

## Fetal Alcohol Spectrum Disorders (FASD) Identification and Evidenced Based Intervention

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## Disclosure

- I have nothing to disclose.



## Objectives

- Review the definition and diagnosis of FASD
- Identify the profile of symptoms experienced by individuals effected by an alcohol exposed pregnancy
- Examine 5 evidenced based interventions presented by CDC Funded Projects
- Learn components of the Treatment Improvement Protocol developed by SAMHSA

## What is Fetal Alcohol Syndrome (FAS)?



–FAS is characterized by:

1. Growth deficiency
2. Unique facial features
3. CNS abnormalities (evidence of structural, neurological, or functional impairment)
4. Prenatal alcohol exposure



## FASD 4-Digit Diagnostic Code



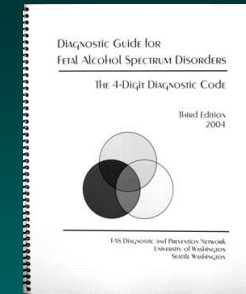
Washington State  
FAS Diagnostic & Prevention Network  
(FAS DPN)

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[www.fasdpn.org](http://www.fasdpn.org)

## FASD Diagnostic Guide and Facial Software



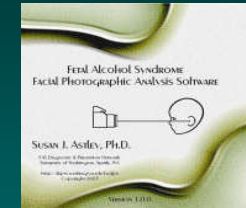
**4-Digit Diagnostic Code Grid**

One Example of FAS

			3	4	4	
significant	significant	definite	4	X	X	X
moderate	moderate	probable	3	X	X	X
mild	mild	possible	2			
rare	rare	unlikely	1			
Growth Deficiency	Full Facial Features	Brain Dysfunction	1			1
						Operational Alcohol



### 4-Digit Online Course



Order from [www.fasdpn.org](http://www.fasdpn.org)

### 1. Growth Deficiency

We are looking for growth deficiency characteristic of a teratogenic insult, not characteristic of postnatal environmental factors such as nutritional deprivation or chronic illness.

We want to answer the question:

'What is the patient's growth potential after controlling for parental height and postnatal environmental influences?'

### Ranking Growth Deficiency

#### 2-Step Process

ABC-Rank	Percentile Range	ABC-Score for Height	ABC-Score for Weight
C	≤ 3 <sup>rd</sup>	<b>C</b>	C
B	> 3 <sup>rd</sup> and ≤ 10 <sup>th</sup>	B	<b>B</b>
A	> 10 <sup>th</sup>	A	A

4-Digit Diagnostic Code Rank	Growth Deficiency Category	Height - Weight ABC-Score Combinations
4	Severe	CC
<b>3</b>	<b>Moderate</b>	<b>CB</b> BC
2	Mild	CA, BB, AC
1	None	BA, AB, AA

## The FASD 4-Digit Diagnostic Code

significant	severe	definite	4	<div style="text-align: center; font-size: 2em; color: yellow;">3</div> <table border="1" style="width: 100px; height: 100px; margin: 0 auto;"> <tr><td></td><td></td><td></td></tr> <tr><td style="text-align: center; color: yellow;">X</td><td></td><td></td></tr> <tr><td></td><td></td><td></td></tr> <tr><td></td><td></td><td></td></tr> </table>				X									<table border="1" style="width: 50px; height: 100px; margin: 0 auto;"> <tr><td></td></tr> <tr><td></td></tr> <tr><td></td></tr> <tr><td></td></tr> </table>					4	high risk
X																							
moderate	moderate	probable	3			3	some risk																
mild	mild	possible	2			2	unknown																
none	none	unlikely	1			1	no risk																

Growth
Face
CNS
Alcohol
Prenatal
Alcohol

Growth Deficiency
FAS Facial Features
CNS Damage

## 2. The Three Diagnostic Facial Features of FAS

**Diagnostic Features**  
All 3 must be present.

**Other Anomalies**  
May be present, but not required to be present.

small eyes (PFL)  
smooth philtrum  
thin upper lip

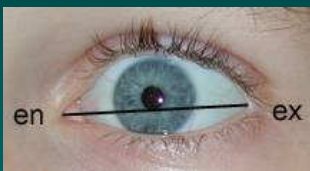


FAS Facial Phenotype

hirsut (facial hair)  
clown eyebrows  
ptosis (drooping eyelids)  
epicanthal folds  
hypertelorism  
flat nasal bridge  
short nose

