THE FETAL ALCOHOL SYNDROME DIAGNOSTIC AND PREVENTION NETWORK
MEDICAL SUMMARY REPORT
SEATTLE, WASHINGTON
CLINIC DATE: _____

Final Diagnosis: **(1) STATIC ENCEPHALOPATHY**
(2) ALCOHOL EXPOSED

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, no growth deficiency or characteristic set of facial features were found so the patient does not have FAS, but there was evidence of significant CNS damage/dysfunction as you will see noted on the attached pages. There was also a clear history of exposure to significant amounts of alcohol during gestation. In this situation, we use the term "static encephalopathy" to describe the patient's condition. On the attached sheets are the specific findings in this patient's case that led us to this conclusion. The diagnosis of static encephalopathy does not mean that alcohol is the only cause of the problem. A number of other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth. These kinds of differences may partly explain why there is so much variability in the kinds of specific difficulties that patients with static encephalopathy face.

Individuals with significant CNS abnormalities have structural, neurological, and/or cognitive/behavioral evidence of CNS damage/dysfunction, and should be viewed as individuals with disabilities. The diagnosis of static encephalopathy has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific problems that have been identified that need attention.

_____ _____

<Name>, MD Date
University of Washington School of Medicine
Pediatrician, FAS DPN Clinic

Diagnosis: Static encephalopathy (alcohol exposed)

				4-Digit Diagnostic Code					
				1	2	3	3		
Significant	Severe	Definite	(4)					(4)	High risk
Moderate	Moderate	Probable	(3)			X	X	(3)	Some risk
Mild	Mild	Possible	(2)		X			(2)	Unknown
None	Absent	Unlikely	(1)	X				(1)	No risk
Growth Deficiency	**FAS Facial Features**	**CNS Damage**		**Growth**	**Face**	**CNS**	**Alcohol**		**Gestational Alcohol**

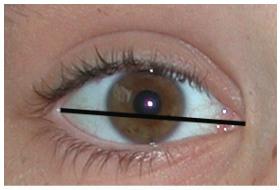
Overview of Evaluation Procedure:

<Name> was accompanied today in clinic by her adoptive mother, grandmother, and a support specialist. An interdisciplinary diagnostic evaluation using the 4-Digit Diagnostic Code[1] was conducted by the FAS DPN clinical team composed of a pediatrician, a public health specialist, an occupational therapist, a social worker, a family advocate, a school psychologist and a licensed psychologist. In the weeks leading up to this clinic appointment, prior school, medical, psychological and social service records were obtained and reviewed by the clinic coordinator, psychologist, family advocate and social worker. Upon arrival today, <Name> had her height, weight and OFC measured and a clinical photograph taken of her face. While this was taking place, her caregivers completed standardized questionnaires. Concurrently, the FAS diagnostic team participated in a 30-minute case presentation conducted by the lead psychologist. Upon completion of the case presentation, the team pediatrician and lead psychologist conducted a 2-hour clinical interview with the child's caregiver. Concurrently, the child received a 2-hour multi-disciplinary screening conducted by the occupational/physical therapist and school psychologist. After the caregiver interview and child screening, the child received a targeted physical exam by the pediatrician. The team reconvened for 2 hours and derived a diagnosis and treatment plan and shared it with the child's caregivers. Finally, the caregiver met with the lead psychologist for a 30-minute period of debriefing.

1. Astley SJ. Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code. 3rd Edition, Seattle WA: University of Washington Publication Services, pp. 132, 2004. www.fasdpn.org

Growth: Individuals with FAS are often growth deficient either pre- or postnatally. Two key indices for growth are height and weight adjusted for age. <Name> presents with no growth deficiency (Growth Rank 1). After a term birth, <Name> was found to weigh 3255 g and was 49.5 cm in length. These measures were in the 75th and 70th percentiles respectively. Her current weight and height are 21.8 kg and 114.8 cm at 5 years 7 months of age. These are the 79th and 66th percentiles for age respectively.

