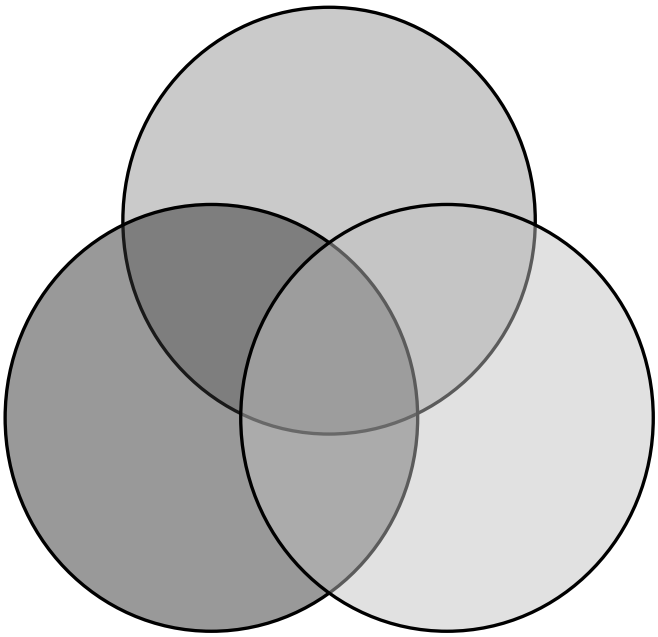
Diagnostic Guide for Fetal Alcohol Spectrum Disorders

The 4-Digit Diagnostic Code™

Third Edition

2004



FAS Diagnostic and Prevention Network
University of Washington
Seattle Washington

Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code

Third Edition

2004.

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Preface

What's New in this Third Edition?

The first and second editions of the Diagnostic Guide were printed in 1997 and 1999 (Astley and Clarren, 1997, 1999). The key updates in this third edition are presented below. These updates are based on our use of the 4-Digit Code for the past seven years on over 2,000 patients, advancements in medical research, U.S. and Canadian efforts to establish National Diagnostic Guidelines, and feedback from over 70 clinical teams trained to use the 4-Digit Diagnostic Code. We will continue to make modifications that enhance accuracy, improve clarity, and increase ease of use. We hope you will find this comprehensive approach to the diagnosis of individuals with prenatal alcohol exposure helpful and broadly applicable.

Key updates in this 3rd edition include:

1. Re-Classification of Nineteen 4-Digit Codes across Seven Diagnostic Categories. Based on current efforts in the U.S. and Canada to establish National Diagnostic Guidelines, and our own experience using the 4-Digit Code, we have reclassified 19 of the 246 4-Digit Codes. Most of these reclassifications reflect the widespread consensus to relax the growth criteria. A detailed presentation of which codes were reclassified, why they were reclassified, and the impact the reclassification has on the prevalence of each diagnostic category can be found on the FAS DPN website (http://depts.washington.edu/fasdpn).

2. Modification of the growth deficiency case-definitions to harmonize with the U.S. and Canadian Diagnostic case-definitions for growth deficiency. This modification allows one to document and differentiate growth deficiency at both the 3rd and 10th percentiles.

3. Updated FASD Diagnostic Form with a new Functional Domains page. The FASD Diagnostic Form has been updated to provide a more comprehensive format. An additional page has been added to allow one to document "Domains of Brain Dysfunction". Documentation of impaired domains (e.g., cognition, memory, executive function, etc.) is a key component of the Canadian and U.S. National Diagnostic Guidelines and has always been required to derive/support a CNS Rank 3 classification when using the 4-Digit Code.

4. Updated Growth Charts. The most recent 2000 CDC growth charts are included with reference to their website for computerized charting of growth.

5. New Caucasian and African American Lip-Philtrum Guides, 2004. A new Caucasian Lip-Philtrum Guide was printed that uses higher-resolution, higher quality photographs. The magnitude of lip thinness and philtrum smoothness remain unchanged from the 1999 Caucasian Lip-Philtrum Guide. A new African American Lip-Philtrum Guide has also been created. The cut-off values for each of the five ranks in the African American Guide were set to be comparable to the percentile cutoffs used in the Caucasian Lip-Philtrum Guide. Both Guides require a Rank 4 or 5 lip and philtrum to meet the criteria for the FAS facial phenotype. The 2004 modified growth table is printed on the backside of each Lip-Philtrum Guide.

I. Introduction

A. What are Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD)

FAS is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The definition of the FAS has changed little since the 1970's when the condition was first described and refined (Jones and Smith, 1973; Rosett, 1980; Clarren and Smith, 1978; Sokol and Clarren, 1989; Stratton *et al*., 1996). The condition has been broadly characterized by prenatal and/or postnatal growth deficiency, a unique cluster of minor facial anomalies, and central nervous system (CNS) abnormalities. FAS is the leading known cause of mental retardation/developmental disabilities in the Western World (Abel & Sokol, 1987) and is entirely preventable. The prevalence of FAS is estimated to be 1 to 3 per 1,000 live births (Stratton et al., 1996) in the general population, but has been documented to be as high as 10 to 15 per 1,000 in some high-risk populations (Astley et al., 2002).

The physical, cognitive, and behavioral deficits observed among individuals with prenatal alcohol exposure are not dichotomous, that is either normal or clearly abnormal. Rather, the outcomes, and the prenatal alcohol exposure, all range along separate continua from normal to clearly abnormal and distinctive. This full range of outcomes observed among individuals with prenatal alcohol exposure has come to be called Fetal Alcohol Spectrum Disorders (FASD). The term FASD is not intended for use as a clinical diagnosis. A patient would not receive a diagnosis of FASD, for the term is too broadly defined to be of clinical value. FAS, on the other hand, is a clinical diagnosis and is one of several alcohol-related diagnoses that fall under the umbrella of FASD.

Although reference to the harmful effects of prenatal alcohol exposure on infant outcome dates back to the biblical literature, it was not until 1968 when the first reference was published in the medical literature by Lemoine and colleagues from France (Lemoine et al., 1968). Ulleland and colleagues from the United States published similar research findings in 1970 and 1972 (Ulleland et al., 1970; Ulleland, 1972). Using today's terminology, one could say Lemoine and Ulleland were the first to describe FASD in the medical literature. In 1973, Jones and Smith coined the term FAS (Jones & Smith, 1973) to describe a subset of alcohol-exposed children, obtained from Dr. Ulleland's study and their own clinical records, who shared a common pattern of malformation (Jones et al., 1973).

B. The Diagnostic Challenge

FASD can present a daunting, but not insurmountable challenge for diagnosis. Individuals with prenatal alcohol exposure present with a wide range of outcomes, most of which are not specific to prenatal alcohol exposure and often manifest differently across the lifespan. Professionals from multiple disciplines (medicine, psychology, speech-language pathology, occupational therapy, etc.) are needed to accurately assess and interpret the broad array of outcomes that define the diagnoses. The pattern and severity of outcome is dependent on the timing, frequency, and quantity of alcohol exposure (which is rarely known with any level of accuracy), and is frequently confounded by other adverse prenatal and postnatal exposures and events.

In the absence of accurate, precise, and unbiased methods for measuring and recording the severity of exposures and outcomes in individual patients, diagnoses have varied widely from clinic to clinic (Aase, 1994; Astley & Clarren 2000; Chavez et al., 1988; Stratton et al., 1996). From a clinical perspective, diagnostic misclassification leads to inappropriate patient care, increased risk for secondary disabilities (Streissguth & Kanton, 1997) and missed opportunities for primary prevention. From a public health perspective, diagnostic misclassification leads to inaccurate estimates of incidence and prevalence (Stratton et al., 1996). Inaccurate estimates thwart efforts to allocate sufficient social, educational, and health care services to this high-risk population, and preclude accurate assessment of primary prevention intervention efforts. From a clinical research perspective, diagnostic misclassification reduces the power to identify clinically meaningful contrasts between FAS and control groups (Astley & Clarren, 2001). Non-standardized diagnostic methods prevent valid comparisons between studies.

The 4-Digit Diagnostic Code was originally created in 1997 to address the following limitations in the conventional gestalt approach to diagnosing individuals with prenatal alcohol exposure.

1. *There have been no standardized operational definitions for FAS or for any of the other diagnoses that fall under the umbrella of FASD. Rather, there have been diagnostic guidelines that physicians have been encouraged to follow, but the guidelines have not been sufficiently specific to assure diagnostic accuracy or precision.*

   For example, according to the diagnostic guidelines published by Sokol and Clarren (1989), which were a minor modification of the 1980 definition of FAS by the Fetal Alcohol Study Group of the Research Society for Alcoholism (Rosett, 1980), which, in turn, were derived from the work of Clarren and Smith (1978): "The diagnosis of FAS can only be made when the patient has signs of abnormality in each of the three categories: 1) Prenatal and/or postnatal growth retardation [weight and/or length below the 10^{th} percentile when corrected for gestational age], 2) central nervous system involvement (including neurological abnormality, developmental delay, behavioral dysfunction or deficit, intellectual impairment, and/or structural abnormalities, such as microcephaly [head circumference below the 3^{rd} percentile or brain malformations found on imaging studies or autopsy] and 3) a characteristic face, currently qualitatively described as including short palpebral fissures, an elongated midface, a long and flattened philtrum, thin upper lip, and flattened maxilla."

   The 1996 guidelines for the diagnosis of FAS proposed by the Institute of Medicine (Stratton et al., 1996) took a similar approach. The diagnosis of FAS can be made when the patient presents with: "1) Evidence of growth retardation, as in at least one of the following: a) low birth weight for gestational age; b) decelerating weight over time not due to nutrition; or c) disproportional low weight to height; 2) Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface); and 3) Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following: a) decreased cranial size at birth; b) structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia);c) neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination."

Although these descriptions do provide guidance, they are not sufficiently specific to assure diagnostic accuracy and precision. They reflect a more "gestalt" approach to diagnosis. The guidelines for CNS abnormalities do not address how many areas of deficit must be present, how severe the deficits must be, or what level of documentation must exist to substantiate the presence of the deficit. The guidelines for the facial phenotype are equally nonspecific. How many facial features must be present, how severe must the features be, and what scale of measurement should be used to judge the severity? One need only read the clinical literature or review medical records, birth certificates, birth defect registries or ICD-9 codes to see how variably these criteria are interpreted, applied and reported (CDC, 1995, 1995a; Cordero et al., 1994; Ernhart et al., 1995; Stratton et al., 1996).

New U. S. diagnostic guidelines for FAS (Bertrand et al., 2004) and Canadian diagnostic guidelines for FASD (Chudley et al., 2004) offer more standardized, case-defined criteria than those published in previous guidelines (Sokol and Clarren, 1989, Stratton et al., 1996). Both are slated for release in 2004.

2. *There has been a lack of objective, quantitative scales to measure and report the magnitude of expression of key diagnostic features*

   For example, although a thin upper lip and smooth philtrum are key diagnostic features (Astley & Clarren, 1996; Clarren & Smith, 1978; Jones & Smith, 1973; Smith, 1979; Stratton et al., 1996), quantitative measurement scales were never used to measure thinness or smoothness, and guidelines had never been established for how thin or smooth the features must be. Objective quantitative scales not only improve accuracy and precision, but also establish a common numeric language for communicating outcomes in medical records and in the medical literature.

3. *The term fetal alcohol effects (FAE) was broadly used and poorly defined.*

   The term 'suspected fetal alcohol effects' was first introduced into the medical literature in 1978 and was defined as 'less complete partial expressions' of FAS in individuals with prenatal alcohol exposure (Clarren & Smith, 1978). Based on this definition, an individual whose mother drank a few glasses of wine intermittently throughout pregnancy and presented with attention deficit hyperactivity disorder would meet the criteria for FAE. So would an individual whose mother drank a fifth of vodka daily throughout pregnancy and presented with microcephaly, severe mental retardation, growth deficiency and no facial anomalies. The broad use of this term and the reluctance to abandon it points to the clear need to develop diagnostic terms for individuals with prenatal alcohol exposure who present with physical anomalies and/or cognitive/behavioral disabilities, but do not meet the criteria for FAS. New diagnostic terms that more finely differentiate the variable exposures and outcomes of individual patients, without implying alcohol as the sole causal agent, are needed.

4. *Clinical terms like FAE* (Aase et al., 1995)*, alcohol-related birth defects (ARBD) (Stratton et al., 1996) and alcohol-related neurodevelopmental disorder (ARND) (Stratton et al., 1996) imply a causal link between alcohol exposure and outcome in a given individual that, to date, cannot be medically confirmed. Leading dysmorphologists in the field of FAS diagnosis have formally requested that the term FAE no longer be used for this reason (Aase et al., 1995; Sokol & Clarren, 1989).*

With the likely exception of the full facial phenotype, no other physical anomalies or cognitive/behavioral disabilities observed in an individual with prenatal alcohol exposure are necessarily specific to (caused only by) their prenatal alcohol exposure (Stratton et al., 1996). Features such as microcephaly, neurological abnormalities, attention deficit, mental retardation, and growth deficiency frequently occur in individuals with prenatal alcohol exposure, and frequently occur in individuals with no prenatal alcohol exposure. The diagnostic terms ARBD and ARND introduce the same limitation as does FAE, namely, implying alcohol exposure caused the birth defect or neurobehavioral disorder in an individual patient. The 4-Digit Code avoids this problem by using a nomenclature that reports the patient was *exposed* to prenatal alcohol rather than reporting the patient's outcomes are *alcohol effects* or *alcohol-related outcomes*. The 4-Digit Code also requires that all other adverse prenatal and postnatal exposures and events be documented for they too serve as important risk factors that must be taken into consideration when deriving a diagnosis and intervention plan.

5. *Too often diagnoses depicting FASD are reported in the medical records and medical literature with no documentation of the method used to derive the diagnosis and little or no documentation of the data used to support the diagnosis.*

   Failure to report this information can limit the patient's ability to qualify for and receive appropriate intervention services from subsequent health care, social service, and educational providers. For example, simply reporting that an individual has FAS does little to convey the individual's strengths and disabilities. Some individuals with FAS have low IQs, some have normal IQs, some have attention deficits, some do not, some have problems with memory, while others have language deficits. From a public health perspective, failure to report these data also prevents surveillance efforts from accurately tracking the prevalence of FASD diagnoses in the population. The supportive data are needed to validate the diagnoses. Accurate surveillance is vital for setting public health policy and assessing the effectiveness of primary prevention efforts. The 4-Digit Code requires that data be collected not just to support the diagnosis, but to derive the diagnosis. The 4-Digit Code provides a comprehensive FASD Diagnostic Form for recording all supportive data and provides a numeric classification scheme that is readily incorporated into clinical, research, and surveillance databases.