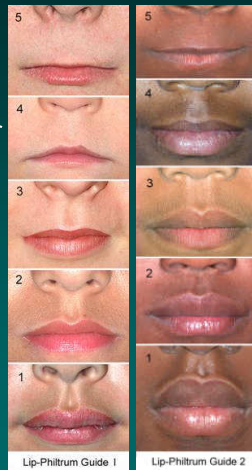
## The Three Diagnostic Facial Features of FAS

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

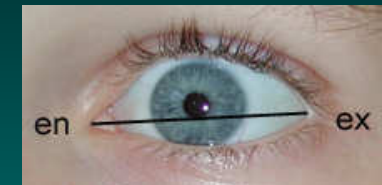
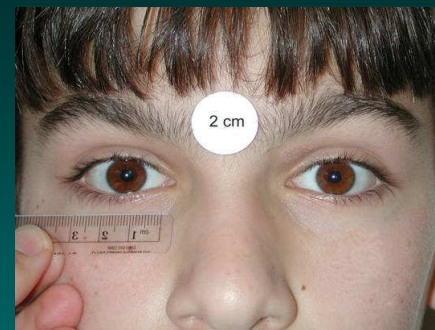


Palpebral fissure length (PFL) = endocanthion to exocanthion

FAS

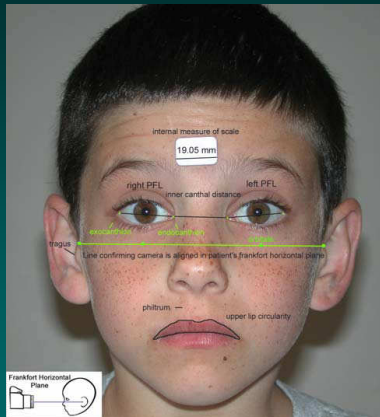


## Two methods to measure Palpebral Fissure Length



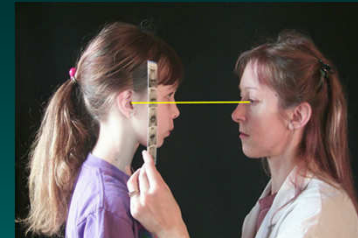
1. Measure eye directly using ruler.

## Two methods to measure Palpebral Fissure Length



2. Measure eye in digital photo using FAS Facial Analysis Software.

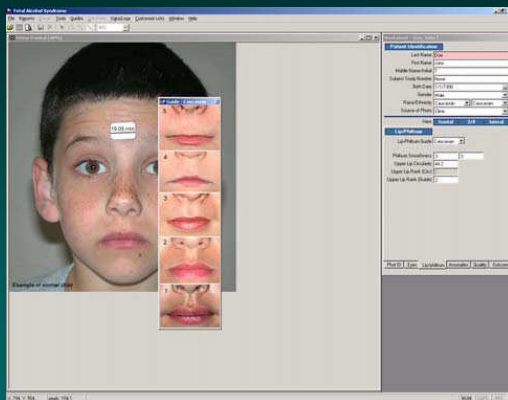
## Three Methods to Measure Lip Thinness



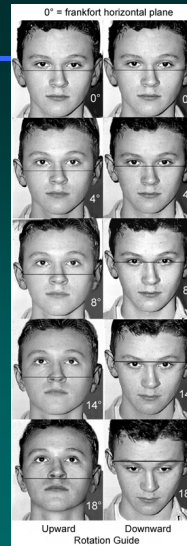
1. Measure directly with Lip-Philtrum Guide. Align in patient's frankfort horizontal plane.
2. Measure lip circularity (perimeter<sup>2</sup>/area) from digital photograph using FAS Facial Analysis Software. Outline lip with mouse.