Face: The face of fetal alcohol syndrome is characterized by the presence of all three of the following features: small eyes (as measured by palpebral fissure length), a thin upper lip and a smooth philtrum (the vertical groove between the nose and the upper lip). The palpebral fissures must be two or more standard deviations below the norm and the thin upper lip and smooth philtrum must be a Rank 4 or 5 on the Lip-Philtrum Guide. Based on the 4-Digit Code, if all three of these features are present, the Face is assigned a Rank 4. Moderate and mild expressions these FAS facial features receive Face Ranks of 3 and 2 respectively. If none of these three facial features are present, the face receives a Rank 1.



palpebral fissure length

Lip-Philtrum Guide I

<Name>'s palpebral fissure lengths were small (21.8 mm, estimated to be 3.5 SD below the mean) for her age and race. She has a normal philtrum (Rank = 2) and a normal upper lip (Rank = 2) based on a use of the Lip-Philtrum Guide 1. Based on these facial measures, <Name> receives a Facial ABC-Score of CAA (or 4-Digit Face Rank = 2). <Name> DOES NOT present with the FAS facial features. No other craniofacial anomalies were observed.

Brain: Brain damage may be evidenced by abnormal brain structure (such as microcephaly or abnormal structure identified through brain imaging), abnormal neurological signs of presumed prenatal origin (such as seizures, tics or spasticity) and/or significant brain dysfunction as measured by standardized psychometric assessments. Based on the 4-Digit Diagnostic Code, a Brain Rank = 4 is assigned when structural and/or neurological evidence of impairment is present, a Brain Rank = 3 is assigned when there is evidence of significant brain dysfunction, a Brain Rank = 2 is assigned when there is some evidence of brain dysfunction or delayed development, but not at the level of a Rank 3, and a Brain Rank = 1 is assigned when there is no functional evidence of impairment.

Based on the information available to us to date, <Name> met the criteria for a Brain Rank = 3. This information is described more fully below.

Structurally, <Name>'s head circumference is in the normal range. At birth her OFC was 35.6 cm (90th percentile for 38 weeks gestation) and is currently 49.8 cm (40th percentile) at 5 years 7 months of age. <Name> has never reportedly had her brain imaged. Neurologically, <Name> does not have any reported history of seizures or other neurologic problems.

Brain function was assessed both prior to and during this clinic visit. Previous assessments are summarized below. Psychometric assessments administered today in clinic at 5 years 7 months of age include the following:

Child Behavior Checklist for ages 1.5-5 (CBCL/1.5-5)

NEPSY-A Developmental Neuropsychological Assessment (NEPSY)
The Short Sensory Profile (SSP)
Developmental Test of Visual Motor Integration (VMI) 4th Edition
Bruininks-Oseretsky Test of Motor Proficiency-Short Form
Child Communicative Checklist-2 (CCC-2)

The standardized testing and clinical observations carried out in this FAS diagnostic clinic are conducted solely for the purposes of diagnosing alcohol-related disabilities and making related recommendations and referrals. This is not a comprehensive assessment of skills. To more completely understand the child's unique cognitive and behavioral profile, additional comprehensive psychological, neuropsychological, occupational therapy and speech assessments carried out by qualified professionals may be necessary.

Unless otherwise indicated, standard scores are based on a scale in which the mean is 100 and the standard deviation is 15. This means that most individuals attain a score between 90 and 110 (the "average" range). Scores below 70 are considered to be significantly below the mean. Some subtests use scaled scores, in which an average score falls between 7 and 13 (mean is 10, standard deviation is 3). Percentile ranks indicate where the individual's score falls relative to his or her age peers. Average scores fall between the 25th to the 75th percentile (50% is average, and corresponds to a standard score of 100).

Psychological Screen conducted in clinic today at chronological age 5 years, 7 months:
The Achenbach *Child Behavior Checklist 1.5-5 (CBCL/1.5-5)* is a checklist completed by caregivers that provides information about a child's competencies and behavioral and/or emotional problems to serve as one component of multi-axial empirically based assessment. The CBCL/1.5-5 was completed by <Name>'s adoptive mother to obtain her perceptions of <Name>'s problems. <Name>'s scores on this measure are as follows:

Index/Scale	T-Score	Range	Percentile
Total Problems	**75**	**Clinical**	**>97**
Internalizing	66	Clinical	95
Externalizing	68	Clinical	97
Syndrome Scales	**T-Score**	**Range**	**Percentile**
Emotionally Reactive	67	Borderline	96
Anxious/Depressed	63		90
Somatic Complaints	58		79
Withdrawn	67	Borderline	96
Sleep Problems	76	Clinical	>97
Attention Problems	73	Clinical	>97
Aggressive Behavior	65	Borderline	93

These scores indicate that further attention to sleep, attention, aggression, emotion, and social withdrawal is

warranted.