C. Meeting the Diagnostic Challenge

Each of the above limitations has been largely overcome with the development of the "*4-Digit Diagnostic Code*". The four digits reflect the magnitude of expression of four key diagnostic features of FASD in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) CNS abnormalities, and (4) prenatal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. Thus, the 4-Digit Code 4444 reflects the most severe expression of FAS (significant growth deficiency, all three FAS facial features, structural/neurological evidence of CNS damage, and confirmed prenatal exposure to high levels of alcohol). At the opposite end of the scale is the 4-Digit Code 1111 reflecting normal growth, none of the three FAS facial features, no evidence of CNS abnormalities, and confirmed absence of prenatal alcohol exposure. Every combination of 4-Digit Code has been observed in the Washington State FAS Diagnostic & Prevention Network.

This diagnostic method was developed through the combined expertise of the University of Washington FAS Diagnostic and Prevention Network (FAS DPN) interdisciplinary clinical team (Clarren & Astley, 1997; Clarren et al., 2000) and the comprehensive records of over 2,000 patients (birth to 53 years of age) diagnosed through the FAS DPN.

D. Benefits of the 4-Digit Diagnostic Code

The 4-Digit Diagnostic Code:

1. Greatly increases diagnostic precision and accuracy through the use of objective, quantitative measurement scales, image analysis software, and specific case definitions.
2. Diagnoses the full spectrum of outcomes (FASD) observed in individuals of all ages with prenatal alcohol exposure.
3. Offers an intuitively logical numeric approach to reporting outcomes and exposure that reflects the true diversity and continuum of disability associated with prenatal alcohol exposure.
4. Documents the presence of prenatal alcohol exposure without judging its causal role.
5. Documents all other prenatal and postnatal adverse exposures and events that can also impact outcome.
6. Provides a quantitative measurement and reporting system that can be used independent of diagnostic nomenclature.
7. Can be taught to a wide array of health care and social service providers, thus greatly expanding the availability of diagnostic services. (Appendix 1)

The 4-Digit Code currently serves as the cornerstone of a fully integrated and highly successful screening, diagnostic, prevention and surveillance program in Washington State (Astley et al., 2002; Astley, 2004).

While this document might at first appear overly complex and perhaps daunting, one will find that this diagnostic approach is logical and easy to use, and will greatly facilitate the proper description and classification of patients presenting with all possible combinations of outcomes and exposures.

E. Other Syndromes

The methods of diagnosing fetal alcohol syndrome arise from the larger fields of teratology and dysmorphology (clinical genetics). It is essential to remember that many birth defect syndromes share *isolated* features, but each is differentiated by a unique *constellation* of features. A few examples of conditions that share some, but not all, of the features of FAS include fetal hydantoin syndrome, maternal PKU fetal effects, and fetal valproate syndrome. Although this guide is "FASD-specific", this in no way should imply that the diagnostician need not consider alternate or co-existing syndromic, medical or psychiatric conditions at all times. A differential diagnosis is essential in making an accurate diagnosis.

II. FASD Diagnostic Form

The FASD Diagnostic Form guides the interdisciplinary clinical team in the collection, recording, and interpretation of all key information used to derive accurate and precise diagnoses across the full spectrum of outcomes. Comprehensive assessments lead to accurate diagnoses and informed intervention plans. Although space has been provided to record a full complement of data, we are not implying that all of these assessments must be conducted to derive a diagnosis. It is the responsibility of the clinical team to select the most appropriate assessment battery for each patient.

The form also serves as a centralized data repository for efficient generation of the final medical report and is designed to facilitate data entry into a database.

Where is the Information for the Diagnostic Form Obtained?

The information recorded in the FASD Diagnostic Form is obtained from four primary sources:

1. The New Patient Information Form completed by the caregivers prior to the diagnostic evaluation (Appendix 2).

2. Medical/psychological/educational assessments conducted prior to the diagnostic evaluation.

3. Assessments administered by the clinical team at the time of the diagnostic evaluation.

4. The caregiver/patient interview conducted at the time of the diagnostic evaluation

When is the Form Completed and by Who?

Diagnosis of fetal alcohol spectrum disorders by a multidisciplinary team of professionals (physician, psychologist, speech-language pathologist, occupation therapist, etc.) will result in the most accurate assessment and interpretation of the broad array of outcomes (growth deficiency, facial anomalies, and structural/neurological/functional CNS abnormalities) that define the diagnoses. The FASD Diagnostic Form is completed by the clinical team before and during the patient's clinic visit. Typically, the physician completes the sections pertaining to growth, structural and neurological measures of the CNS, facial features and other physical findings. The occupational therapist, psychologist, speech language pathologist, and/or other team members complete the sections pertaining to psychometric measures of CNS function. All team members participate in the derivation of the 4-Digit Code and intervention plan.

FASD Diagnostic Form

Medical #		Clinic		Clinic Date	
Patient's Name	First	MI	Last	Age (y)	Birth date

Name person(s) accompanying patient			
Relationship(s) to patient		Patient's Gender	M F

Patient's Race	
Form completed by:	
Diagnosis made by:	
Diagnosis	

4-Digit Diagnostic Code Grid

(See instructions in Diagnostic Guide for FASD)

Growth Deficiency	FAS Facial Features	CNS Damage		Growth	Face	CNS	Alcohol		Prenatal Alcohol
Significant	Severe	Definite	4					4	High risk
Moderate	Moderate	Probable	3					3	Some risk
Mild	Mild	Possible	2					2	Unknown
None	None	Unlikely	1					1	No risk

GROWTH

Prenatal Growth

	Gestational Age	Birth Length			Birth Weight		
Date	(wks)	(cm)	(inches)	(percentile)	(gm)	(lbs/oz)	(percentile)

Postnatal Growth

		Height					Weight		
Date	Age (yrs/months)	(cm)	(inches)	Unadjusted (percentile)	Mid-birthparent Adjustment (cm)	Parent-Adjusted (percentile)	(kg)	(lbs)	(percentile)

Birth Parent's Heights

Birth Mother Height		Birth Father Height		Mid-Parent Height
cm	inches	cm	inches	cm

ABC-Score for Growth Deficiency

See instructions in the "Diagnostic Guide for FASD" for deriving the ABC-score for growth and translating it into a 4-Digit Diagnostic Code

≤ 3rd percentile = **C**
>3rd and ≤ 10th percentile = **B**
> 10th percentile = **A**

Circle the ABC Scores for:

Height	Weight
C	C
B	B
A	A

This ABC Score reflects the patient's growth between _____ years and _____ years of age.

FACIAL FEATURES (and other physical findings)

CURRENT PHENOTYPE: (Age _____ yrs/months)

Direct Measures

	True estimate (mm)	z-score	Normal Chart Used
Left PFL			
Right PFL			
Mean PFL			
Inner Canthal Distance			

	5-Point Rank	Lip-Philtrum Guide Used
Philtrum		
Upper Lip		

Clinic Photograph

Frontal digital photo filename	Internal measure of scale (dot on forehead)		
	True dot size	Units (mm, cm, inches)	Dot size in photo

	Length in photo (pixel or mm)	True estimate (mm)	z-score	Normal Chart Used
Left PFL				
Right PFL				
Mean PFL				
Inner Canthal Distance				

Photo filename		5-Point Rank	Lip-Philtrum Guide Used	
	Philtrum			Upper Lip Circularity
	Upper Lip			

PAST PHENOTYPE (Age _____ yrs/months) (Date _____/_____/_____)

Source of Information	Internal measure of scale (dot on forehead)		
	True dot size	Units (mm, cm, inches)	Dot size in photo (pixels)
Photo:			
Text Record:			

	Length in photo (pixel or mm)	True estimate (mm)	z-score	Normal Chart Used
Left PFL				
Right PFL				
Mean PFL				
Inner Canthal Distance				

Photo filename		5-Point Rank	Lip-Philtrum Guide Used	
	Philtrum			Upper Lip Circularity
	Upper Lip			

FACIAL ABC-SCORE *See instructions in the "Diagnostic Guide for FASD" for deriving the ABC Score and 4-Digit Code*

5-Point Likert Rank for Philtrum & Lip	Z-score for Palpebral Fissure Length	*Circle the ABC Scores for:* Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	>-2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A
Source of Data for each Facial Feature ➜				

OTHER PHYSICAL FINDINGS / SYNDROMES / MEDICAL CONDITIONS

CENTRAL NERVOUS SYSTEM (CNS)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Significant

Severity **STRUCTURAL**

0 1 2 3										
	OFC	cm	%tile	age (yrs/mos)	cm	%tile	age (yrs/mos)	cm	%tile	age (yrs/mos)

0 1 2 3 Structural anomalies seen on brain imaging _____

0 1 2 3 Other: _____

NEUROLOGICAL

0 1 2 3 Seizures: type: _____ meds._____ Age at onset _____ (yrs/mos)

0 1 2 3 Other neurological signs: _____

_____

FUNCTIONAL/Standardized Measures *Document most recent, valid test scores.*

0 1 2 3 **Cognition** (e.g., WISC-III, WAIS, DAS, Stanford-Binet, etc.)

Test Name					*Age (yr/mos) or Date*		*FSIQ*	*PIQ*	*VIQ*	*Verb. Comp*	*Percept Org.*	*Free. Distr.*	*Process. Speed*
Info	*Simil.*	*Arith.*	*Voc.*	*Comp*	*Digit.*		*Pict. C.*	*Pict. A.*	*Block*	*Obj.*	*Coding*	*Mazes*	*Symbol*

Other Test/Subtest Names	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Other Test/Subtest Names*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

0 1 2 3 **Academic Achievement** (e.g., WIAT, Woodcock Johnson, WRAT, etc)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

0 1 2 3 **Adaptive Behavior / Social Skills** (e.g., VABS, BASC, Adaptive Behavior Assessment System, etc)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

CNS (Continued)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Significant

Severity

0 1 2 3 **Neuropsychological** (e.g., CVLT, D-KEFS, WRAML, CMS, Rey Complex Figure Test, WCST, NEPSY, etc)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

0 1 2 3 **Motor / Sensory Integration** (e.g., PDMS, SSP, QNST, VMI, Brunuinks-Oseretsky Scales of Motor Dev, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

0 1 2 3 **Language/Social Communication** (e.g., TOLD, PLS-3, Narrative production, Mental state reasoning, etc)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

CNS (Continued)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Significant

Severity

0 1 2 3 **Mental Health/Psychiatric Conditions:** (e.g., ODD, Generalized Anx. Disorder, Maj. Depression, etc)

Disorder	*Age (yr/mos) or Date Diagnosed*	*Disorder*	*Age (yr/mos) or Date Diagnosed*	*Disorder*	*Age (yr/mos) or Date Diagnosed*

Medication. √ if Currently Taking	*Response (+, -, none)*	*Medication. √ if Currently Taking*	*Response (+, -, none)*	*Medication. √ if Currently Taking*	*Response (+, -, none)*

0 1 2 3 **Behavior/Attention/Activity Level** (e.g., CBCL, Conners Rating Scale, Continuous Perform. Test, IVA, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

0 1 2 3 **Development** (e.g., Bayley Scales of Infant Dev., Battelle Dev. Invent., Miller Assessment of Preschoolers, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Age (yr/mos) or Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Age (yr/mos) or Date*

CNS (Continued)

FUNCTIONAL / Non-Standardized Observational Measures

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed, Too Young **1** = Within Normal Limits **2** = Mild to Moderate **3** = Significant

Severity

Caregiver Interview

Planning / Temporal Skills

0 1 2 3 Needs considerable help organizing daily tasks _____
0 1 2 3 Can not organize time _____
0 1 2 3 Does not understand concept of time _____
0 1 2 3 Difficulty in carrying out multi-step tasks _____
0 1 2 3 Other _____

Behavioral Regulation/ Sensory Motor Integration

0 1 2 3 Poor management of anger / tantrums _____
0 1 2 3 Mood swings _____
0 1 2 3 Impulsive _____
0 1 2 3 Compulsive _____
0 1 2 3 Perseverative _____
0 1 2 3 Inattentive _____
0 1 2 3 Inappropriately [high or low] activity level _____
0 1 2 3 Lying/stealing _____
0 1 2 3 Unusual [high or low] reactivity to [sound touch light] _____
0 1 2 3 Other _____

Abstract Thinking / Judgment

0 1 2 3 Poor judgment _____
0 1 2 3 Cannot be left alone _____
0 1 2 3 Concrete, unable to think abstractly _____
0 1 2 3 Other _____

Memory / Learning / Information Processing

0 1 2 3 Poor memory, inconsistent retrieval of learned information _____
0 1 2 3 Slow to learn new skills _____
0 1 2 3 Does not seem to learn from past experiences _____
0 1 2 3 Problems recognizing consequences of actions _____
0 1 2 3 Problems with information processing speed and accuracy _____
0 1 2 3 Other _____

Spatial Skills and Spatial Memory

0 1 2 3 Gets lost easily, has difficulty navigating from point A to point B _____
0 1 2 3 Other _____

Social Skills and Adaptive Behavior

0 1 2 3 Behaves at a level notably younger than chronological age _____
0 1 2 3 Poor social/adaptive skills _____
0 1 2 3 Other _____

Motor/Oral Motor Control

0 1 2 3 Poor/delayed motor skills _____
0 1 2 3 Poor balance _____
0 1 2 3 Other _____

CNS (Continued)

FUNCTIONAL DOMAINS

Examples include, but are not limited to Memory, Cognition, Language, Executive Function, and Attention.

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Significant

Severity

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

0 1 2 3 Name of Domain: ______
Supportive Evidence: ______

See the "Diagnostic Guide for FASD" for instructions on deriving the 4-Digit Diagnostic Code for CNS

MATERNAL ALCOHOL USE

Alcohol Consumption of the Birth Mother

Before Pregnancy	**average number of drinks** per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of **drinking days per week**:					
	Type(s) of alcohol	wine	beer	liquor	unknown	Other (specify)

During Pregnancy	**average number of drinks** per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of **drinking days per week**:					
	Type(s) of alcohol	wine	beer	liquor	unknown	Other (specify)

Trimester(s) in which alcohol was consumed	1st	2nd	3rd	unknown	none
Was the birth mother ever reported to have a **problem** with alcohol?	yes	suspected	no	unknown	
Was the birth mother ever **diagnosed** with alcoholism?	yes	suspected	no	unknown	
Did the birth mother ever **receive treatment** for alcohol addiction?	yes	suspected	no	unknown	
Was alcohol use during this pregnancy **positively confirmed**?	yes	no			
If yes, **source** of confirmation:					
Reported use of alcohol during this pregnancy is:	Reliable	Somewhat reliable		Unk. reliability	
Other information about alcohol use **during** this pregnancy					

4-DIGIT RANK for Alcohol Exposure

4-Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description
4	High Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Exposure pattern is consistent with the medical literature placing the fetus at "high risk" (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy).
3	Some Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Level of alcohol use is less than in Rank (4) or level is unknown.
2	Unknown Risk	● Alcohol use during pregnancy is UNKNOWN.
1	No Risk	● Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

Circle the 4-Digit Diagnostic Rank in the table above that best reflects the patient's Prenatal Alcohol Exposure

OTHER PRENATAL AND POSTNATAL EXPOSURES / EVENTS

PRENATAL

High risk	Some risk	Unknown risk	No risk
4	3	2	1

See the "Diagnostic Guide for FASD" for instructions on deriving the rank for Prenatal Exposures/Events

Prenatal

1. Parity ____, Gravity ____ of this birth. Birth order if child is the result of a multiple birth pregnancy: _____ of _____
2. Prenatal care: ____ Yes, (If yes, when did it start?_____), ___ No, ___ Unknown
3. Complications (specify) _____

Genetics

1. Parental learning difficulties (e.g. Special Ed., ADD, MR, did not complete high school, etc.*)*

   Mother _____ Yes _____ Suspected _____ No _____ Unknown

   Father _____ Yes _____ Suspected _____ No _____ Unknown

   If yes, specify Maternal _____

   Paternal _____
2. Other conditions of heritability or malformation that may be relevant to this case. *(specify)*

   _____

Prenatal Exposure to Other Substances (e.g., medications, tobacco, illicit drugs, other teratogens, etc.)

