disorders (FASD)?
Alcohol use during pregnancy is a leading preventable cause of mental retardation and learning disabilities in the U.S. (CDC, 2009). 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 effects on the fetus due to prenatal alcohol exposure including the timing and quantity of alcohol use 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 individuals who were prenatally exposed to alcohol. It is the most recognizable of the conditions caused by prenatal alcohol exposure. Although there is a lot of variability among individuals with FAS, the three main diagnostic criteria are:

Central Nervous System— the brain is particularly sensitive to alcohol, and prenatal exposure can affect the structure and function of the Cerebral cortex, hippocampus, cerebellum, corpus callosum, and basal ganglia resulting in cognitive disabilities; processing, learning, and memory problems; and much more.

Growth Deficits— 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 affect the development of a number of facial features resulting in small eye openings (short palpebral fissures), a smooth ridge between the upper lip and nose philtrum), and a thin upper lip.

What are the other effects of prenatal alcohol exposure? If some but not all of the characteristics of FAS—along with a history of prenatal alcohol exposure—are present, an individual may be diagnosed with one of the following conditions:

- Partial FAS (pFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)
- Neurodevelopmental disorder associated with prenatal alcohol exposure (DSM-5)
Why is a diagnosis important?
Although a physician makes the diagnosis of FAS or one of the other FASDs, 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.

What are the benefits of a diagnosis?
- Provides answers and may lead to changes in expectations for individuals, families, and providers
- Creates eligibility for services
- Facilitates appropriate interventions and support

The following pages provide diagnostic options in Wisconsin. If you need assistance in scheduling, or need assistance with payment for the assessment, please contact WTOP staff at 1-608-262-6590
Section 2: Wisconsin Diagnostic Services

Children’s Hospital of Wisconsin Genetics Center

Diagnosticians: William Rhead, MD, PhD
Donald Basel, MD

Address: PO Box 1997
9000 W. Wisconsin Avenue
Milwaukee, WI 53226

Telephone: 414-266-3347

Central Scheduling: 414-607-5280

Gundersen Lutheran Medical Center

Diagnostician: Kerry Baldwin Jedele, MD

Address: 1900 South Avenue
La Crosse, WI 54601

Telephone: 800-362-9567 Ext. 52599
608-775-2599
Marshfield Clinic
Genetic & Birth Defects Clinic

Diagnostician: FACMG
Ariel Brautbar, MD

Address: 1000 N Oak Avenue
Marshfield, WI 54449

Telephone: 877-216-8535
715-221-7400

Outreach Site: Eau Claire Center
2116 Craig Road
Eau Claire, WI 54701
UW-Madison, Clinical Genetics Center

Diagnosticians:  David Wargowski, MD  
                 Greg Rice, MD  

Address:  Waisman Center  
          1500 Highland Avenue  
          Madison, WI 53705  

Telephone:  Cindy  
            Coordinator Madison Clinic  
            608-262-2507  
            *Please specify that you are calling for an assessment for fetal alcohol syndrome by Dr. Wargowski.  

Outreach Site:  Alyson  
                Appleton  
                920-831-1296  

Outreach Site:  Green Bay  
                920-433-8559
Section 3: FASD Resources

A. Wisconsin Family Support/Advocacy Services

**Aging and Disability Resource Centers (ADRC)**

Aging and Disability Resource Centers (ADRCs) are the first place to go to get accurate, unbiased information on all aspects of life related to aging or living with a disability.

**Address:**
Department of Health Services  
1 West Wilson Street  
Madison, WI 53703

**Telephone:** 608-266-1865  
**Email:** DHSRCTeam@wi.gov  
**Website:** www.dhs.wisconsin.gov/ltcare/adrc/

**The Arc-Wisconsin**

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

**Address:**  
2800 Royal Avenue, Suite 209  
Madison, WI, 53713

**Telephone:** 608-222-8907  
877-272-8400

**Fax:** 608-222-8908  
**Email:** arcw@att.net  
**Website:** www.arc-wisconsin.org
Children and Youth With Special Healthcare Needs Program

The Children and Youth with Special Health Care Needs Program collaborates with national, state and community based partners to link children to appropriate services, close service gaps, reduce duplication and develop policies to better serve families.

