

Slide 1

Fetal Alcohol Spectrum Disorders

From Discovery to Prevention
in Washington State

Washington State
FAS Diagnostic & Prevention Network
FAS DPN

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Slide 2

Fetal Alcohol Syndrome

What is FAS?

- Growth deficiency (height or weight below 10%)
- CNS damage/dysfunction (evidence of structural, neurological or functional impairment)
- Unique cluster of minor facial anomalies (small eyes, smooth philtrum, thin upper lip)
- Prenatal alcohol exposure

Prevalence: 1 to 3 per 1,000 live births.
Leading known cause of mental retardation / developmental disabilities.
Entirely preventable.

Slide 3

What is Fetal Alcohol Spectrum Disorders (FASD)?

- FASD is an umbrella term that refers to the full spectrum of outcomes observed among individuals with prenatal alcohol exposure.
- FASD is **NOT** a diagnostic term. An individual would **NOT** receive a diagnosis labeled FASD. The term is too broad to serve as a meaningful diagnostic category.
- Diagnoses that fall under the umbrella of FASD include FAS, partial FAS, Static Encephalopathy / alcohol exposed, and Neurobehavioral Disorder / alcohol exposed.

Slide 4


WA History: From Discovery to Prevention

- 1968 Christy Ulleland, MD, Chief Resident at Harborview Medical Center, discovers link between alcohol and adverse birth outcomes.
- 1968 Independently discovered in France by Lamoine.
- 1973 David Smith, M.D. University of Washington Pediatrician, coins the term FAS.
- 1981 U.S. Surgeon General's Advisory on Alcohol and Pregnancy.
- 1988 Warnings placed on alcohol beverage labels in U.S.
- 1973-92 Public health education, research, and prevention intervention statewide, but with limited funding.

Slide 5

WA History: From Discovery to Prevention

- 1992 First interdisciplinary FAS Diagnostic Clinic opens at the University of Washington.
- 1993 Pregnancy Risk Assessment Monitoring System (PRAMS). Tracks maternal drinking during pregnancy statewide.
- 1995 WA State Senate Bill 5688, Establishes Statewide Network of FAS Diagnostic Clinics (FAS DPN).
- 1996 WA State Parent-Child Assistance Program established to help women reduce drinking during pregnancy.




Slide 6

Washington State FAS DPN

Washington State FAS Diagnostic & Prevention Network (FAS DPN).

- The FAS DPN is a network of 5 interdisciplinary FASD Diagnostic Clinics in Washington State.
- All use the FASD 4-Digit Diagnostic Code.
- Each interdisciplinary team includes a physician, psychologist, speech-language pathologist, occupational therapist and family advocate.
- Established in 1992.
- Mission:
 - Primary and secondary prevention of FASD through
 - Screening Surveillance
 - Diagnosis Training
 - Prevention Research



Slide 7

WA History: From Discovery to Prevention

1996 Computerized FAS Facial Photographic Analysis Software created.

1997 FASD 4-Digit Diagnostic Code created to improve diagnostic accuracy.

Slide 8

The FASD 4-Digit Diagnostic Code

				3	4	4	4		
significant	severe	definite	4	X	X	X	X	4	high risk
moderate	moderate	probable	3	X				3	some risk
mild	mild	possible	2					2	unknown
none	none	unlikely	1					1	no risk
				Growth	Face	CNS	Alcohol		
Growth	FAS Facial	CNS							Prenatal
Deficiency	Features	Damage							Alcohol

Slide 9

Example of 4-Digit Codes for FAS and Partial FAS

A Fetal alcohol syndrome (alcohol exposed)

2433 3433 4433
 2434 3434 4434
 2443 3443 4443
 2444 3444 4444

B Fetal alcohol syndrome (alcohol exposure unknown)

2432 3432 4432
 2442 3442 4442

C Partial fetal alcohol syndrome (alcohol exposed)


1333 1433 2333 3333 4333
 1334 1434 2334 3334 4334
 1343 1443 2343 3343 4343
 1344 1444 2344 3344 4344

Slide
10


The Three Diagnostic Facial Features of FAS

1) Short PFL	≤ -2 SD
2) Smooth Philtrum	Rank 4 or 5
3) Thin Upper Lip	Rank 4 or 5

FAS



Palpebral fissure length (PFL) =
endocanthion to exocanthion



Slide
11


The Face of FAS Across Race and Age

Photos removed to protect confidentiality

Slide
12

WA History: From Discovery to Prevention

- 1998 National FAS DPN Training Program: (Clinics established worldwide)
- 2004 WA State FASD website established. www.fasdwa.org
- 2004 FASD 4-Digit Diagnostic Code Online Course established.
- 2006 Lip-Philtrum Guide translated into Russian.



Slide
13

FAS Screening, Diagnosis, Prevention and Surveillance

To implement and assess prevention efforts, one must be able to accurately and efficiently screen, diagnose, and intervene with high-risk populations.

In Washington State this has been accomplished through the establishment of:

- PRAMS maternal drinking during pregnancy data (1993)
- WA State FAS Diagnostic & Prevention Network of Clinics (1993)
- Parent Child Assistance Program (P-CAP) (1994)
- FASD Facial Photographic software (1996)
- FASD 4-Digit Diagnostic Code (1997)
- Foster Care FAS Screening Program (1999)

Slide
14

WA History: From Discovery to Prevention


1999 FAS Screening in Foster Care (King County) using FAS Facial Analysis Software.

Results

FAS Prevalence	1 per 100
Participation Rate	98 %
Screened to date	2000

Screening Tool Performance

Sensitivity	100 %
Specificity	99 %
Predictive Value Positive	86 %
Predictive Value Negative	100 %



Slide
15

FAS Prevention in Washington State: Evidence of Success

Maternal report of drinking during pregnancy
PRAMS data (1993 – 1998)
Significant decline in maternal drinking during pregnancy from 1993 to 1998.
Exceeded Healthy People 2010 goal of 6% in 1997.

Prevalence of FAS in Foster Care
Among children born in 1993 – 1998.
Significant reduction in prevalence of FAS in each successive birth cohort from 1993 to 1998.

Slide
16

FAS Prevention in Washington State: Evidence of Success

So... how did WA State prevent FASD ?

Two ways to prevent FASD.

1. Don't drink while pregnant (Alcohol treatment)
2. Don't get pregnant while drinking. (Family planning)

Answer: Primarily through success with #1.

See 40 year history of WA State FASD prevention efforts on www.fasdwa.org

Slide
17

FAS DPN Website

All Publications, Diagnostic Tools, Guides, and Training Programs
can be found on our website

www.fasdpn.org