_____

_____

POSTNATAL

High risk	Some risk	Unknown risk	No risk
4	3	2	1

See the "Diagnostic Guide for FASD" for instructions on deriving the rank for Postnatal Exposures/Events

Perinatal Difficulties

_____

_____

Issues of Nurture

1. Abuse: Physical _____ Sexual _____
2. Number of home placements _____
3. Other (e.g., neglect, adverse home environment, significant traumas, etc.*)* _____

   _____

   _____

   _____

Other Issues That Could Explain CNS Abnormalities (e.g., head injury, substance abuse by patient, etc.)

_____

_____

FAS Diagnostic and Prevention Network
Preliminary Summary and Recommendations

A final comprehensive medical summary will be mailed to you.

Patient's Name: _____ Clinic: _____

Birth Date: ____ / ____ / ____ Clinic Date: ___ / ___ / ___ Clinic phone: _____

Diagnostic Outcome: _____

Result(s) of assessment(s) performed in Clinic (if applicable):

FAS Diagnostic and Prevention Network
Preliminary Summary and Recommendations

Patient Name: _____ Birth Date: _____ / _____ / _____

Recommendations for Follow-Up

A. Medical Issues

B. Developmental, Educational, Vocational, Mental Health, and Family Issues

III. Instructions for Deriving the 4-Digit Code

A. The 4-Digit Diagnostic Code

What are the 4 Digits?

The four digits reflect the magnitude of expression of the four key diagnostic features of FASD in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) CNS abnormalities, and (4) prenatal alcohol exposure. The 4-Digit Diagnostic Code is generated at the completion of the diagnostic evaluation using information recorded on the FASD Diagnostic Form. The code is derived following the directions in Sections III. B. 1 through B. 4.

4-Digit Diagnostic Code Grid

				3	4	4		4		
Severe	Severe	Definite	(4)		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 Deficiency	**FAS Facial Features**	**CNS Damage**		Growth	Face	CNS		Alcohol		**Prenatal Alcohol**

The 4-Digit Diagnostic Code 3444 inserted in the grid is one of twelve 4-Digit Codes that meet the diagnostic criteria for FAS.

How are the 4 Digits Ranked?

The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. Specific guidelines for ranking the magnitude of each of the FAS features are presented in Section III.B.

How Many 4-Digit Diagnostic Codes are There?

There are 256 possible 4-Digit Diagnostic Codes ranging from 1111 to 4444. The 256 codes and their corresponding clinical names are listed in numerical order in Section VI.

How Many Different Clinical Diagnostic Categories are There?

Each 4-Digit Diagnostic Code falls into one of 22 unique Clinical Diagnostic Categories (labeled A through V). A list of the 22 Diagnostic Categories is presented in Section IV. A list of the 4-Digit Diagnostic Codes, which fall within each Clinical Diagnostic Category, is presented in Section V.

What are the Names of the Clinical Diagnostic Categories?

The following terms are used in varying combinations to name the 22 diagnostic categories. They include:

- **Sentinel Physical findings:**
  The term "S*entinel Physical Findings*" is used in this diagnostic system when the patient presents with growth deficiency at the Rank 3 or 4 level and/or presents with the FAS facial phenotype at the Rank 3 or 4 level. The adjective *"sentinel"* refers to physical findings that are key diagnostic features of FAS. These include a unique cluster of minor facial anomalies (short palpebral fissures, thin upper lip, and a smooth philtrum) and growth deficiency. Other physical findings (major or minor anomalies) may be detected instead of or in addition to these sentinel findings that may suggest alternate or additional conditions. There are places on the Diagnostic Form to record and interpret other physical findings.

- **Static Encephalopathy:**
  The term *"encephalopathy"* refers to "any significant abnormal condition of the structure or function of brain tissues" (Anderson, 2002). The term *"static"* means that the abnormality in the brain is unchanging; neither progressing nor regressing. The term *"Static Encephalopathy"* is used in this diagnostic system when the patient presents with significant structural, neurological, and/or functional abnormalities that strongly support the presence of underlying CNS damage at the Rank 3 and/or Rank 4 levels. The term does not define or suggest any specific pattern of structural, neurological, or functional abnormality.

- **Neurobehavioral Disorder:**
  The term *"Neurobehavioral Disorder"* is used in this diagnostic system when the patient presents with cognitive/behavioral dysfunction at the Rank 2 level and no evidence of structural, neurological or functional abnormalities at the Rank 3 or Rank 4 levels.

- **Alcohol (Exposed, Not Exposed, Exposure Unknown):**
  These terms are used to reflect prenatal alcohol exposure and its potential risk to the unborn child. Alcohol exposure is reported <u>independently</u> of outcome(s) and does not imply that a causal association exists between the exposure and the outcome(s).

- **Fetal Alcohol Syndrome (alcohol exposed)**
  The term FAS is used to refer to patients who present with one of twelve 4-Digit Diagnostic Code combinations reflecting growth deficiency; the full FAS facial phenotype; significant structural, neurological, and/or functional CNS abnormalities; and confirmed prenatal alcohol exposure. These 12 Codes are presented in Section V.

- **Fetal Alcohol Syndrome (alcohol exposure unknown)**
  A diagnosis of FAS can be rendered when prenatal alcohol exposure is "unknown" but only when the outcomes (growth, face, and CNS) are at the severe end of the spectrum to maintain the specificity of these outcomes to prenatal alcohol exposure. (Astley et al., 2001) Six 4-Digit Codes fall under this category (Section V).

- **Partial Fetal Alcohol Syndrome (alcohol exposed):**
  This term is used for patients who present with static encephalopathy, most (but not all) of the growth and/or facial features of FAS, and have a confirmed history of prenatal alcohol exposure. Given the fact that variable presentation is the rule rather than the exception after teratogenic exposures, we felt it was appropriate to establish this diagnostic category. Twenty 4-Digit Codes fall under this category (Section V).

- **Fetal Alcohol Syndrome Phenocopy (no alcohol exposure):**
  This term is used for patients who meet the growth, face and CNS criteria for FAS, but have a confirmed absence of alcohol exposure during gestation. We have never seen such a case (or phenocopy), but we may some day.

The names assigned to each diagnostic category reflect the patient's clinical outcome and alcohol exposure. The names are listed in Sections IV and V. The first three categories (A through C) meet the criteria for a clinical diagnosis of FAS and are named as such. The fourth category (D) applies to the patient who presents with all of the features of FAS, but has a confirmed *absence* of prenatal alcohol exposure from conception to birth. This category is referred to as a FAS Phenocopy and has yet to be observed. The remaining 19 categories (E through V) do not meet the minimum criteria for FAS or partial FAS. These are subsequently named to reflect the Likert ranking of each digit in the 4-Digit Diagnostic Code. For example, a code of 3243 is the Diagnostic Category called "*Sentinel physical finding(s) / static encephalopathy (alcohol exposed)*".

Which Diagnostic Categories are Comparable to PFAE, ARND and ARBD?

Many 4-Digit Codes within Diagnostic Categories E through I would previously have been referred to as "possible fetal alcohol effects" (PFAE), "alcohol-related birth defects" (ARND) or "alcohol-related neurodevelopmental disorder" (ARBD). (Sokol & Clarren, 1989; Stratton et al., 1996) A report that translates which 4-Digit Codes meet the criteria for ARND and ARBD can be found on the FAS DPN website http://depts.washington.edu/fasdpn. Categories J through V are categories that describe a large number of patient groups who have never been adequately classified or described by previous FASD diagnostic guidelines.

Ultimately, establishing terms that are both clinically accurate, broadly applicable, and facilitate access to services remains a challenge. It is important to remember that the 4-Digit Code provides a numeric measurement and reporting system for exposures and outcomes that can be used independently of the proposed diagnostic nomenclature.

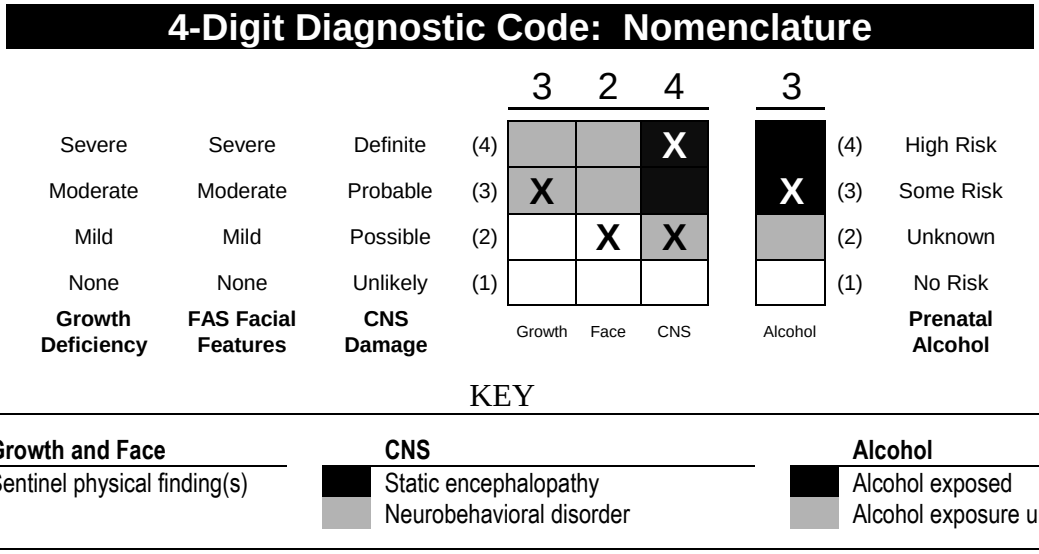
How are the Names of the Clinical Diagnostic Category Constructed?

- Growth deficiency and facial features are physical features. When either feature receives a rank of 3 or 4, *Sentinel physical finding(s)* is placed at the beginning of the name.

- When CNS receives only a Rank 2, the term *Neurobehavioral Disorder* is included in the name. When CNS receives a Rank 3 or 4, the term *Static Encephalopathy* is included in the name.

- When alcohol exposure receives a Rank 3 or 4, (*alcohol exposed*) is placed at the end of the name. When alcohol exposure receives a Rank 2, (*alcohol exposure unknown*) is placed at the end of the name.

- When the criteria for FAS or PFAS are met, those clinical terms are used in place of the more generic terms. For example the term FAS is used rather than *Sentinel physical finding(s / static encephalopathy (alcohol exposed).*



The 4-Digit Code 3243 would receive the clinical name *Sentinel physical finding(s) / static encephalopathy (alcohol exposed).* Note that the CNS received both Rank 4 and Rank 2. The higher Rank is used to derive the 4-Digit Code and construct the name. A code of 1222 would receive the clinical name *Neurobehavioral disorder (alcohol exposure unknown).*

How Do You Explain the Diagnosis to the Patient?

Generic summaries of each of the 22 Clinical Diagnostic Categories are presented in Section VII. These summaries can be used as the first page of the patient's final Medical Summary Note. Subsequent pages in the Medical Summary Note should document the findings and recommendations specific to the patient. We recommend the growth, face, CNS, and exposure data, used to generate the 4-Digit Code, be reported in the Medical Summary Note to provide essential information to subsequent medical professionals and facilitate records-based public health surveillance efforts.

III. Instructions for Deriving the 4-Digit Code

B.1. Ranking Growth

What Type of Growth Deficiency Are We Looking For?

We are looking for growth deficiency characteristic of a teratogenic insult, not characteristic of postnatal environmental factors such as nutritional deprivation or chronic or acute illness. We want to answer the question *'What is the patient's growth potential after controlling for parental height and postnatal environmental influences?'* Growth deficiency of teratogenic origin is likely to present as a relatively consistent impairment over a period of time (i.e., the patient's growth follows the normal curve, but is below genetic expectation for family background). In contrast, growth deficiency due to postnatal environmental influences is likely to present as periodic fluctuations in the curve. Separating the two growth patterns requires astute clinical judgment.

The method described below allows one to rank a patient's overall growth pattern on a single 4-point Likert scale with 1 equal to 'normal' and 4 equal to significantly deficient. Not all patients will have complete growth curves available, therefore, a guide is provided below for prioritizing the ranking of the patient's growth over a lifetime

How to Measure and Rank Growth: The 1st Digit of the 4-Digit Diagnostic Code

A. The height percentile should be age and gender adjusted. Because there is a significant genetic component in attained stature, adjustment for mid-parent stature is also recommended when both parents' heights are known. Himes et. al., (1985) provide charts for mid-parent adjustment of recumbent length (birth to 3 years) and stature (3 to 18 years) of US children relative to National Center for Health Statistics growth charts.

B. The weight percentile should be age and gender adjusted. Weight is not adjusted for height.

   CDC 2000 Growth Charts are provided in Section VIII. Other valid growth charts may be used. We recommend electronic computation of percentiles for increased accuracy. CDC offers a free software program called Epi Info that will compute percentiles and plot data on the CDC Growth Charts. This software can be obtained from the CDC website www.cdc.gov/epiinfo.

C. For ranking purposes, the growth record is separated into two parts:
   1. Prenatal growth (birth measures)
   2. Postnatal growth (all measures collected after birth)

   Select the part of the growth record with the greatest deficiency in the height percentile.

   If the prenatal height percentile is lower than all postnatal height percentiles, proceed to section D for instructions on how to rank prenatal growth.

If any of the postnatal height percentiles are lower than the prenatal height percentile, select the point or consecutive points in the growth record that reflect the lowest height percentiles that cannot be attributed to postnatal environmental influences such as nutritional deprivation or chronic illness. If the height deficiency is reflected in a series of points in the growth record, as opposed to a single point, rank the level of deficiency based on the percentile range where the majority of the points fall. Proceed to section D for instructions.