Telephone: 608-266-8178

Disability Rights Wisconsin (DRW)

DRW provides protection and advocacy for people with disabilities throughout the state. They are completely independent of state government and direct service providers.
Website: www.disabilityrightswi.org

Madison (DRW)
Address: 131 W. Wilson St., Suite 700
Madison, WI 53703
Telephone: 800-928-8778
608-267-0214

Rice Lake (DRW)
Address: 217 W. Knapp St.
Rice Lake, WI 54868
Telephone: 715-736-1232
877-338-3724
Fax: 715-736-1252

Milwaukee (DRW)
Address: 6737 W. Washington St., Ste 3230
Milwaukee, WI 53214
Telephone: 414-773-4646
800-708-3034
Fax: 414-773-4647
FASD Education and Outreach Projects

Contact: Angelica Salinas, MS, CRC
Address: UW School of Medicine and Public Health
Department of Family Medicine
1100 Delaplaine Court
Madison, WI 53715
Telephone: 608-262-6590
Fax: 608-263-5813
Email: Angelica.Salinas@fammed.wisc.edu
Website: www.pregnancyandalcohol.org
Facebook: www.facebook.com/WisconsinTreatmentOutreachProject

Contact: Lindsey Peterson, MS, CRC
Address: UW School of Medicine and Public Health
Department of Family Medicine
1100 Delaplaine Court
Madison, WI 53715
Telephone: 608-265-6392
Fax: 608-263-5813
Email: Lindsey.Peterson@fammed.wisc.edu
Website: www.pregnancyandalcohol.org
Facebook: www.facebook.com/WisconsinTreatmentOutreachProject

Marilyn Holschuh, LCSW
A Wisconsin Licensed Clinical Social Worker (LCSW) who works with children with a FASD diagnosis and attachment issues.

Contact: Marilyn Holschuh, LCSW, ACSW
Address: Woodview Counseling Center
330 South Whitney Way, Suite 303
Madison, WI 53705
Telephone: 608-268-0341 Ext. 91
Email: mh@woodviewcounseling.com
Genetics in Wisconsin: Resources for Families and Professionals

The Wisconsin Statewide Genetics webpage was created to give families and healthcare providers access to genetic information, screening, and education. The webpage was developed as part of the Wisconsin Genetic Service Plan. The website features links to many other websites that may be helpful to families and professionals. The family stories are an especially important part of the website as they give a face to those in the state who benefit from genetic services.

Website: www.slh.wisc.edu/genetics

Katy Gorman, LCSW
A Wisconsin Licensed Clinical Social Worker (LCSW) who works with children with a FASD diagnosis and their families.

Contact: Katy Gorman, LCSW
Address: Calm Waters Family Therapy
33 South 1st Street
Bayfield, WI 54814
Telephone: 715-779-0234
My Baby and Me Program

My Baby & Me is a fetal alcohol spectrum disorders (FASD) prevention program sponsored by the Wisconsin Department of Health Services (DHS). It is a collaborative, system-level effort to improve the ability of prenatal care coordination (PNCC) providers to address alcohol use by pregnant women. The goal of the project is to increase the number of women in Wisconsin who do not drink alcohol while pregnant.

Contact: Chelsea Stover, Program Manager
Address: Wisconsin Women’s Health Foundation
2503 Todd Drive
Madison, WI 53713
Telephone: 608-251-1675, ext. 112
Fax: 608-251-4136
Email: cstover@wwhf.org
Website: www.wwhf.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:** 555 West Washington Ave, Suite 200  
Madison, WI 53703

**Telephone:** 608-284-0580  
**Website:** www.wccf.org

**Wisconsin Dept. of Health Services, Division of Mental Health and Substance Abuse Services**

**Contact:** Bernestine Jeffers, Women’s Alcohol and Other Drug Abuse (AODA) Treatment Coordinator; FASD State Coordinator

**Address:** 1 West Wilson Street, Room 850  
Madison, WI 53702

**Telephone:** 608-261-0651 or 414-227-4613  
**Email:** bernestine.jeffers@dhs.wisconsin.gov

**Wisconsin Family Ties**
Wisconsin Family Ties is a statewide non-profit organization, run by families for families who have children 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 230  
Madison, WI 53703