The *NEPSY-A Developmental Neuropsychological Assessment (NEPSY*) looks at how children process information. It breaks cognitive processes into 5 major areas. Children perform tasks which often require manipulating parts (either physical, visual, or linguistic) in order that their processes and strategies can be observed.

The Speeded Naming subtest measures the ability to rapidly access and produce the names of colors, sizes, and shapes. On this measure, <Name> received a scaled score of 4. This score is below the average range.

The Memory for Faces subtest looks at how children remember faces both immediately and across time. On this measure, <Name> received a scaled score of 9, which is well within the average range.

The third administered subtest, Visual Attention, was deemed invalid due to <Name>'s attentional difficulties.

<Name> demonstrated high levels of impulsivity, inattention, and bodily activity. In addition, she had difficulties with tolerating challenging tasks and avoided taking risks. She did, however, enjoy being physical and responded well to the rewards as a motivator for tasks.

Occupational Therapy Screen at chronological age 5 years, 7 months:
The *Short Sensory Profile (SSP)* measures a caregiver's report of behaviors related to sensory processing and integration abilities. The SSP is a standardized questionnaire of sensory processing abilities in children ages 3 to 10 years. The scores in each category are classified as Typical Performance, Probable Difference or Definite Difference. Probable or Definite Differences may suggest sensory processing and integration difficulties that are affecting behavior and daily life.

Test/Subtest	**Outcome**
Total Test	Definite Difference
Taste/Smell Sensitivity	Typical Performance
Tactile Sensitivity	Definite Difference
Movement Sensitivity	Probable Difference
Low Energy/weak	Definite Difference
Under-responsive/Seeks Sensation	Definite Difference
Auditory Filtering	Definite Difference
Visual/Auditory Sensitivity	Definite Difference

Based on the reported behaviors and responses to sensory input, <Name> demonstrated significant sensory processing challenges. <Name>'s score on the SSP was 96/190 with the areas of Tactile Sensitivity, Underresponsive/seeks sensation, Auditory Filtering, Low energy, and Visual/Auditory sensitivity receiving

section scores in the Definite Difference range and would benefit from sensory accommodations and therapy with a sensory integration component.

The *Bruininks-Oseretsky Test of Motor Proficiency-Short Form* measures fine and gross motor skills. On this measure, <Name> received a standard score of 24 (raw score 6, <1st percentile). This score is felt to be a low representation of her actual motor abilities. Her scores and performance was greatly impacted by impulsivity, decreased task attention, and difficulty engaging and persisting in challenging activities.

Speech and Language Screen at chronological age 5 years, 7 months:
The Child Communicative Checklist-2 (CCC-2) is a parent-report checklist that assists in identifying communication problems. This checklist was completed by <Name>'s adoptive mother. On this measure, <Name> received a General Communication Composite scaled score of 33, (1st percentile), which is in the below average range. The Social Interaction Deviance Composite score was 6, which is within normal limits.

Previous Testing:
Records from the following previous assessments were also available for our review and consideration:

- On <Date>, <Name> received a speech and language evaluation. She was administered the *Clinical Evaluation of Language Fundementals-Preschool (CELF-P)* as well as an articulation test.
- On <Date>, <Name> received a school-based evaluation. She was administered the *Peabody Developmental Motor Scales, Second Edition (PDMS-2),* and *Short Sensory Profile.*
- On <Date>, <Name> received a school-based evaluation. She was administered the *Developmental Indicators for the Assessment of Learning-3 (DIAL-3).*
- On <Date>, <Name> received a psychological evaluation. She was administered the *Reynaolds Intellectual Assessment Scales (RIAS), Peabody Picture Vocabulary Test-3rd Edition (PPVT-3-Form III-B), Beery Developmental Test of Visual-Motor Integration (VMI),* and *Behavioral Assessment for Children(BASC) Parent Rating Scales-Ages 2.5-5.*
- On <Date>, <Name> received a school-based evaluation. She was administered the *Preschool Language Scale-3 (PLS-3)* and *Photo Articulation Test-3 (PAT-3).*

Caregiver Interview:
We had the pleasure of an interview with <Name>'s adoptive mother and her therapist. They note marked issues with impulsivity, inattention, and hyperactivity. School is difficult for her, and she has been disruptive. She does not seem to learn from past experiences, needs lots of help with daily tasks, and seems to be operating at the 3-4 year old level in many ways. She has a somewhat frantic, ritualistic component to her play, with a droning hum, but no noted tics. Motor skills and balance are concerns, as is sleep, with prominent issues with fighting sleep, snoring, night fears, crying out, and being cranky in the morning. <Name>'s strengths are her cheerful, spunky, and passionate nature, and that she works hard and tries to please.