D. Rank the level of deficiency of the height and weight percentiles, for the part of the growth record with greatest deficiency in the height percentile by circling A, B, or C in the ABC-Score table at the bottom of page 1 of the FASD Diagnostic Form. This ABC-Score table is duplicated below as Table 1. The height and weight percentiles selected for ranking should be matched sets. For example, if the height at 10 years of age is selected for ranking, the corresponding weight percentile at 10 years of age should also be selected for ranking. One does not rank the height at one age and the weight at another age to generate an ABC-Score.

Table 1: Deriving the ABC-Score for Growth

	Circle the ABC-Scores for:	
Percentile Range	Height	Weight
$\leq 3^{rd}$	C	C
$>3^{rd}$ and $\leq 10^{th}$	B	B
$>10^{th}$	A	A

E. Next, refer to Table 2 to determine the *4-Digit Diagnostic Rank* of the Height-Weight ABC-Score recorded in Table 1. Transfer the resulting 4-Digit Diagnostic Rank for growth to the 4-Digit Diagnostic Code Grid at the top of page 1 of the FASD Diagnostic Form.

Table 2: Converting the Growth ABC-Score to a 4-Digit Diagnostic Rank for Growth

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

Example for Scoring Growth Deficiency

Patient's Growth Record:

	Age (years)	Height Percentile	Weight Percentile
birth	0.0	8 %	1 %
	1.5	14 %	16 %
	5.0	12 %	15 %
	7.0	12 %	15 %
	15.5	15 %	15 %

Assume the clinical records rule-out any environmental influence on postnatal measures and mid-parental height is unknown.

Ranking:

- Priority would be placed on ranking the birth length and weight because the birth length percentile is lower than all postnatal height percentiles recorded.
- Birth length (8 %) would receive an **ABC-Score = B** (> 3rd and ≤ 10th percentile) (Table 1).
- Birth weight (1 %) would receive an **ABC-Score = C** (≤ 3rd percentile) (Table 1).
- The Height-Weight ABC-Score combination would be **BC** (Table 1).

Table 1: Deriving the ABC Score for Growth

	Circle the ABC-Scores for:	
Percentile Range	Height	Weight
≤ 3rd	C	**C**
>3rd and ≤ 10th	**B**	B
>10th	A	A

- The Height-Weight ABC-Score of **BC** reflects **Moderate** growth deficiency (Table 2)
- **Moderate** growth deficiency would receive a **Rank 3** in the 4-Digit Diagnostic Code (Table 2).

Table 2: Converting the Growth ABC-Score to a 4-Digit Diagnostic Rank for Growth

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

- **Rank 3** would be transferred to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (as duplicated below).

Result:

4-Digit Diagnostic Code Grid

				3					
Severe	Severe	Definite	(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 Deficiency	**FAS Facial Features**	**CNS Damage**		Growth	Face	CNS	Alcohol		**Prenatal Alcohol**

III. Instructions for Deriving the 4-Digit Code

B.2. Ranking the Facial Phenotype

The FAS Facial Phenotype

The face of FAS is distinguished by the simultaneous expression of three facial features:

1. Small palpebral fissure lengths (2 or more standard deviations below the mean) (Figure 2)
2. Smooth Philtrum (Rank 4 or 5 on the Lip-Philtrum Guide) (Figure 3).
3. Thin upper lip (Rank 4 or 5 on the Lip-Philtrum Guide) (Figure 3).

David Smith, M.D., who coined the term FAS in 1973, identified these features as the *key* diagnostic facial features in 1979 (Smith, 1979). A series of analytic studies conducted 20 years later confirmed the sensitivity and specificity of these features to FAS, and served to case-define the magnitude of expression required to maximize sensitivity (100%) and specificity (99%) (Astley & Clarren, 1996, 2000, 2001). Relaxation of these criteria substantially reduces sensitivity and specificity. The clinical validity of these features has been confirmed through population-based screening and surveillance studies (Astley et al., 2002; Astley, 2004) and empirical studies documenting remarkably strong correlations between these midline facial anomalies and underlying brain damage/dysfunction (Astley & Clarren, 2001). As the FAS facial phenotype increases in severity of expression from Rank 1 to Rank 2 to Rank 3 to Rank 4, the prevalence of underlying brain damage/dysfunction also increases linearly. The FAS facial phenotype, including partial expressions of the phenotype, serves as a sensitive marker of brain damage/dysfunction.

How to Measure and Rank the Face: The 2nd Digit of the 4-Digit Diagnostic Code

There are two methods for measuring the facial features: 1) direct measurement and 2) computerized analysis of a digital facial photograph using the FAS Facial Photographic Analysis Software. The latter is the most accurate and is described in detail in Astley & Clarren (2001). The facial analysis software can be obtained from the FAS Diagnostic & Prevention Network website [http://depts.washington.edu/fasdpn]. The computerized method for analyzing facial features was designed to use a *standard* digital camera to maximize clinical access to this technology, while maintaining the highest level of accuracy. An instructional CD-ROM called FAS TUTOR ™ demonstrates how to accurately measure the facial features. It too can be obtained from the FAS DPN website.

A. Palpebral Fissure Length (PFL)

Direct measurement: The PFLs are measured to the nearest mm with a clear plastic, 15-cm ruler, held as close as possible to the eye without touching the eye or eye-lashes (Figures 1A, 1B). We choose not to use calipers because we find our patients are often too young and active to cooperate safely. The patient is asked to open their eyes fully to allow accurate identification of the endocanthion and exocanthion landmarks (Astley et al., 1999; Farkas, 1994). Epicanthal folds should be gently pulled to the midline to expose the endocanthion. It is difficult to obtain accurate measures of the PFL by direct measure. The physician should confirm the accuracy of their measurement technique against a gold standard (perhaps by measuring a colleague's PFL with a ruler that was previously measured with calipers). See the FAS-TUTOR CD for instructional animations (Astley et al.1999).

Computer measurement: A digital photo of the face is taken with a ¾ inch paper sticker placed between the eyebrows to serve as an internal measure of scale (Astley & Clarren, 2001). The photo is analyzed using the FAS Facial Photographic Analysis Software (Astley, 2003). The PFL is measured by clicking the mouse on the endocanthion and exocanthion landmarks of the right and left eyes. The length of each palpebral fissure and its z-score (number of standard deviations above or below the norm) are computed automatically based on formulas and normal charts embedded in the software. More detailed instructions are provided with the software.

Ranking: The PFL is ranked according to its z-score (or how many standard deviations above or below the mean it is on a normal anthropometric chart). If the eyes are substantially different in size, (more than 2 mm different) rank the larger PFL. If the eyes are comparable in size, rank the mean of the right and left PFL. Normal palpebral fissure length charts for Caucasians are provided in Section VIII (Hall et al., 1989). Normal PFL charts adjusted for race should be used if available and confirmed valid. There is general agreement among medical professionals that new more accurate and valid norms for palpebral fissure charts are needed. Until new charts are available, we have chosen to use the Hall Caucasian Charts for they reflect a composite of several published Caucasian charts and best reflect the rate of growth from birth to 16 years of age that we have observed among normally developing Caucasian children.

B. Upper Lip Thinness and Philtrum Smoothness

Direct measurement: Upper lip thinness (the red or vermilion portion of the upper lip) and philtrum smoothness are measured independent of one another using the 5-point pictorial Likert scale presented on the Lip-Philtrum Guides (Figure 3). Two Guides are available, one for Caucasians and one for African Americans. The Guide that best matches the phenotypic profile of the patient's race should be used. The physician holds the Lip-Philtrum Guide next to the patient's face and identifies the picture that best matches the patient's upper lip and identifies the picture that best matches the patient's philtrum. Lips must be *gently closed* with *no* smile to obtain accurate measures (Figure 4) (Astley et al., 1999). The physician's eyes must be in the patient's frankfort horizontal plane (represented by a line drawn from the external auditory canal through the lowest border of the bony orbital rim [orbitale]) to obtain accurate, standardized measures of upper lip thinness (Figure 5). This alignment is readily achieved with a handheld Guide. Stereotaxic equipment is not required.

Computer measurement: A digital photograph of the face is taken with the camera lens aligned in the patient's frankfort horizontal plane. The image is imported into the FAS Facial Photographic Analysis Software. The red (or vermilion) portion of the upper lip is outlined with the mouse to compute circularity (perimeter^2/area) (Figure 1). The thinner the upper lip, the greater the circularity (Figure 3). Circularity is not influenced by the size of the photograph. Each Rank on the Lip-Philtrum Guide is defined by a range of circularities (Figure 3). The software automatically ranks lip thinness using the circularity measure. The philtrum is measured by selecting the picture on the Lip-Philtrum Guide that best matches the patient's philtrum. More detailed instructions are provided with the software.

Figure 1. An example of the upper lip outlined to compute circularity. The circularity of this lip is 44.2, which is equivalent to Rank 2 on Lip-Philtrum Guide 1.

C. Deriving the Facial ABC-Score

Rank palpebral fissure length, philtrum smoothness, and upper lip thinness by circling A, B, or C in each column in the ABC-Score table at the bottom of page 2 of the FASD Diagnostic Form. This table is duplicated below as Table 3. The three facial features must be measured at the same age. In other words, one would NOT rank PFL at 10 years of age and philtrum and lip at 15 years of age. If facial measures are available at more than one age, rank the age when the FAS phenotype is expressed the most. If FAS features are never expressed, score the face between the ages of 3 and 10 years, or at any age if this age range is not available.

Table 3: Deriving the ABC-Score for Facial Phenotype

5-Point Likert Rank for Philtrum & Lip	Z-score* for Palpebral Fissure Length	Circle the ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	>-2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

* Z-Score = (patient's PFL - mean PFL for normal population) / (standard deviation of mean PFL for normal population)

The z-score reflects how many standard deviations above or below the mean the patient's PFL is.

D. Deriving the 4-Digit Rank for Face

Next, refer to Table 4 to determine the *4-Digit Diagnostic Rank* based on the ABC-Score derived from Table 3. Transfer the resulting 4-Digit Diagnostic Rank for face to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

Table 4: Converting the Facial ABC-Score to a 4-Digit Diagnostic Rank for Face

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure - Philtrum - Lip ABC-Score Combinations
4	Severe	CCC
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

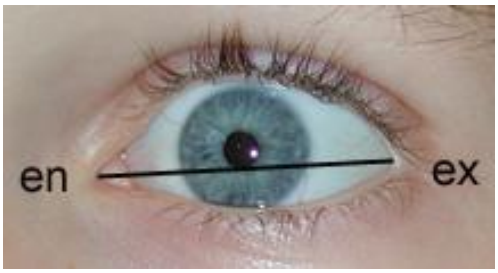


Figure 2A. Palpebral Fissure Length (PFL). Distance from endocanthion to exocanthion.

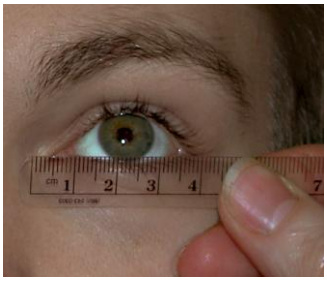


Figure 2B. PFL measured with a small ruler while patient looks up to fully expose exocanthion.

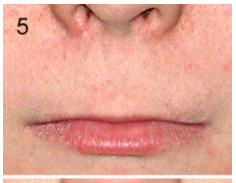
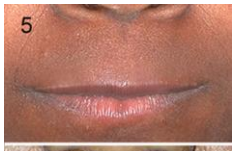
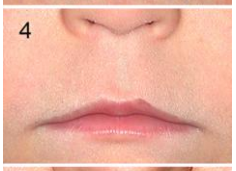
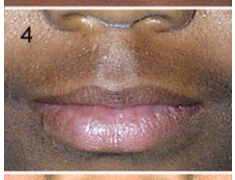
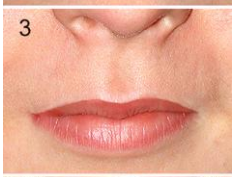
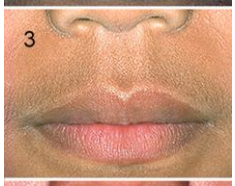
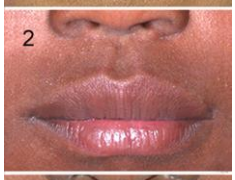
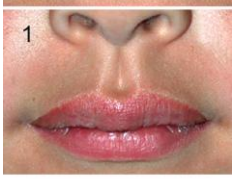
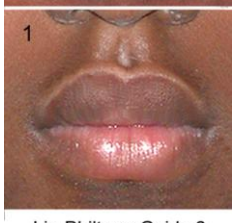
Lip-Philtrum Guide 1: Caucasian			ABC Scores		Lip-Philtrum Guide 2: African American		
	Upper Lip Circularity		Philtrum	Upper Lip	Upper Lip Circularity		
Rank	Range	Lip Pictured	Smoothness	Thinness	Lip Pictured	Range	Rank
 5	≥ 131.5	178	C	C	80	≥ 62.1	 5
 4	131.4 to 75.5	85	C	C	57	62.0 to 52.1	 4
 3	75.4 to 57.5	65	B	B	39	52.0 to 30.1	 3
 2	57.4 to 42.5	50	A	A	29	30.0 to 27.5	 2
 1	≤ 42.4	35	A	A	25	≤ 27.4	 1
Lip-Philtrum Guide 1							Lip-Philtrum Guide 2

Figure 3. Lip-Philtrum Guides 1 and 2. Pictorial examples of the 5-point Likert scales and the ABC-Scale used to rank upper lip thinness and philtrum smoothness in Caucasians and African Americans. Circularity is perimeter^2/area and is measured using the FAS Facial Photographic Analysis software. Laminated Lip-Philtrum Guides with the Growth and Face Tables printed on the backside are available at http://depts.washington.edu/fasdpn.

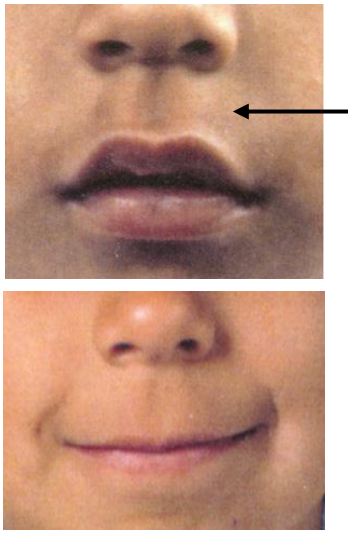


Figure 4. It is important that the patient have a relaxed facial expression (no smile). A smile can alter lip thinness and philtrum smoothness. This is the same person with and without a smile. Note that without the smile, the lip and philtrum would both receive a correct Likert rank of # 1 on the Caucasian Lip-Philtrum Guide 1. With a smile, the lip and philtrum would both receive an *incorrect* Likert rank of # 4.

