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KITSAP COUNTY CHILD HEALTH NOTES

Promoting early identification and partnerships between families, primary health care providers & the community.

Distributed by: Kitsap County Medical Home Leadership Network in conjunction with [Holly Ridge](#), [Kitsap Public Health District](#), [PCAP \(Parent Child Assistance Program\)](#) & the [Kitsap County Parent Coalition](#)

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FETAL ALCOHOL SYNDROME (FAS) AND FETAL ALCOHOL SPECTRUM DISORDERS (FASD)



IF UNSURE, REFER

"Stop and think. If you're pregnant, don't drink."

HOW COMMON IS FAS? FAS is the leading known cause of intellectual disability in the developed world and is 100% preventable. If a woman doesn't drink alcohol while she is pregnant, her child cannot have an FASD.

- Approximately 12% of pregnant women in the U.S. still drink alcohol.
- Prevalence of FAS in the general population has been estimated at from 1-3 per 1,000 to as high as 7 per 1,000.
- The cost to the nation for FAS alone is about \$6 billion a year.
- Each year in the U.S., as many as 40,000 babies are born with a FASD.

WHAT IS FASD?

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term that refers to the full spectrum of outcomes observed among individuals with prenatal alcohol exposure. **These effects may include physical, mental, behavioral, and/or learning disabilities, with possible lifelong implications.** Diagnoses that fall under the FASD umbrella include Fetal Alcohol Syndrome (FAS), partial FAS (FAS without the growth deficiency), Neurodevelopmental Disorders/Alcohol Exposed (ND/AE) and Static Encephalopathy/Alcohol Exposed (SE/AE).

HOW IS FASD DIAGNOSED? Several diagnostic guidelines for FASD are in clinical use, including the FASD 4-Digit Diagnostic Code (Astley and Clarren), which is used at the University of Washington Fetal Alcohol Syndrome Clinic, as well as the CDC FAS guidelines, revised Institute of Medicine FASD guidelines (Hoyme et al.) and the Canadian FASD guidelines (Chudley et al.). These guidelines all agree on the **4 criteria for FAS:**

1. **Pre- and/or post-natal growth deficiency**
2. **3 minor facial anomalies:** including a thin upper lip, a smooth philtrum and short palpebral fissures
3. **CNS dysfunction and/or structural brain anomalies:** Structural evidence can include microcephaly, seizures or abnormal brain imaging. Functional evidence for FAS includes significant impairments in at least 3 developmental domains, or global severe deficits. FASD can include less severe deficits.
4. **Alcohol exposure during gestation:** This is recorded as *absent*, *unknown*, *confirmed* or *high risk* (multiple binge-drinking occasions at least weekly during early pregnancy.)

WHAT IS THE FETAL ALCOHOL SYNDROME DIAGNOSTIC AND PREVENTION NETWORK (FAS DPN)?

FAS DPN is a network of **Washington State community-based interdisciplinary FASD diagnostic clinics** linked by the core clinical/research/training clinic at the Center on Human Development and Disability at the University of Washington in Seattle, WA. Each clinic in the network uses the same interdisciplinary approach to diagnosis and the same systematic diagnostic method: the 4-Digit Diagnostic Code. The mission of the FAS DPN is primary and secondary prevention of FAS through screening, diagnosis, intervention, training, education, and research. The WA State FAS DPN began diagnosing patients in 1993 and has diagnosed over 2,000 Washington patients to date.

HOW DO I GET A PATIENT EVALUATED FOR FAS?

To request a diagnostic evaluation, call the University of Washington FAS DPN Clinic at (206) 598-7666. Your request will be forwarded to the clinic closest to you. Clinics are located in Everett, Seattle, Yakima, Pullman and Spokane. Other alternatives for diagnosis include referrals to a developmental pediatrician or child development clinic.

Provider Resources:

Washington State Diagnostic Clinics	www.fasdpn.org
National Organization on Fetal Alcohol Syndrome (NOFAS)	www.nofas.org
State of WA affiliate – includes family support	www.nofaswa.org
CDC information	www.cdc.gov/fasd
Substance Abuse and Mental Health Services Administration	www.fasdcenter.samhsa.govAAP
AAP Fetal Alcohol Spectrum Disorders (FASD) Toolkit	www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx

A free 1-day FASD training for health care professionals is available at the University of Washington. Email Faye Louie, Clinic Coordinator, at fasdclin@uw.edu to register for this training.

Special Needs Information and Family Resources:	
Local:	
Holly Ridge Center	Jamie Ream Cistulli 360-373-2536
Kitsap PCAP (Parent Child Assistance Program) FASD provider lending library (videos, research articles & books; connected to UW's Fetal Alcohol Drug Unit)	Linda Segur 360-377-0370 http://agapekitsap.org/pcap/2616531
Kitsap Public Health District Children with Special Health Care Needs Coordinator	Karina Mazur 360-728-2235 www.kitsappublichealth.org/cshcn
Regional:	
WithinReach Family Health Hotline	1-800-322-2588, 1-800-833-6388 TTD www.withinreachwa.org
Early Support for Infants and Toddlers Program (formerly ITEIP)	https://del.wa.gov/providers-educators/early-support-infants-and-toddlers-esit Main number: (360) 725-3500
Parent to Parent Support Programs of Washington	(800) 821-5927 www.arcwa.org/parent_to_parent.htm
Washington State Medical Home	http://medicalhome.org
NOFAS Washington State	www.nofaswa.org
WA State Fetal Alcohol Spectrum Disorders	www.fasdwa.org
National/ Internet:	
American Academy of Pediatrics	www.aap.org
AAP Developmental and Behavioral Pediatrics	www.dbpeds.org
American Academy of Family Physicians	www.aafp.org
CDC Act Early	www.cdc.gov/ncbddd/actearly/index.html
Family Voices (Links to national and state family support networks)	www.familyvoices.org

References:

- Astley, Clarren. Diagnosing the full spectrum of fetal alcohol-exposed individuals: introducing the 4-digit diagnostic code. Alcohol. 2000; 35(4): 400-410.
- Hoyme, et al. A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: clarification of the 1996 Institute of Medicine criteria. Pediatrics. 2005; 115(1):39-47.
- Chudley, et al. Fetal Alcohol spectrum disorder: Canadian guidelines for diagnosis. CMAJ. 2005; 172 (5 Suppl);S1-S21.
- Bertrand, et al. FAS Prevention Team, Division of Birth Defects and Developmental Disabilities, national Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CD). Guidelines for identifying and referring persons with Fetal Alcohol Syndrome. MMWR Rec. Rep. 2005; 54 (RR-11):1-14.