Alcohol Exposure:
Based on information available to us to date, <Name>'s biological mother reports consuming 1-2 alcoholic beverages once a week during the first trimester. Reported exposure of this quantity and frequency meets the 4-Digit Diagnostic criteria for an Alcohol Rank 3.

Co-Morbidities
When assessing the potential impact of prenatal alcohol exposure on an individual, it is important to document all other significant prenatal and postnatal exposures and events, for they too serve as potential risk factors for cognitive/behavioral dysfunction. Prenatal risk factors may include, but are not limited to poor prenatal care, genetic conditions that may run in the family and other potential teratogenic exposures. Postnatal risk factors may include but are not limited to perinatal difficulties, adverse home environments, multiple home placements, neglect, abuse and other events that could explain brain dysfunction like head injuries or the patient's own chronic substance abuse. While it is not possible with today's medical technology to determine which risk factor(s) may be responsible for each adverse outcome, it remains important to document all exposures and events and take them into consideration when deriving a diagnosis and intervention plan.
Potential risk factors reported to the clinic to date include:

Prenatal:
- Reported tobacco exposure

Postnatal:
- Reported neglect in early childhood
- 6 home placements

Conclusions and Recommendations:

Please note that recommendations that involve medical issues should be shared with the patient's primary care physician before initiating any action

Medical:

- <Name> has such prominent ADHD, combined-subtype, that we will want to thoroughly investigate medications, ideally with child psychiatry consultation given a history of poor response to meds, prominent perseverative/compulsive behaviors, and a strongly positive family history of mood disorders.

- Sleep issues are prominent, with a score 62 on the Children's Sleep Habits Questionnaire (above 41 leads to referral). We recommend contacting _____, MD, (phone number) at _____ Medical Center to evaluate this further.

Developmental, Educational, Mental Health and Family Issues:

- Continued use of visual strategies to assist in understanding expectations, anticipating routines, and increasing independence. We recommend that all those involved in <Name>'s care openly share strategies that are helpful in order to increase consistency across settings. See www.usevisualstrategies.com for ideas such as the Time Timer and books by Linda Hogdon (information sheets were provided in clinic).

- Safety is a critical focus for any environment for <Name>. Environmental supports for safety (alarms, locks, line-of-sight supervision, etc.) may be necessary to ensure <Name>'s safety. Again, idea-sharing between her caregiving team is recommended. An ID bracelet is also recommended.

- Continue speech/language/communication services as recommended (school and private).

- Work with an occupational therapist with experience working with sensory processing/integration difficulties—focus on environmental accommodations (i.e. Southpaw Bear Hug compression vest, weighted blanket for sleep) as well as direct work with <Name>. See the book *The Out of Sync Child* for additional information. <Name>'s IEP can include sensory accommodations and goals. <Name> and <Name> at _____ Center are recommended occupational therapists. See also www.sensorycomfort.com for additional accommodations.

- Continue close monitoring/assessment of <Name>'s skills and progress across all areas of functioning. Thorough intellectual testing and estimates of adaptive skill levels are recommended for improved understanding of <Name>'s individual profile and resulting accurate expectation-setting. When <Name> is approximately 8 years of age, a thorough neuropsychological evaluation (memory, executive functioning, IQ, etc.) will likely be useful to improve understanding of <Name>'s strengths and weaknesses

- Social skills: consider assessing and adding goals to IEP.

- FASt Friends is a local support network for family and community members working with children with FASDs. A flyer was provided in clinic.

- A resource list with information resources for FASDs was provided in clinic. In particular, the education guide download on this list may be helpful for <Name>'s education providers.

- <Name> is at increased risk for developing alcohol dependence/abuse problems herself. We recommend that prevention education efforts begin early and are repeated frequently (make sure they are developmentally appropriate).

It was a pleasure seeing <Name> in clinic today. If you have any questions please call our clinic at <phone number>.

_____ _____

<Name>, MD Date
Pediatrician, FAS DPN Clinic