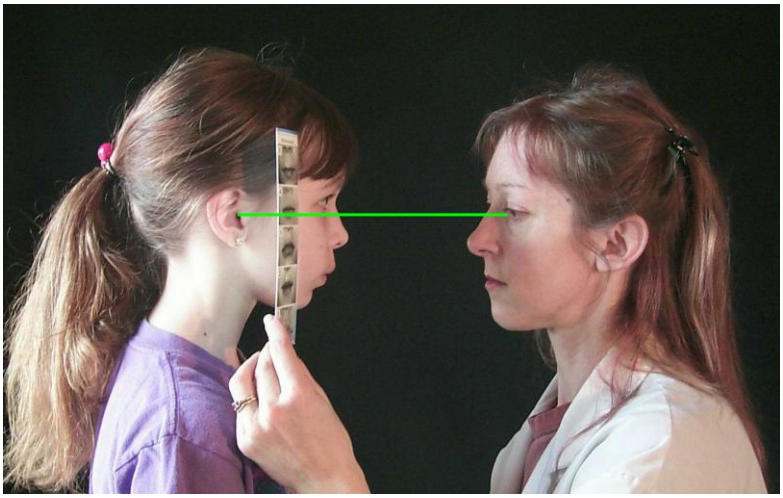


Figure 5. Illustration of a physician aligned in the patient's frankfort horizontal plane while using the Lip-Philtrum Guide to rank upper lip thinness and philtrum smoothness. The frankfort horizontal plane is defined by a line that passes through the patient's external auditory canal and the lowest border of the bony orbital rim (orbitale). The physician's eyes (or camera lens) should be directly in line with this plane. If the physician stood above this plane looking down on the patient, the patient's upper lip could appear thinner than it truly is.

Example: Ranking the Facial Phenotype

Patient Measurements at 10 Years of Age (Caucasian):

- Left PFL = 25.2 mm. Right PFL = 24.8 mm. Mean PFL = 25.0 mm
  Z-score = **-2.7** using Hall's PFL normal charts. (This means the PFL is 2.7 SDs below the norm)
  - Z-score = (25.0 – 28.7)/1.35 = -2.7.
  - Mean PFL for 10 years of age using Hall's Normal PFL chart = 28.7 mm.
  - 1 standard deviation on Hall's PFL normal chart = 1.35 mm.
  - The z-score is automatically computed by the FAS Facial Photographic Analysis Software.

- Philtrum smoothness received a **Rank 5** on the Caucasian Lip-Philtrum Guide (Figure 3).

- The circularity of the upper lip was 65.5. Thus, upper lip thinness received a **Rank 3** on the Caucasian Lip-Philtrum Guide (Figure 3). The circularity range for Rank 3 is 57.5 to 74.9.

Ranking

- The mean PFL z-score of -2.7 would receive an **ABC-Score = C** (≤ -2 SD) (Table 3).

- The Rank 5 philtrum would receive an **ABC-Score = C** (Table 3).

- The Rank 3 upper lip would receive an **ABC-Score = B** (Table 3).

- The ABC-Score combination for Palpebral Fissure - Philtrum - Lip would be **CCB** (Table 3).

Table 3: Deriving the ABC-Score for Facial Phenotype

5-Point Likert Rank for Philtrum & Lip	Z-score for Palpebral Fissure Length	Circle the ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	**C**	**C**	C
3	>-2 SD and ≤ -1 SD	B	B	**B**
1 or 2	> -1 SD	A	A	A

- The Facial ABC-Score of **CCB** reflects a **Moderate** level of expression of the FAS facial phenotype (Table 4).

- A **Moderate** expression of the FAS facial phenotype would receive a **Rank 3** in the 4-Digit Diagnostic (Table 4).

Table 4: Converting the Facial ABC-Score to a 4-Digit Diagnostic Rank

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure - Philtrum - Lip ABC-Score Combinations
4	Severe	CCC
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

- **Rank 3** would be transferred to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (as duplicated below).

Result:

4-Digit Diagnostic Code Grid

				3					
Severe	Severe	Definite	(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 Deficiency	**FAS Facial Features**	**CNS Damage**		Growth	Face	CNS	Alcohol		**Prenatal Alcohol**

III. Instructions for Deriving the 4-Digit Code

B.3. Ranking CNS

Alcohol's Impact on the Developing Brain

Alcohol is a teratogen that can alter the developing brain in a variety of ways from gross structural anomalies to subtle alterations in neurochemical levels (Stratton et al., 1996; West, 1986). Alterations in brain structure and/or chemistry can lead to altered brain function. Our ability to detect structural, neurological, and functional CNS abnormalities is dependent on the sensitivity of today's measurement tools, which will continue to improve over time. Not all structural or neurological abnormalities result in *measurable* dysfunction and not all functional abnormalities are due to underlying brain damage. Some functional abnormalities result from adverse postnatal environmental factors and are transient in nature if the environment is improved.

How to Rank CNS: The 3rd Digit of the 4-Digit Diagnostic Code

The 4-point Likert Scale for CNS documents: 1) that individuals with prenatal alcohol exposure can present with structural, neurological and/or functional CNS abnormalities; 2) that these CNS abnormalities occur along a continuum of severity; and 3) that not all functional abnormalities are due to underlying brain damage.

An important point to keep in mind is that the CNS scale performs as two scales in one. In its first use, the full scale (from 1 to 4) documents increasing "probability" of underlying CNS damage based on structural, neurological, and/or functional evidence. *The higher the Rank from 1 to 4, the stronger the evidence or higher the probability that there is underlying CNS damage*. In its second use, the scale (from 1 to 3) also documents increasing severity of brain dysfunction. *The higher the Rank from 1 to 3, the more severe and global the dysfunction.*

The descriptive labels assigned to Ranks 1 through 4 reflect the increasing probability that underlying CNS damage exists. Rank 4 is labeled "definite" because structural/neurological abnormalities are definitive evidence of CNS damage. Ranks 1, 2, and 3 are labeled "unlikely", "possible", and "probable" evidence of CNS damage, respectively, because measures of dysfunction are not definitive evidence of CNS damage, but the probability of underlying CNS damage increases with increasing severity of dysfunction. Data from the University of Washington FAS DPN show this to be true. Among the first 1,500 patients diagnosed, those presenting with Rank 2 or Rank 3-level dysfunction had a 5.8-fold and 10.8-fold increased risk of having structural/neurological damage, respectively, relative to patients with no evidence of dysfunction (Rank 1). As stated in the Institute of Medicine report (Stratton et al., 1996) "FAS can be characterized by behavioral or cognitive problems that are thought to result from *organic brain damage*, are not easily related to genetic background or environmental influences, and are resistant to improvement with traditionally effective intervention techniques".

All patients receive a Rank 1, 2 or 3 to document their level of brain dysfunction. Patients who present with significant structural and/or neurological evidence of CNS damage will also receive a Rank 4. Thus, all patients with structural/neurological evidence of CNS damage will have two CNS Ranks, one documenting their structural/neurological damage (Rank 4) and one documenting their level of dysfunction (Rank 1, 2 or 3). More specifically, they will receive either: (a) Ranks 4 and 3 (structural/neurological damage with Rank 3 level dysfunction); (b) Ranks 4 and 2 (structural/neurological damage with Rank 2 level delay/dysfunction); or (c) Ranks 4 and 1 (structural/neurological damage with no current evidence of delay/dysfunction). When two CNS Ranks are applicable, the 4-Digit Code and Diagnostic Category are based on the *highest* CNS rank received, for it reflects the highest level of certainty there is underlying CNS damage. Both CNS ranks would be marked by an '**X'** in the CNS Column of the Diagnostic Grid, but only the number of the highest rank would be inserted into the 4-Digit Code (See 4-Digit Diagnostic Code Grid below).

4-Digit Diagnostic Code Grid

						4			
Severe	Severe	Definite	(4)			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 Deficiency	**FAS Facial Features**	**CNS Damage**		Growth	Face	CNS	Alcohol		**Prenatal Alcohol**

Definitions of CNS Ranks 1 through 4.

CNS Rank 4: (Structural/Neurological Abnormalities)
"Definite" Evidence of CNS Damage.

Rank 4 Description: This rank is selected when the evidence for CNS damage is defined through a traditional medical approach. It is our impression that "brain damage" or static encephalopathy is readily diagnosed by physicians when 'significant' structural abnormalities of the brain are detected or when neurological findings of presumed prenatal origin are found.

Structural evidence of CNS damage may include, but is not limited to:

1. Microcephaly, defined as an occipital frontal circumference (OFC) 2 or more standard deviations below the mean. It is important to take race/ethnicity into consideration when assessing OFC. Head circumference 2 or more standard deviations below the mean has been associated with mental deficiency in the literature (Dolk, 1991; Pryor & Thelander, 1968).

2. Significant brain abnormalities of presumed prenatal origin observable through imaging techniques. Abnormalities may include, but are not limited to hydrocephaly, heterotopias, and change in shape and/or size of brain regions. These abnormalities should be determined by appropriately trained medical professionals.

Neurological evidence of CNS damage may include, but is not limited:

1. Seizures not due to a postnatal insult or other postnatal process.
2. Other hard neurological signs of presumed prenatal origin.

Rank 4 Criteria: At least one "significant" structural or neurological finding is required for a classification of CNS Rank 4 (Table 5). A significant finding is one that is 2 or more standard deviations below the norm if measured on a standardized scale or deemed "clinically significant" when assessed by an appropriate trained professional like a clinical radiologist or neurologist. Findings deemed significant should receive a Severity Score = 3 (see below).

Documenting the Evidence that Supports a Rank 4 Classification: Structural and neurological findings are recorded under the STRUCTURAL and NEUROLOGICAL headings of the CNS section (page 3) of the FASD Diagnostic Form. A 'Severity Score' is provided along the left margin of the Form to allow the clinical team to rank the severity of all structural and neurological findings. Only structural and/or neurological findings that receive a Severity Score = 3 (Significant) can contribute toward a CNS Rank 4 classification. For example, a seizure disorder not due to a postnatal insult would receive a Severity Score = 3. Often this type of seizure would warrant medical treatment. A seizure that occurred just once during a high fever would receive a Severity Score = 2. Absence of any seizure-like activity would receive a Severity Score = 1. An OFC $\leq$ -2 SDs ($\leq 2.5^{th}$ percentile) would receive a Severity Score = 3. An OFC > 2.5^{th} percentile and $\leq 10^{th}$ percentile would receive a Severity Score = 2. An OFC > 10^{th} percentile would receive a Severity Score = 1. This Severity Score allows one to rapidly scan the FASD Diagnostic Form and identify significant findings that support a Rank 4 classification.

CNS Rank 3: (Significant Dysfunction)
"Probable" Evidence of CNS Damage.

Rank 3 Description: Through our experience with hundreds of patients who have been exposed to potentially teratogenic doses of alcohol, we have found that many would not qualify as having static encephalopathy using the definition above, but neither could the possibility that they have static encephalopathy be dismissed out of hand. These patients typically have problems across multiple domains that may include, but are not limited to, executive function, memory, cognition, social/adaptive skills, academic achievement, language, motor, attention or activity level. These patients have problems that seem likely due to underlying brain damage rather than to adverse postnatal environmental experiences.

Rank 3 is selected based on evidence generated by standardized, validated psychometric assessments (e.g., WISC-III, WIAT-II, TOLD, PLS3, D-KEFS, VMI-II, etc), that are administered directly to the affected individual, or obtained from reliable informants, and interpreted by qualified professionals (e.g., psychologists, psychiatrists, occupational therapists, speech-language pathologists, etc). Rank 3 is assigned when this testing evidence documents "significant" impairment in three or more domains of brain function. "Significant" impairment is generally defined as performance 2 or more standard deviations below the mean (or its equivalent) on a standardized test. Developmental instruments, such as the Bayley Scales of Infant Development-II

would typically not be used as a source of psychometric data to support a classification of "static encephalopathy", for developmental delay is not always predictive of brain damage/dysfunction. The one exception to this rule would be developmental scores that are so low (e.g., Bayley Scales of Infant Development-II standard scores: MDI < 50, PDI < 50) that relevant literature finds these scores highly predictive of significant brain damage/dysfunction.

Rank 3 Criteria: "Significant" impairment across three or more domains of brain function is required for a classification of CNS Rank 3 (Table 5). Global delay, in which multiple domains are (by definition) affected, can comprise evidence for a Rank 3. Domains of brain function may include, but are not limited to: executive function, memory, cognition, social/adaptive skills, academic achievement, language, motor, attention or activity level. The "domains" of interest, in each diagnostic evaluation, are determined by the experienced clinical professionals involved in assessing the affected individual. Evidence to support a Rank 3 classification must come from standardized psychometric tests. "Significant" impairment is generally defined as performance 2 or more standard deviations below the norm on a standardized psychometric test.

Documenting the Evidence that Supports a Rank 3 Classification: The clinical team records which functional domains are delayed/impaired and which tests/scores support their decisions on the Functional Domains page (page 7) of the FASD Diagnostic Form. Evidence to support a Rank 3 classification must come from standardized psychometric tests. The outcomes of these psychometric tests are recorded on pages 3-5 of the FASD Diagnostic Form. A 'Severity Score' is provided along the left margin of the Functional Domains page (page 7) to allow the clinical team to rank the severity of delay/impairment for each assessed domain. A functional domain must receive a Severity Score = 3 (Significant) to contribute toward a Rank 3 classification. The Severity Score is described more fully below.

CNS Rank 2 (Mild to Moderate Delay/Dysfunction). "Possible" Evidence of CNS Damage.

Rank 2 Description: This Rank should be given to two groups of patients, all of whom should have histories of behavioral, cognitive, and/or developmental problems. One group of patients is those who have not yet had the types of testing that would move them into Rank 3, if positive. The reason for lack of testing is usually because the patients are too young to be tested (typically less than 6 years of age). Children in this group should be re-assessed, when old enough, to rule out whether testing evidence meets criteria for CNS Rank 3. *Note that the term "neurobehavioral disorder" is assigned to CNS Rank 2. When this Rank is being assigned to young children based primarily on developmental data, the clinical team may decide to forego the use of the term "neurobehavioral disorder".* The other group of patients is those whose testing did not reveal compelling evidence for Rank 3 classification, but for whom, in the clinical team's judgment, the possibility of CNS damage cannot be wholly dismissed. In these cases, the behaviors of the patient cannot be conceptualized as, for example, normal variants or transient emotional responses to environmental problems. Alternative testing or alternative diagnostic assessment procedures should usually be considered. But if adequately sensitive and appropriate testing has been carried out without clear evidence of dysfunction or developmental delay, it is unlikely a Rank 2 classification would be given.