## Three methods to measure Lip Thinness



3. Compare Lip-Philtrum Guide to correctly aligned photo



## Ranking Facial Phenotype

5-Point Rank for	Z-scores for	ABC-Score		
Philtrum or Lip	Palpebral Fissure Length (PFL)	PFL	Philtrum	Upper Lip
4 or 5	≤ -2 SD	<b>C</b>	<b>C</b>	<b>C</b>
3	> -2SD and ≤ -1 SD	<b>B</b>	<b>B</b>	<b>B</b>
1 or 2	> -1 SD	<b>A</b>	<b>A</b>	<b>A</b>

4-Digit Diagnostic Code Rank	Level of Expression of FAS Facial Features	Palpebral Fissure - Philtrum - Lip ABC-Score Combinations
<b>4</b>	<b>Severe</b>	<b>CCC</b>
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

### The FASD 4-Digit Diagnostic Code

significant	severe	definite	4		3	4				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 Deficiency
FAS Facial Features
CNS Damage
Prenatal Alcohol

### 3. Ranking CNS Abnormality

4-Digit Rank	CNS Damage Scale	Confirmatory Findings
4	<u>Definite</u>	<b>Microcephaly</b> OFC 2 or more SDs below the mean (nonfamilial) and / or <b>Abnormalities on brain images</b> diagnostic of prenatal alteration and / or <b>Evidence of idiopathic seizures or other hard neurological findings</b> likely to be of prenatal origin
	<i>Static Encephalopathy</i>	
3	<u>Probable</u>	<b>Significant impairment (fx at less than -2 sd) in 3 or more domains of brain function</b> such as, but not limited to: development, cognition, achievement, adaptive, memory, executive function, motor, visual motor, language, ADHD, neurological 'soft' signs, or other mental health disorders.
	<i>Static Encephalopathy</i>	
2	<u>Possible</u>	<b>Evidence of delay or dysfunction that suggest the possibility of CNS damage (fx at less than -2 sd in only 1-2 areas, or between -1 and -2 sd), but data to this point do not permit a Rank 3 classification</b>
	<i>Neurobehavioral Disorder</i>	
1	<u>Absent</u>	<b>No current evidence of delay or dysfunction likely to reflect CNS damage</b>

### The FASD 4-Digit Diagnostic Code

significant	severe	definite	4		3	3				4	high risk
moderate	moderate	probable	3	X					X	3	some risk
mild	mild	possible	2							2	unknown
none	none	unlikely	1							1	no risk

Growth
Face
CNS
Alcohol

Growth Deficiency
FAS Facial Features
CNS Damage
Prenatal Alcohol

### 4. Ranking Prenatal Alcohol Exposure

4-Digit Rank	Definition
4	<u>Confirmed</u> exposure. <u>Level</u> is <u>high</u> (weekly+ in 1 <sup>st</sup> trimester)
3	<u>Confirmed</u> exposure. <u>Level</u> is <u>less or unknown</u> .
2	<u>Unknown</u> exposure
1	<u>Confirmed absence of exposure</u> from conception to birth.

## Fetal Alcohol Spectrum Disorder

4 Diagnoses	Description
FAS	Severe brain dysfunction, facial features, growth deficiency
Partial FAS	FAS without the growth deficiency
Static Encephalopathy/Alcohol-Exposed	Severe brain dysfunction without the facial features
Neurobehavioral Disorder/Alcohol-Exposed	Moderate brain dysfunction without the facial features

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## Prevalence:

- 1 to 3 per 1,000 live births (equivalent to down syndrome).
- Leading known cause of developmental disabilities.
- 100% preventable.
  - Statistics from the CDC and IOM



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## Is Prevalence Under-estimated? Probably

Methods have included surveillance systems, prenatal clinic-based studies, and special referral clinics

May, et.al.\* Tiered model:

1. Measure children (Consented group of 2033),
2. <25<sup>th</sup> percentile completed Tier II-> Dysmorphology assessment resulting in a dysmorph score

\* November 2014 in Pediatrics (Vol. 1134, #5)

## Prevalence and Characteristics of FASD (May, et.al.)

3. Developmental and Behavioral assessments
4. Maternal Interviews:
  - Most predictive maternal risk variables were:
    - Late recognition of pregnancy
    - Quantity of alcohol consumed 3 mo before pregnancy
    - Father's alcohol intake



## Results

- FAS in the test community ranged from 6-9 per 1000
- PFAS from 11-17 per 1000
- Total rate of FASD was estimated at 24-48 per 1000

### Previous counts:

- 1 to 3 per 1,000 live births (equivalent to down syndrome)

## Profile of individuals born to AEP



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## WA State FAS DPN Patient Profile (n = 1,400)

The outcomes are reported in:

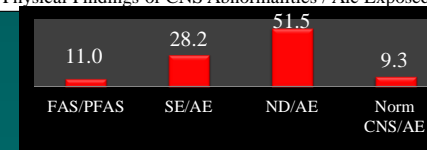
Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network.