**Telephone:** 800-422-7145  
608-267-6888

**Website:** www.wifamilyties.org
B. FASD Training of Trainers (TOT) Certificate Program

The TOT Certificate Program provides evidence-based information on FASDs; promotes skills and strategies to provide effective FASD education to a range of health and human services providers; and shares awareness and education materials. It utilizes the “FASD Competency Based Curriculum Development Guide for Medical and Allied Health Education and Practice” developed by the Centers for Disease Control and Prevention and their collaborators. Participants who successfully complete the five-day training, and conduct and evaluate two independent trainings will earn the “FASD Educator Certificate” from the University of Wisconsin-Madison Department of Professional Development and Applied Studies.

For more information contact:

FASD Education and Outreach Projects
University of WI School of Medicine and Public Health
Department of Family Medicine
1100 Delaplaine Court
Madison, WI 53715
1-800-752-3157
fasdtc@fammed.wisc.edu
www.FASDeducation.org
C. 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 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:** john.dunbar@samhsa.hhs.gov
fasdcenter1@ngc.com

**Website:** www.fasdcenter.samhsa.gov
**Substance Abuse and Mental Health Services Administration (SAMHSA)**
Publication ordering from SAMHSA offers resource information about substance abuse prevention and addiction treatment; including materials related to FASD.

**Address:** SAMHSA’s Health Information Network  
1 Choke Cherry Road  
Rockville, MD 20857  
**Telephone:** 800-487-4889  
**Website:** www.samhsa.gov

**National Institute on Alcohol Abuse and Alcoholism (NIAAA)**
NIAAA supports and conducts biomedical and behavioral research on 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 4: FASD Materials

A. FASD-Related Websites

The University of Wisconsin Department of Family Medicine and Community Health has a series of podcasts addressing the following related topics: Foundations of Fetal Alcohol Syndrome, Screening and Brief Interventions for Women, Models of Addiction, Biological Effects of Alcohol on the Fetus, Diagnosis and Assessment of FASD, FASD Diagnostic Supplement, Treatment Strategies for Individuals with FASD, Ethical, Legal, and Policy Issues. These podcast can be found at: www.youtube.com/user/WIFamilyMedicine

The Centers for Disease Control & Prevention
www.cdc.gov/ncbddd/fasd

FAS Community Resource Center
www.come-over.to/FASCRC

The FASD Center for Excellence
www.fasdcenter.samhsa.gov

Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)
www.mofas.org

The National Organization on Fetal Alcohol Syndrome (NOFAS)
www.nofas.org

Wisconsin Clearinghouse for Prevention Resources
www.wiclearinghouse.org

Wisconsin FASD Education and Outreach Projects
http://fasdeducation.org/
B. FASD-Related Curricula

Fetal Alcohol Spectrum Disorders Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice

This guide will enhance the knowledge and skills of health care providers to recognize and prevent FASDs. It is for use in developing educational programs and materials. It is available free in both print and CD formats.

FREE-Find it online:

Tools for Success Curriculum: Working with Youth and FASD in the Juvenile Justice System

Tools for Success is a training to promote strategies to identify needs of youth in corrections with FASD and to develop and present more effective intervention strategies.

FREE-Find it online:
www.store.samhsa.gov
Partnership to Prevent Fetal Alcohol Spectrum Disorders Public Education Program Manual

Provides strategies to plan FASD prevention programs, involve providers, disseminate materials, and conduct follow-up evaluations. Combines guidance in mobilizing FASD community partnership programs with research from four successful pilot communities.

FREE—Find it online:
http://store.samhsa.gov/product/MS957

Other Related Resources

Alcohol and Drug Abuse Helpline and Treatment
Telephone: 800-234-0420

Substance Abuse Treatment Facility Locator
To identify a treatment facility near you, use on the following link:
www.findtreatment.samhsa.gov/TreatmentLocator
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University of Wisconsin Department of Family Medicine and Community Health
1100 Delaplaine Court
Madison, WI 53715
Phone: 608-262-6590
Email: WTOP@fammed.wisc.edu
www.pregnancyandalcohol.org

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