Rank 2 Criteria: Rank 2 reflects a range of delay and/or dysfunction that suggests the possibility of CNS damage. At the mild end of the Rank 2 range are those who present with developmental delay that, by clinical judgment, precludes a Rank 1 classification. At the severe end of the Rank 2 range are those who present with clear evidence of dysfunction, but the dysfunction is not sufficiently severe and wide-ranging to meet the criteria for Rank 3 (Table 5). A Rank 2, by definition, is assigned to all who fall between Ranks 1 and 3. Evidence to support a Rank 2 classification can come from standardized psychometric tests, observational data, and/or caregiver interview. Deficiencies (or definite differences from normative expectations) recorded in the FUNCTIONAL section (pages 3-7) of the FASD Diagnostic Form serve to support a Rank 2 classification.

Documenting the Evidence that Supports a Rank 2 Classification: The clinical team records which functional domains are delayed or impaired and which tests/scores support their decisions on the Functional Domains page (page 7) of the FASD Diagnostic Form. Evidence to support a Rank 2 classification can come from standardized psychometric tests, observational data, and/or caregiver interview. These data are recorded on pages 3-6 of the FASD Diagnostic Form. A 'Severity Score' is provided along the left margin of the Functional Domains page (page 7) to allow the clinical team to rank the severity of delay or impairment for each assessed domain. Typically a patient who meets the criteria for Rank 2 will have at least one domain with a Severity Score = 2 (mild to moderate delay or impairment), but less than three domains with a Severity Score = 3 (significant impairment). The Severity Score is described more fully below.

CNS Rank 1 (No Current Evidence of Delay/Dysfunction)
"No" Current Evidence of CNS Damage.

A Rank 1 classification is assigned when no functional or developmental problems are discerned that are likely to reflect CNS damage. Evidence to support a Rank 1 can come from standardized psychometric tests, observational data, and/or caregiver interview. While this classification is typically quite rare in an FASD Diagnostic Clinic, it might help to think of this outcome in the context of a well-child assessment conducted in a general pediatric clinic where most children would be classified as Rank 1.

Completing the CNS Section of the FASD Diagnostic Form

The CNS section appears on pages 3 through 7 of the FASD Diagnostic Form. These pages serve as a place to record pertinent structural, neurological, psychometric, and caregiver interview data available on the patient. Although space has been provided to record a full complement of assessments, we are not implying that all of these assessments must be conducted to derive a diagnosis. It is the responsibility of the clinical team to select the most appropriate assessment battery for an individual patient. Recording data for the structural, neurological, and psychometric sections is self-explanatory. The Caregiver Interview section, however, warrants further explanation.

An important aspect of the FASD evaluation is an in depth interview of the caregivers of the patient. This interview takes approximately one hour and is conducted by a qualified member(s) of the clinical team. At the University of Washington FAS DPN clinic, this interview is conducted jointly by the physician and psychologist while the patient is being formally assessed by the other clinical

team members. As in any diagnostic situation, once records are reviewed and there is a preliminary case formulation, the diagnostic interview will address several questions, such as: What are the problems that led to the diagnostic referral? What do the caregivers hope to gain from the assessment? What are the caregivers' views of the patient's overall strengths and weaknesses? What is the child's social and medical history, pertinent to this diagnostic evaluation? In an FASD diagnostic evaluation, we have found it very useful to also methodically ask questions that review age-appropriate functional abilities in areas that, according to the literature, are commonly problematic for alcohol-exposed individuals. These areas (planning/temporal skills, behavioral regulation/sensory motor integration, abstract thinking/judgment, memory/learning/information processing, spatial skills/spatial memory, social skills/adaptive behavior, and motor/oral motor control) are presented on the FASD Diagnostic Form (page 6). Routinely inquiring about the patient's capabilities in these areas serves several purposes. First, the caregivers' answers to these questions give insight into their interpretation of the patient's behaviors and about their general relationship with the patient. Second, it is often helpful to compare this subjective assessment to the psychometric profile. This can reveal information about the pattern of neurodevelopmental and neurobehavioral difficulties that standardized testing may miss, or provide evidence that is supportive of test results. The data recorded on page 6 of the Diagnostic Form are non-standardized observational measures.

Severity Score [0, 1, 2, 3]

Along the left margin of each CNS page is a Severity Score. This Severity Score serves two purposes. 1) It allows one to rapidly scan the left margin of the CNS pages to see what structural, neurological, and functional areas are most impacted. 2) The Severity Scores in the Structural/Neurological Sections and the Functional Domains page also serve to document what evidence was present to meet the criteria for CNS Ranks 2, 3, and 4, as described above. For example, at least one area in the Structural or Neurological Sections should have a Severity Score = 3 to meet criteria for a CNS Rank 4. At least three domains on the Functional Domains page should a Severity Score = 3 to meet criteria for a CNS Rank 3.

The clinical team ranks the level of impairment/abnormality as follows:

0	Unknown, Not Assessed
1	Within Normal Limits
2	Mild to Moderate
3	Significant

For outcomes measured on standardized scales, in general, outcomes two or more standard deviations below the norm would be judged significant, whereas outcomes between one and two standard deviations below the norm could be judged mild to moderate.

A comprehensive assessment will identify domains of strength, as well as domains with mild or significant impairment. Documenting the outcomes of all assessed domains, not just those with significant impairment, is important for treatment planning.

Table 5: Criteria for CNS Ranks 1 through 4

4-Digit Diagnostic Rank*	Probability of CNS Damage	Confirmatory Findings
4	Definite **Structural and/or Neurological Abnormalities** *Static Encephalopathy*	● Microcephaly: OFC 2 or more SDs below the norm. *and / or* ● Significant abnormalities in brain structure of presumed prenatal origin. *and / or* ● Evidence of hard neurological findings likely to be of prenatal origin.
3	Probable **Significant Dysfunction** *Static Encephalopathy*	● Significant impairment in three or more domains of brain function such as, but not limited to: cognition, achievement, memory, executive function, motor, language, attention, activity level, neurological 'soft' signs.
2	Possible **Mild to Moderate Delay or Dysfunction** *Neurobehavioral Disorder*	● Evidence of delay or dysfunction that suggest the possibility of CNS damage, but data to this point do not permit a Rank 3 classification.
1	Unlikely	● No current evidence of delay or dysfunction likely to reflect CNS damage.

* Transfer the resulting 4-Digit Diagnostic Rank for CNS to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

III. Instructions for Deriving the 4-Digit Code

B.4. Ranking Alcohol Exposure

Method for Ranking Alcohol: The 4th Digit of the 4-Digit Diagnostic Code

Alcohol exposure is ranked according to the quantity, timing, frequency, and certainty of exposure during pregnancy (Table 6). The case-definitions for the four Ranks address two important issues: 1) that exposure information in a clinical setting can be of limited availability or of unknown accuracy and 2) a clear consensus is not available concerning the amount of alcohol that can actually be toxic to each individual fetus (Stratton et al., 1996).

The case-definitions for prenatal alcohol exposure differentiate four clinically meaningful groups (Rank 4: confirmed exposure to high levels of alcohol; Rank 3: confirmed exposure, but the level is less than Rank 4 or the level is unknown; Rank 2: unknown exposure (neither confirmed absent nor confirmed present); and Rank 1: confirmed absence of exposure from conception to birth). High exposure is defined generally to be a blood alcohol concentration of greater than 100 mg/dL (a level that typically can be reached by a 55-kg woman consuming six to eight beers) weekly, early in pregnancy. In the absence of a clear consensus on the amount of alcohol that can actually be toxic to the fetus, this general definition should only serve as a guide, not a threshold.

One example of a 'Rank 4' exposure is the birth mother reported drinking to the point of intoxication weekly throughout pregnancy. Two examples of 'Rank 3' exposures include: 1) birth mother was observed to be drinking during pregnancy, but the amount is unknown, 2) birth mother reported drinking a glass of wine weekly, but stopped drinking as soon as she learned she was pregnant at 3 months. Two examples of when alcohol exposure is ultimately unknown and thus coded as Rank 2 include: 1) the child is adopted and the records are closed, and 2) the birth mother is known to have a problem with drinking, but there are no records or direct observation of her drinking during the index pregnancy. A Rank 1 classification (confirmed absence of drinking from conception to birth) is relatively rare in the general population since it is unlikely to occur unless a pregnancy is either planned or the woman never drinks.

Table 6: Criteria for Prenatal Alcohol Exposure Ranks 1 through 4

4-Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description of Alcohol Use During Pregnancy
4	High Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Exposure pattern is consistent with the medical literature placing the fetus at "high risk" (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy).
3	Some Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Level of alcohol use is less than in Rank (4) or level is unknown.
2	Unknown Risk	● Alcohol use during pregnancy is UNKNOWN.
1	No Risk	● Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

Transfer the resulting 4-Digit Diagnostic Rank for Alcohol Exposure to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

III. Instructions for Deriving the 4-Digit

B.5. Ranking Other Pre- and Postnatal Exposures/Events

The Importance of Documenting Other Risk Factors

A comprehensive diagnostic process must take into consideration all other adverse prenatal and postnatal exposures and events, not just prenatal alcohol exposure. Many of the outcomes observed in individuals with prenatal alcohol exposure are not specific to (caused only by) prenatal alcohol exposure. A variety of other prenatal (poor prenatal care, prenatal complications, familial genetics, and exposure to other potentially teratogenic agents, etc.), and/or postnatal (physical/sexual abuse, disrupted placement histories, head injuries, chronic substance abuse by the patient, etc.) exposures and events could also contribute to the outcomes presented by the patient. The 4-Digit Diagnostic method requires the clinical team to record all pertinent prenatal and postnatal exposures and events on the standardized FASD Diagnostic Form, rank their severity using case-defined 4-point Likert scales, report them in the medical summary, and take them into consideration when deriving a diagnosis and intervention plan. It is important to note that the presence of other risk factors does not reduce the teratogenic potential of alcohol. When multiple risk factors are present, including prenatal alcohol exposure, each risk factor has the potential of being fully responsible, partially responsible, or not responsible at all for any particular outcome. The medical technology to determine which risk factor is responsible for which outcome simply does not exist at this point in time.

A. Prenatal Rank Definitions

Rank 4: High Risk

This Rank is reserved for alternate genetic conditions (e.g., Fragile X, velocardiofacial syndrome, down syndrome, etc.) or exposure to known teratogens (e.g., dilantin, valproic acid, etc.) that have been clearly shown to produce physical abnormalities.

Rank 3: Some Risk

This category is used for potential genetic conditions, exposures or prenatal conditions that have been associated with physical or neurodevelopmental problems in a less well-established way, when compared to those falling in Prenatal Rank 4. Examples of conditions that would be placed in this category would include poor prenatal care; patients whose parents have mild mental retardation, attention deficit disorders, significant learning disabilities or learning problems thought to be due to a non-specific (and non-teratogenic) source; prenatal exposure to drugs like marijuana or heroin, in otherwise non-specified frequencies and quantities; and cigarette smoking during pregnancy.

Rank 2: Unknown Risk

This category is used when the details of the family background and gestation are unknown – generally in the circumstance of a closed adoption.

Rank 1: No Known Risk

On occasion, the genetic, teratogenic, and prenatal histories are well documented and no factors can be identified that would explain the abnormalities found in the patient.

B. Postnatal Rank Definitions

Rank 4: High Risk

This Rank is used to note postnatal circumstances that have been shown to have a significant adverse effect on development in most instances. Examples would include clear physical and sexual abuse, multiple disrupted placements with clear impact on the child, neglect resulting in failure to thrive, serious head injury, or medical conditions which lead to brain damage (i.e. kernicterus or persistent neonatal apnea).

Rank 3: Some Risk

This Rank is used to note conditions akin to those in Rank 4, but the circumstances are less severe and so less likely to be a definite factor in the patient's present condition. Obviously, clinical judgment is needed in judging the magnitude of a postnatal problem and interpreting this information into a Rank 3 or 4 placement.

Rank 2: Unknown Risk

This Rank is used when historical information is missing. This is sometimes the case with adopted children or those in foster care. Adult patients may, at times, be unable to reconstruct their own early histories.

Rank 1: No Known Risk

This Rank is used when a well-documented history confirms an absence of adverse postnatal exposures/events.

IV. Diagnostic Categories

The 256 Diagnostic Codes can be logically grouped into 22 Diagnostic Categories

Category	Name
A	Fetal alcohol syndrome (alcohol exposed)
B	Fetal alcohol syndrome (alcohol exposure unknown)
C	Partial fetal alcohol syndrome (alcohol exposed)
D	Fetal alcohol syndrome phenocopy (no alcohol exposure)
E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
F	Static encephalopathy (alcohol exposed)
G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
H	Neurobehavioral disorder (alcohol exposed)
I	Sentinel physical finding(s) (alcohol exposed)
J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
L	Static encephalopathy (alcohol exposure unknown)
M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
N	Neurobehavioral disorder (alcohol exposure unknown)
O	Sentinel physical finding(s) (alcohol exposure unknown)
P	No sentinel physical findings or CNS abnormalities detected (alcohol exposure unknown)
Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
R	Static encephalopathy (no alcohol exposure)
S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
T	Neurobehavioral disorder (no alcohol exposure)
U	Sentinel physical finding(s) (no alcohol exposure)
V	No sentinel physical findings or CNS abnormalities detected (no alcohol exposure)

V. 4-Digit Diagnostic Codes
Within each Diagnostic Category

Category	Diagnostic Name and Codes
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
D	Fetal alcohol syndrome phenocopy (no alcohol exposure) 3431 4431 3441 4441
E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed) 3133 3233 4133 4233 3134 3234 4134 4234 3143 3243 4143 4243 3144 3244 4144 4244
F	Static encephalopathy (alcohol exposed) 1133 1233 2133 2233 1134 1234 2134 2234 1143 1243 2143 2243 1144 1244 2144 2244
G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed) 1323 2323 3123 3323 4123 4323 1324 2324 3124 3324 4124 4324 1423 2423 3223 3423 4223 4423 1424 2424 3224 3424 4224 4424

Category	Diagnostic Name and Codes
H	Neurobehavioral disorder (alcohol exposed) 1123 1223 2123 2223 1124 1224 2124 2224
I	Sentinel physical finding(s) (alcohol exposed) 1313 2313 3113 3313 4113 4313 1314 2314 3114 3314 4114 4314 1413 2413 3213 3413 4213 4413 1414 2414 3214 3414 4214 4414
J	No physical findings or CNS abnormalities detected (alcohol exposed) 1113 1213 2113 2213 1114 1214 2114 2214
K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown) 1332 2332 3132 3332 4232 1342 2342 3142 3342 4242 1432 3232 4132 4332 1442 3242 4142 4342
L	Static encephalopathy (alcohol exposure unknown) 1132 1232 2132 2232 1142 1242 2142 2242
M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown) 1322 2322 3122 3322 4122 4322 1422 2422 3222 3422 4222 4422
N	Neurobehavioral disorder (alcohol exposure unknown) 1122 1222 2122 2222
O	Sentinel physical finding(s) (alcohol exposure unknown) 1312 2312 3112 3312 4112 4312 1412 2412 3212 3412 4212 4412