Can J Clin Pharmacol Vol 17(1) Winter 2010:e132-e164; March 26, 2010.

[www.fasdpn.org/pdfs/astley-profile-2010.pdf](http://www.fasdpn.org/pdfs/astley-profile-2010.pdf)

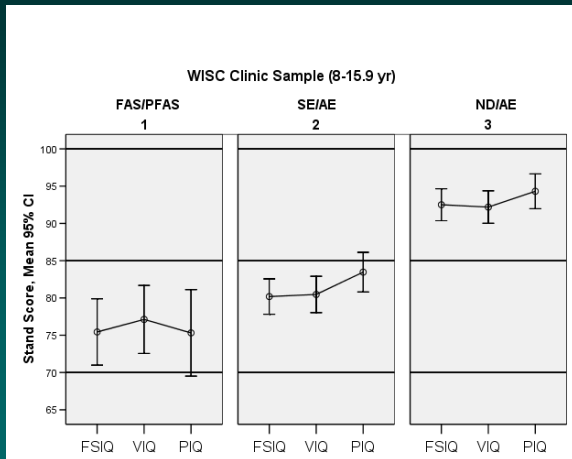
## FASD Diagnostic Outcomes for 1,400 Patients

4-Digit Code FASD Diagnostic Categories	N	%
A. FAS / Alc Exposed	52	3.7
B. FAS / Alc Unknown	7	0.5
C. PFAS / Alc Exposed	95	6.8
E. Sentinel Physical Findings / <b>Static Encephalopathy</b> / Alc Exposed	95	6.8
F. <b>Static Encephalopathy</b> / Alc Exposed	299	21.4
G. Sentinel Physical Findings / <b>Neurobehavioral Disorder</b> / Alc Exposed	160	11.4
H. <b>Neurobehavioral Disorder</b> / Alc Exposed	562	40.1
I. Sentinel Physical Findings / Alc Exposed	34	2.4
J. No Sentinel Physical Findings or CNS Abnormalities / Alc Exposed	96	6.9



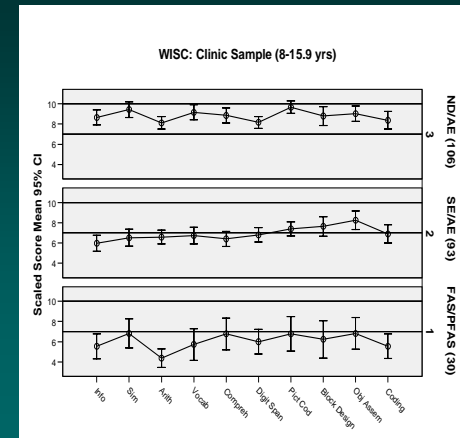
## Cognitive Profiles of FASD: Clinic Sample

WISC



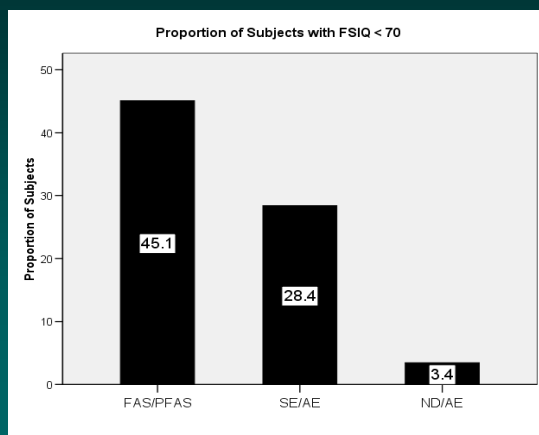
## Cognitive Profiles of FASD: Clinic Sample

WISC



## Cognitive Profiles of FASD: Clinic Sample

FSIQ



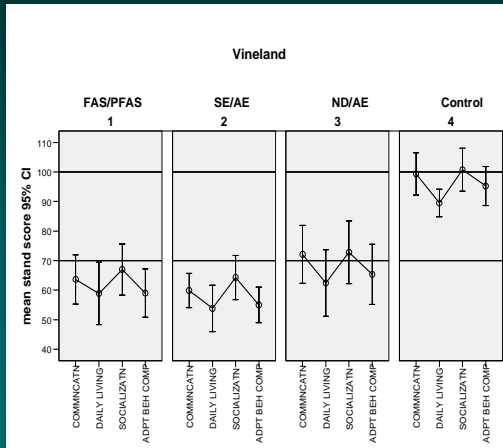
## Significant Differences between FAS/PFAS and SE/AE