Category	Diagnostic Name and Codes
P	No physical findings or CNS abnormalities detected (alcohol exposure unknown) 1112 2112 1212 2212
Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure) 1331 2331 3131 4131 1341 2341 3141 4141 1431 2431 3231 4231 1441 2441 3241 4241 3331 4331 3341 4341
R	Static encephalopathy (no alcohol exposure) 1131 1231 2131 2231 1141 1241 2141 2241
S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure) 1321 2321 3121 3321 4121 4321 1421 2421 3221 3421 4221 4421
T	Neurobehavioral disorder (no alcohol exposure) 1121 2121 2221 1221
U	Sentinel physical finding(s) (no alcohol exposure) 1311 2311 3111 3311 4111 4311 1411 2411 3211 3411 4211 4411
V	No physical findings or CNS abnormalities detected (no alcohol exposure) 1111 2111 1211 2211

VI. 4-Digit Diagnostic Codes Sorted Numerically

Code	Category	Diagnostic Name
1111	V	No sentinel physical findings or CNS abnormalities detected (no alcohol exposure)
1112	P	No sentinel physical findings or CNS abnormalities detected (alcohol exposure unk.)
1113	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
1114	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
1121	T	Neurobehavioral disorder (no alcohol exposure)
1122	N	Neurobehavioral disorder (alcohol exposure unknown)
1123	H	Neurobehavioral disorder (alcohol exposed)
1124	H	Neurobehavioral disorder (alcohol exposed)
1131	R	Static encephalopathy (no alcohol exposure)
1132	L	Static encephalopathy (alcohol exposure unknown)
1133	F	Static encephalopathy (alcohol exposed)
1134	F	Static encephalopathy (alcohol exposed)
1141	R	Static encephalopathy (no alcohol exposure)
1142	L	Static encephalopathy (alcohol exposure unknown)
1143	F	Static encephalopathy (alcohol exposed)
1144	F	Static encephalopathy (alcohol exposed)
1211	V	No sentinel physical findings or CNS abnormalities detected (no alcohol exposure)
1212	P	No sentinel physical findings or CNS abnormalities detected (alcohol exposure unk.)
1213	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
1214	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
1221	T	Neurobehavioral disorder (no alcohol exposure)
1222	N	Neurobehavioral disorder (alcohol exposure unknown)
1223	H	Neurobehavioral disorder (alcohol exposed)
1224	H	Neurobehavioral disorder (alcohol exposed)
1231	R	Static encephalopathy (no alcohol exposure)
1232	L	Static encephalopathy (alcohol exposure unknown)
1233	F	Static encephalopathy (alcohol exposed)
1234	F	Static encephalopathy (alcohol exposed)
1241	R	Static encephalopathy (no alcohol exposure)
1242	L	Static encephalopathy (alcohol exposure unknown)
1243	F	Static encephalopathy (alcohol exposed)
1244	F	Static encephalopathy (alcohol exposed)
1311	U	Sentinel physical finding(s) (no alcohol exposure)
1312	O	Sentinel physical finding(s) (alcohol exposure unknown)
1313	I	Sentinel physical finding(s) (alcohol exposed)
1314	I	Sentinel physical finding(s) (alcohol exposed)
1321	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
1322	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
1323	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)

Code	Category	Diagnostic Name
1324	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
1331	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
1332	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
1333	C	Partial FAS (alcohol exposed)
1334	C	Partial FAS (alcohol exposed)
1341	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
1342	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
1343	C	Partial FAS (alcohol exposed)
1344	C	Partial FAS (alcohol exposed)
1411	U	Sentinel physical finding(s) (no alcohol exposure)
1412	O	Sentinel physical finding(s) (alcohol exposure unknown)
1413	I	Sentinel physical finding(s) (alcohol exposed)
1414	I	Sentinel physical finding(s) (alcohol exposed)
1421	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
1422	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
1423	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
1424	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
1431	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
1432	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
1433	C	Partial FAS (alcohol exposed))
1434	C	Partial FAS (alcohol exposed)
1441	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
1442	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
1443	C	Partial FAS (alcohol exposed)
1444	C	Partial FAS (alcohol exposed)
2111	V	No sentinel physical findings or CNS abnormalities detected (no alcohol exposure)
2112	P	No sentinel physical findings or CNS abnormalities detected (alcohol exposure unknown)
2113	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
2114	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
2121	T	Neurobehavioral disorder (no alcohol exposure)
2122	N	Neurobehavioral disorder (alcohol exposure unknown)
2123	H	Neurobehavioral disorder (alcohol exposed)
2124	H	Neurobehavioral disorder (alcohol exposed)
2131	R	Static encephalopathy (no alcohol exposure)
2132	L	Static encephalopathy (alcohol exposure unknown)
2133	F	Static encephalopathy (alcohol exposed)
2134	F	Static encephalopathy (alcohol exposed)
2141	R	Static encephalopathy (no alcohol exposure)
2142	L	Static encephalopathy (alcohol exposure unknown)
2143	F	Static encephalopathy (alcohol exposed)
2144	F	Static encephalopathy (alcohol exposed)
2211	V	No sentinel physical findings or CNS abnormalities detected (no alcohol exposure)
2212	P	No sentinel physical findings or CNS abnormalities detected (alcohol exposure unknown)
2213	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)

Code	Category	Diagnostic Name
2214	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
2221	T	Neurobehavioral disorder (no alcohol exposure)
2222	N	Neurobehavioral disorder (alcohol exposure unknown)
2223	H	Neurobehavioral disorder (alcohol exposed)
2224	H	Neurobehavioral disorder (alcohol exposed)
2231	R	Static encephalopathy (no alcohol exposure)
2232	L	Static encephalopathy (alcohol exposure unknown)
2233	F	Static encephalopathy (alcohol exposed)
2234	F	Static encephalopathy (alcohol exposed)
2241	R	Static encephalopathy (no alcohol exposure)
2242	L	Static encephalopathy (alcohol exposure unknown)
2243	F	Static encephalopathy (alcohol exposed)
2244	F	Static encephalopathy (alcohol exposed)
2311	U	Sentinel physical finding(s) (no alcohol exposure)
2312	O	Sentinel physical finding(s) (alcohol exposure unknown)
2313	I	Sentinel physical finding(s) (alcohol exposed)
2314	I	Sentinel physical finding(s) (alcohol exposed)
2321	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
2322	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
2323	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
2324	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
2331	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
2332	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
2333	C	Partial FAS (alcohol exposed)
2334	C	Partial FAS (alcohol exposed)
2341	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
2342	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
2343	C	Partial FAS (alcohol exposed)
2344	C	Partial FAS (alcohol exposed)
2411	U	Sentinel physical finding(s) (no alcohol exposure)
2412	O	Sentinel physical finding(s) (alcohol exposure unknown)
2413	I	Sentinel physical finding(s) (alcohol exposed)
2414	I	Sentinel physical finding(s) (alcohol exposed)
2421	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
2422	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
2423	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
2424	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
2431	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
2432	B	FAS (alcohol exposure unknown)
2433	A	FAS (alcohol exposed)
2434	A	FAS (alcohol exposed)
2441	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
2442	B	FAS (alcohol exposure unknown)
2443	A	FAS (alcohol exposed)

Code	Category	Diagnostic Name
2444	A	FAS (alcohol exposed)
3111	U	Sentinel physical finding(s) (no alcohol exposure)
3112	O	Sentinel physical finding(s) (alcohol exposure unknown)
3113	I	Sentinel physical finding(s) (alcohol exposed)
3114	I	Sentinel physical finding(s) (alcohol exposed)
3121	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
3122	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
3123	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3124	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3131	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
3132	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
3133	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3134	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3141	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
3142	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
3143	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3144	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3211	U	Sentinel physical finding(s) (no alcohol exposure)
3212	O	Sentinel physical finding(s) (alcohol exposure unknown)
3213	I	Sentinel physical finding(s) (alcohol exposed)
3214	I	Sentinel physical finding(s) (alcohol exposed)
3221	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
3222	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
3223	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3224	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3231	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
3232	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
3233	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3234	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3241	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
3242	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
3243	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3244	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
3311	U	Sentinel physical finding(s) (no alcohol exposure)
3312	O	Sentinel physical finding(s) (alcohol exposure unknown)
3313	I	Sentinel physical finding(s) (alcohol exposed)
3314	I	Sentinel physical finding(s) (alcohol exposed)
3321	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
3322	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
3323	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3324	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3331	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
3332	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
3333	C	Partial FAS (alcohol exposed)

Code	Category	Diagnostic Name
3334	C	Partial FAS (alcohol exposed)
3341	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
3342	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
3343	C	Partial FAS (alcohol exposed)
3344	C	Partial FAS (alcohol exposed)
3411	U	Sentinel physical finding(s) (no alcohol exposure)
3412	O	Sentinel physical finding(s) (alcohol exposure unknown)
3413	I	Sentinel physical finding(s) (alcohol exposed)
3414	I	Sentinel physical finding(s) (alcohol exposed)
3421	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
3422	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
3423	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3424	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
3431	D	FAS phenocopy (no alcohol exposure)
3432	B	FAS (alcohol exposure unknown)
3433	A	FAS (alcohol exposed)
3434	A	FAS (alcohol exposed)
3441	D	FAS phenocopy (no alcohol exposure)
3442	B	FAS (alcohol exposure unknown)
3443	A	FAS (alcohol exposed)
3444	A	FAS (alcohol exposed)
4111	U	Sentinel physical finding(s) (no alcohol exposure)
4112	O	Sentinel physical finding(s) (alcohol exposure unknown)
4113	I	Sentinel physical finding(s) (alcohol exposed)
4114	I	Sentinel physical finding(s) (alcohol exposed)
4121	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
4122	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
4123	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4124	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4131	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
4132	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
4133	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4134	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4141	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
4142	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
4143	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4144	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4211	U	Sentinel physical finding(s) (no alcohol exposure)
4212	O	Sentinel physical finding(s) (alcohol exposure unknown)
4213	I	Sentinel physical finding(s) (alcohol exposed)
4214	I	Sentinel physical finding(s) (alcohol exposed)
4221	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
4222	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
4223	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4224	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)

Code	Category	Diagnostic Name
4231	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
4232	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
4233	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4234	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4241	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
4242	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
4243	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4244	E	Sentinel physical finding(s) / static encephalopathy (alcohol exposed)
4311	U	Sentinel physical finding(s) (no alcohol exposure)
4312	O	Sentinel physical finding(s) (alcohol exposure unknown)
4313	I	Sentinel physical finding(s) (alcohol exposed)
4314	I	Sentinel physical finding(s) (alcohol exposed)
4321	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
4322	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
4323	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4324	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4331	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
4332	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
4333	C	Partial FAS (alcohol exposed)
4334	C	Partial FAS (alcohol exposed)
4341	Q	Sentinel physical finding(s) / static encephalopathy (no alcohol exposure)
4342	K	Sentinel physical finding(s) / static encephalopathy (alcohol exposure unknown)
4343	C	Partial FAS (alcohol exposed)
4344	C	Partial FAS (alcohol exposed)
4411	U	Sentinel physical finding(s) (no alcohol exposure)
4412	O	Sentinel physical finding(s) (alcohol exposure unknown)
4413	I	Sentinel physical finding(s) (alcohol exposed)
4414	I	Sentinel physical finding(s) (alcohol exposed)
4421	S	Sentinel physical finding(s) / neurobehavioral disorder (no alcohol exposure)
4422	M	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposure unknown)
4423	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4424	G	Sentinel physical finding(s) / neurobehavioral disorder (alcohol exposed)
4431	D	FAS phenocopy (no alcohol exposure)
4432	B	FAS (alcohol exposure unknown)
4433	A	FAS (alcohol exposed)
4434	A	FAS (alcohol exposed)
4441	D	FAS phenocopy (no alcohol exposure)
4442	B	FAS (alcohol exposure unknown)
4443	A	FAS (alcohol exposed)
4444	A	FAS (alcohol exposed)

VII. Clinical Summaries
For each of the 22 Diagnostic Categories

Clinical summaries for each of the 22 Diagnostic Categories are presented on the following pages listed alphabetically from A through V. A complete list of the 22 categories is presented in Section IV.

These summaries can be used as the first page of the final diagnostic report. They often require minor alterations or additions to conform to the specifics of an individual case.

A

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Fetal Alcohol Syndrome**
(2) Alcohol exposed

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction that occur in individuals exposed to alcohol during gestation. On the attached sheets are the specific findings in this patient's case that led to our conclusion that there was sufficient evidence to make the diagnosis of fetal alcohol syndrome.

Although we believe that the patient clearly has fetal alcohol syndrome, this does not mean that alcohol exposure during pregnancy is the only cause of the patient's current problems. A number of other factors could be contributing to the present situation, such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth. Such factors may partly explain why there is so much variability in the kinds of specific difficulties that patients with FAS have.

Individuals with FAS have significant CNS damage/dysfunction and should be viewed as individuals with disabilities. The fetal alcohol syndrome diagnosis has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific concerns that have been identified that need attention.

_____ _____

Physician's Signature Date

B

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Fetal Alcohol Syndrome**
(2) Alcohol exposure unknown

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. On the attached sheets are the specific findings in this patient's case that led to our conclusion that there was sufficient evidence in this case to make a diagnosis of fetal alcohol syndrome even though the history of exposure to alcohol during gestation could not be confirmed.

Although we believe that the patient clearly has fetal alcohol syndrome, this does not mean that alcohol exposure during pregnancy is the only cause of the patient's current problems. 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. Such factors may partly explain why there is so much variability in the kinds of specific difficulties that patients with FAS have.

Individuals with FAS have significant CNS damage/dysfunction and should be viewed as individuals with disabilities. The fetal alcohol syndrome diagnosis has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific concerns that have been identified that need attention.

_____ _____

Physician's Signature Date

C

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Partial FAS**
(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. Indeed, many patients who have been exposed to alcohol show most, but not all, of the classic features of this syndrome. We use the term "Partial FAS" when a patient's characteristic features are very close to the classic features of FAS and the alcohol history strongly suggests that alcohol exposure during gestation was at high risk and likely to have played a role in the syndrome. Patients with Partial FAS either have the full set of facial anomalies found with FAS and evidence of CNS damage/dysfunction, but do not have growth deficiency; or they have growth deficiency and evidence of CNS damage/dysfunction, and most, but not all of the FAS facial features. The severity of CNS damage/dysfunction is comparable between FAS and PFAS. As you can see from the enclosed list of features found in this patient, the patient meets the criteria for Partial FAS. Patients diagnosed with Partial FAS must have confirmed exposure to alcohol during gestation.

In addition to prenatal exposure to alcohol, a number of other factors could be contributing to the patient's current problems, such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth. Such factors may partly explain why there is so much variability in the kinds of specific difficulties patients with Partial FAS experience.

Patients with Partial FAS have significant CNS damage/dysfunction and should be viewed as having a disability. The diagnosis has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific concerns that have been identified that need attention.