	FAS/PFAS	SE/AE
FAS Face	Yes	No
Alcohol: More days/week	6 days / week	4 days / week
Alcohol: All 3 trimesters	77%	59%
Smaller OFC	30 <sup>th</sup> percentile	43 <sup>rd</sup> percentile
Microcephalic	49% of subjects	27% of subjects
Frontal lobe	Disproportionately smaller	
WISC PIQ	76	82
WISC Arith	4	6
WISC mazes	2.8	6.5
Key Math estimation	5	6.4
VMI	77	89



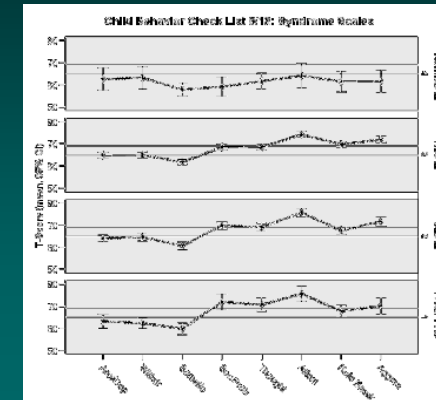
## Cognitive/Behavioral Profiles of FASD

### Vineland Adaptive Behavior Scales



## Parent's Report of Child's Behavior: CBCL

No difference between FASD groups among FAS DPN clinical population 6-18 years of age.



## Prevalence of other Mental Health Disorders

Among the 1,064 FAS DPN patients 5 years of age or older:

- 82% had one or more MH disorders.
- 54% had ADD/ADHD

documented in their records.

Condition	Using Computerized-Diagnostic Interview Schedule for Children			
	Proportion of Subjects with the Condition			
	FAS/PFAS N=20	SE/AE N=24	ND/AE N=21	Control N=16
AD/HD	63	71	67	0
ODD	47	58	52	13
CD	37	21	48	0
Generalized Anxiety	21	8	5	0
Separation Anxiety	16	8	14	0
OCD	11	4	14	0
PTSD	11	4	0	0
Social Phobia	11	4	10	0
Maj Depress / Dysthymic	5	8	5	0
Mania / Hypomania	5	0	0	0
Schizophrenia	5	0	0	0
Panic	0	0	5	0

## How do we Intervene?





## CDC supported research

- In 2001, in response to the Healthy Children Act of 2000, the Centers for Disease Control and Prevention (CDC) provided federal funding to develop systematic, specific, and scientifically evaluated interventions appropriate for children with FASDs and their families.
- Awards were made to five grantees to develop interventions. All five interventions specifically addressed the neurodevelopmental needs of children with FASDs.

## Intervention Sites/Projects

- **Project Bruin Buddies- UCLA**
- **Georgia-sociocognitive Habilitation using the MILE Program- Marcus Institute (KK at Emory)**
- **Neurocognitive habilitation for children with FASD- Children's Research Triangle**
- **PCIT: an EBT to reduce behavior problems among children with FASD- U of OK HSC**
- **Families Moving Forward: a behavioral consultation intervention- U of W**

Characteristic	UCLA	Marcus Institute	Children's R Triangle	U of Oklahoma	U of W
White, Non Hispanic (%)	54	57.4	37.2	39.1	50.0
African American (%)	17.0	38.4	42.3	23.9	25.9
Child Sex Male (%)	51.0	60.7	67.9	60.0	51.9
Child Age (M, SD)	8.59 (1.56)	6.38 (2.00)	8.73 (1.55)	4.70 (1.4)	8.06 (2.07)
Child IQ (K- Bit)	97.24 (14.83)	81.08 (13.4)	89.79 (16.11)	87.90 (11.20)	94.3 (12.50)
Living w Bio-Mother (%)	21.0	1.7	NA	1.1	13.4
DX of FAS (%)	12.0	6.6	14.1	4.6	7.7

### 1. Project Bruin Buddies: a social skills training program to improve peer friendships

- Parent assisted children's friendship training
- Based on Frankel and Myatt's Children's Friendship Training (2003)
- Procedure included parents as facilitators of their children's social skills.
- Parent education about FASD and how to facilitate skills was included.



## 2. Georgia-sociocognitive habilitation using math interactive learning experience (MILE)

- All children received a psycho-ed evaluation, IEP planning and ed consultation, and assessment of readiness to learn
- Intervention Group also received:
  - Workshops for parents: FASD information particularly on ed needs and special education, behavioral regulation management
  - MILE Intervention: “Plan, do, review” method (Perry Preschool), active learning, 6 weeks tutoring



## 3. Neurocognitive Habilitation for children with FASD (Children’s Research Triangle)

- Used the Alert Program (Williams & Schellenberger, 1996)
- Car engine metaphor to help develop state regulation and modulation
- Targeted executive functioning sets: memory, cause and effect reasoning, sequencing, planning, and problem solving



## 4. PCIT: application of an EBP to reduce behavioral problems in children with FASD

- PCIT, which included parent education and direct coaching includes direct work with the child and parent versus
- Parent Support and Management (PSM) program (Barkley, 1997), which was parent only training (Control group)
- PCIT had to be adapted to accommodate the learning and behavioral issues of children with FASD



## 5. Families Moving Forward: Behavioral Consultation Intervention (U of W)

- FMF model was designed to modify specific parenting attitudes and parenting responses toward their child’s problem behaviors.
- Developed a “parent friendly” positive behavior support approach to dealing with challenging child behaviors.
- Based on social learning theory, congruent with evolving literature for children with DD.



## Summary

Projects	Ages Included	Target for Intervention	Positive Features	Negative Features
UCLA: Bruin Buddies	6-12 year olds	Social Skills	Strong long term outcomes	Family involvement essential
Marcus Institute: MILE Program	3-10 year olds	Math Skills	Only 6 week TX, includes EF approach	Math is main target, No ID or MH
Children's R Triangle: Alert Program	6-11 year olds	Executive Functioning	Model can be done with PP and modified	Not for younger children
U of O: PCIT	3-7 year olds	Disruptive Behaviors	Parent coaching model	Expensive model for outcome
U of W: Families Moving Forward	5-11 year olds	Parenting Attitudes	Can address individual needs	Longer TX model

## Lessons Learned

- All 5 tested approaches were used specifically for children with FASD and their families
- Important Elements to Intervention:
  - Parent education or training
  - All studies showed improved parent knowledge of FASD and how the knowledge is applicable to parenting
  - Explicit instruction on working with a child with FASD was essential

## Treatment Improvement Protocol Published by SAMHSA

- <http://store.samhsa.gov/shin/content//SMA13-4803/SMA13-4803.pdf> (2014)
- The (TIP) series, which has been published by the (SAMHSA) within (HHS) since 1993, has generally offered best-practices guidelines for the treatment of substance use disorders.

## References

- 
- Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol*. Vol 17(1) Winter 2010:e132-e164; March 26, 2010.
- Astley et al., Neuropsychological and behavioral outcomes from a comprehensive magnetic resonance study of children with FASD. *Canadian J Clinical Pharmacology*, 2009;16(1):e178-201.
- Astley et al., MRI outcomes from a comprehensive magnetic resonance study of children with FASD. *Alcoholism: Clinical Experimental Research* 2009;33(10).
- Astley et al., MRS outcomes from a comprehensive magnetic resonance study of children with FASD. *Magnetic Resonance Imaging Magnetic Resonance Imaging*, 2009;27:760-778.
- Astley et al., fMRI outcomes from a comprehensive magnetic resonance study of children with FASD. *J Neurodevelopmental Disorder* 2009;1:61-80.
- Astley SJ. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*, 3<sup>rd</sup> edition, University of Washington Publication Services, Seattle WA, 2004.
- Astley SJ. Graphic cognitive/behavioral/psychiatric profiles of FASD. Slide show presented to NIAAA/CDC in 2009.

All literature referenced in this presentation can be obtained at the following weblinks:  
[www.fasdnpn.org/htmls/literature.htm](http://www.fasdnpn.org/htmls/literature.htm)  
[www.fasdnpn.org/pdfs/astley-graphicprofile-2009secure.pdf](http://www.fasdnpn.org/pdfs/astley-graphicprofile-2009secure.pdf)