_____ _____

Physician's Signature Date

D

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Fetal Alcohol Syndrome Phenocopy**
(2) No alcohol exposure

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. On the attached sheets are the specific findings in this patient's case that led to our conclusion that the patient has all of the features of FAS. However, there is good reason to believe this patient was not exposed to alcohol during gestation.

Most syndromes can occasionally arise from an alternate cause. Presumably, this is the situation here. A number of other factors could be contributing to the present situation, such as the patient's genetic background and other potential exposures or problems during pregnancy, and various experiences since birth.

Whatever the cause of this patient's syndrome, he/she has structural, neurological and/or cognitive/behavioral problems and should be viewed as a person with a disability. This diagnosis has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific concerns that have been identified that need attention.

_____ _____

Physician's Signature Date

E

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis:
(1) Sentinel physical finding(s)
(2) Static encephalopathy
(3) Alcohol exposed

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

In this patient's case, some but not all of the characteristic growth and facial features associated with FAS were present and there was evidence of CNS damage and/or 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 terms "static encephalopathy" and "Sentinel physical finding(s)" to describe the patient's condition. The patient's CNS abnormalities may include structural, neurological and/or functional problems. The diagnoses of "Static encephalopathy and Sentinel physical finding(s)" in the presence of alcohol exposure do 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 gestation, 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 and alcohol exposure have.

The diagnoses made today are based on the information available at the time of this assessment. If this patient's alcohol exposure was considered "low risk" and new information is uncovered which documents higher exposures; or if the patient's facial features, growth, or neurobehavioral problems were judged "probable" and further growth or development suggest a "definite" problem is present, then reconsideration of the diagnosis of fetal alcohol syndrome would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with significant CNS abnormalities have structural, neurological, and/or cognitive/behavioral problems 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.

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Physician's Signature Date

F

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

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.

_____ _____
Physician's Signature Date

G

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Sentinel physical finding(s)**
(2) Neurobehavioral disorder
(3) Alcohol exposed

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS. On the attached sheets you will find our specific observations in this case. We found that some, but not all, of the characteristic physical findings seen in patients with FAS were present. There was not strong evidence that the patient's cognitive/behavioral problems were clearly due to CNS damage, but there were suggestions that this was the case. In this situation we use the term "neurobehavioral disorder" to emphasize the possibility that the problems may not be entirely due to postnatal experiences. Certainly a number of other factors could be contributing to the patient's condition such as genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnoses made today are based on the information at hand. If further testing is done which makes the likelihood of significant CNS damage/dysfunction of prenatal cause more likely, then an alternate diagnosis could be considered. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need consideration.

In any event, the diagnosis of neurobehavioral disorder 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.

_____ _____

Physician's Signature Date

H

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Neurobehavioral disorder**
(2) Alcohol exposed

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant central nervous system (CNS) damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

On the attached sheets you will find our specific observations in this case. There was not strong evidence that the patient's cognitive/behavioral problems were clearly due to CNS damage, but there were suggestions that this was the case. In this situation we use the term "neurobehavioral disorder" to emphasize the possibility that the problems may not be entirely due to postnatal experiences. Certainly a number of other factors could be contributing to the patient's condition such as genetic background, other potential exposures or problems during gestation, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. If this patient's alcohol exposure was considered "low risk" and new information is uncovered which documents higher exposure, or if the patient's facial features or growth become more abnormal or if further testing finds further evidence of significant CNS damage/dysfunction, then further diagnostic consideration would be appropriate.

Whatever the cause, the diagnosis of neurobehavioral disorder 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.

_____ _____

Physician's Signature Date

I

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Sentinel physical finding(s)**
(2) Alcohol exposed

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS. Some individuals have the growth deficiency and/or facial characteristics, but do not have evidence of CNS damage/dysfunction. We refer to this condition as "Sentinel physical finding(s) / Alcohol exposed". On the attached sheets are the specific findings in this patient's case which indicate that the characteristic growth deficiencies and/or facial features are, to some extent, compatible with FAS, but at this time there is no clear evidence of cognitive or behavioral problems that strongly suggest CNS damage. At such time in the future that CNS damage/dysfunction is found through images of the brain, neurological testing or cognitive behavioral assessment, then the diagnosis of fetal alcohol syndrome should be reconsidered. Other birth defect syndromes that are not related to alcohol exposure should also be considered as alternate explanations for the patient's problems.

_____ _____

Physician's Signature Date

J

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis **(1) No sentinel physical findings or CNS abnormalities detected**
(2) Alcohol exposed

In this current assessment, we conclude that this patient was exposed to alcohol during gestation, but no specific cognitive, behavioral, or characteristic physical findings were detected in our examination.

No alcohol-related diagnoses are offered at this time. Re-evaluation would be appropriate in the future if problems arise that strongly suggest central nervous system (CNS) damage/dysfunction, growth deficiency, or facial dysmorphology.

_____ _____

Physician's Signature Date

K

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis
(1) Sentinel physical finding(s)
(2) Static encephalopathy
(3) Alcohol exposure unknown

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant central nervous system (CNS) damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some but not all of the characteristic growth and facial features associated with FAS were present, and there was evidence of significant CNS damage/dysfunction as you will see noted on the attached pages. In this situation, we use the terms "Static encephalopathy" and "Sentinel physical finding(s)" to describe the patient's condition. Although it is unknown whether this patient was exposed to alcohol during gestation, a number of other factors could be contributing to the patient's current cognitive/behavioral problems 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 CNS abnormalities have.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal, then further diagnostic consideration would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with significant static encephalopathy have evidence of CNS damage/dysfunction and should be viewed as a person with a disability. 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.

_____ _____

Physician's Signature Date

L

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Static encephalopathy**
(2) Alcohol exposure unknown

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant 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. 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. Although it is unknown whether this patient was exposed to alcohol during gestation, a number of other factors could be contributing to the patient's current cognitive/behavioral problems 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 patients with static encephalopathy face.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal, then further diagnostic consideration would be appropriate.

Individuals with static encephalopathy have evidence of CNS damage and/or 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.

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Physician's Signature Date

M

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis:
(1) Sentinel physical finding(s)
(2) Neurobehavioral disorder
(3) Alcohol exposure unknown

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS. On the attached sheets you will find our specific observations in this case. We found that some, but not all, of the characteristic physical findings seen in patients with FAS were present and a confirmed history of alcohol exposure during gestation was not available. There was not strong evidence that the patient's cognitive/behavioral problems were clearly due to CNS damage, but there were suggestions that this was the case. In this situation we use the term "neurobehavioral disorder" to emphasize the possibility that the problems may not be entirely due to postnatal experiences. Certainly a number of other factors could be contributing to the patient's condition such as genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnoses made today are based on the information at hand. If further testing is done which makes the likelihood of significant CNS damage/dysfunction of prenatal cause more likely, then an alternate diagnosis would be considered. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

In any event, the diagnosis of neurobehavioral disorder 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.

_____ _____

Physician's Signature Date

N

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Neurobehavioral disorder**
(2) Alcohol exposure unknown

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant central nervous system (CNS) damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

On the attached sheets you will find our specific observations in this case. There was not strong evidence that the patient's cognitive/behavioral problems were clearly due to CNS damage, but there were suggestions that this was the case. In this situation we use the term "neurobehavioral disorder" to emphasize the possibility that the problems may not be entirely due to postnatal experiences. Certainly a number of other factors could be contributing to the patient's condition such as genetic background, other potential exposures or problems during gestation, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal or if further testing finds further evidence of significant CNS damage/dysfunction, then further diagnostic consideration would be appropriate.

Whatever the cause, the diagnosis of neurobehavioral disorder 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.

_____ _____

Physician's Signature Date

O

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Sentinel physical finding(s)**
(2) Alcohol exposure unknown

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

Some individuals have the growth deficiency and/or facial characteristics, but do not have evidence of CNS damage/dysfunction. We refer to this condition as "Sentinel physical finding(s)". On the attached sheets are the specific findings in this patient's case which indicate that the characteristic growth deficiencies and/or facial features are, to some extent, compatible with FAS, but alcohol exposure during gestation is unknown and at this time there is no clear evidence of CNS damage or dysfunction. At such time in the future that CNS damage/dysfunction is found through images of the brain, neurological testing or cognitive behavioral assessment, and a confirmed history of alcohol exposure is obtained, then further diagnostic consideration would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

_____ _____

Physician's Signature Date

P

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis **(1) No sentinel physical findings or CNS abnormalities detected**
(2) Alcohol exposure unknown

In this current assessment, it is unknown whether or not this patient was exposed to alcohol during gestation. Furthermore, no specific cognitive, behavioral, or characteristic physical findings were detected in our examination.

No alcohol-related diagnoses are offered at this time. Re-evaluation would be appropriate in the future if further history of alcohol use in pregnancy is documented or problems arise that strongly suggested central nervous system (CNS) damage/dysfunction, growth deficiency, or facial dysmorphology.

_____ _____

Physician's Signature Date

Q

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis
(1) Sentinel physical finding(s)
(2) Static encephalopathy
(3) No alcohol exposure

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant central nervous system (CNS) damage/dysfunction in individuals exposed to alcohol during gestation.

In this patient's case, some but not all of the characteristic growth and facial features associated with FAS were present, there was evidence of significant CNS damage/dysfunction, and the patient was reportedly not exposed to alcohol during gestation. Based on these observations, which are documented on the attached pages, this patient does not have FAS, but does have significant CNS abnormalities and some of the physical characteristics found after alcohol exposure. A number of factors other than alcohol could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth. The physical findings may suggest that other syndrome diagnoses be considered.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal, then further diagnostic consideration would be appropriate. . Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with static encephalopathy have evidence of structural, neurological, and/or cognitive/behavioral deficits and should be viewed as a person with a disability. 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.

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Physician's Signature Date

R

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Static encephalopathy**
(2) No alcohol exposure

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation.

In this patient's case, no growth deficiency or characteristic set of facial features were found and the patient was not exposed to alcohol during gestation 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. 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. A number of factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal, then further diagnostic consideration would be appropriate. . Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with static encephalopathy have evidence of structural, neurological, and/or cognitive/behavioral deficits and should be viewed as a person with a disability. 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.

_____ _____

Physician's Signature Date

S

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis
(1) Sentinel physical finding(s)
(2) Neurobehavioral disorder
(3) No alcohol exposure

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation.

On the attached sheets you will find our specific observations in this case. We found that some, but not all, of the sentinel physical finding(s) seen in patients with FAS were present and the patient was reportedly not exposed to alcohol during gestation. There was not strong evidence that the patient's cognitive/behavioral problems were clearly due to CNS damage, but there were suggestions that this may be the case. In this situation we use the term "neurobehavioral disorder" to emphasize the possibility that the problems may not be entirely due to postnatal experiences. The patient also had some of the physical characteristics often found with alcohol exposure. In this case, however, there was no alcohol exposure, therefore, these physical findings might suggest that other syndrome diagnoses be considered. Certainly a number of factors could be contributing to the patient's condition such as genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal or if further testing finds further evidence of significant CNS damage/dysfunction, then further diagnostic consideration would be appropriate.

In any event, the diagnosis of neurobehavioral disorder 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.

_____ _____

Physician's Signature Date

T

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Neurobehavioral disorder**
(2) No alcohol exposure

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant central nervous system (CNS) damage/dysfunction in individuals exposed to alcohol during gestation.

On the attached sheets you will find our specific observations in this case. In this patient's case, no growth deficiency or characteristic set of facial features were found and the patient was not exposed to alcohol during gestation so the patient does not have FAS. Although there was not strong evidence that the patient's cognitive/behavioral problems were clearly due to CNS damage, there were suggestions that this may be the case. In this situation we use the term "neurobehavioral disorder" to emphasize the possibility that the problems may not be entirely due to postnatal experiences. Certainly a number of other factors could be contributing to the patient's condition such as genetic background, other potential exposures or problems during gestation, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event that a confirmed history of alcohol exposure is obtained, or if the patient's facial features or growth become more abnormal or if further testing finds further evidence of significant CNS damage/dysfunction, then further diagnostic consideration would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Whatever the cause, the diagnosis of neurobehavioral disorder 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.

_____ _____

Physician's Signature Date

U

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis: **(1) Sentinel physical finding(s)**
(2) No alcohol exposure

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant central nervous system (CNS) damage/dysfunction occurring in patients exposed to alcohol during gestation.

On the attached sheets are the specific findings in this patient's case which indicate that characteristic growth deficiencies and/or facial features, compatible with FAS, were present even though the patient was not exposed to alcohol during gestation. In this case, these physical findings might suggest that other syndrome diagnoses be considered.

At such time in the future that CNS damage/dysfunction is found through images of the CNS, neurological testing or cognitive behavioral assessment, and/or a confirmed history of alcohol exposure is obtained, then further diagnostic consideration would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

_____ _____

Physician's Signature Date

V

THE FETAL ALCOHOL SYNDROME CLINIC
DIAGNOSTIC SUMMARY

Final Diagnosis **(1) No sentinel physical findings or CNS abnormalities detected**
(2) No alcohol exposure

In this current assessment, we conclude that this patient was not exposed to alcohol during gestation. Furthermore, no specific cognitive, behavioral, or characteristic physical findings were detected in our examination.

No diagnoses are offered at this time. Re-evaluation would be appropriate in the future if further history of alcohol use in pregnancy is documented or problems arise that strongly suggested central nervous system (CNS) damage/dysfunction, growth deficiency, or facial dysmorphology.

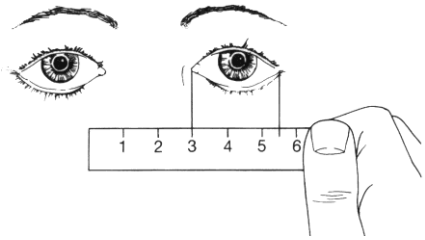
_____ _____

Physician's Signature Date

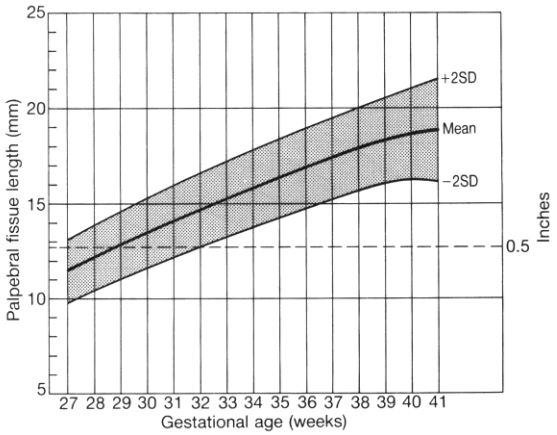
VIII. Reference Charts of Normal Growth

Provided for your convenience are normal anthropometric charts for palpebral fissure length, inner canthal distance, head circumference, height, and weight. Other valid growth charts may be used.

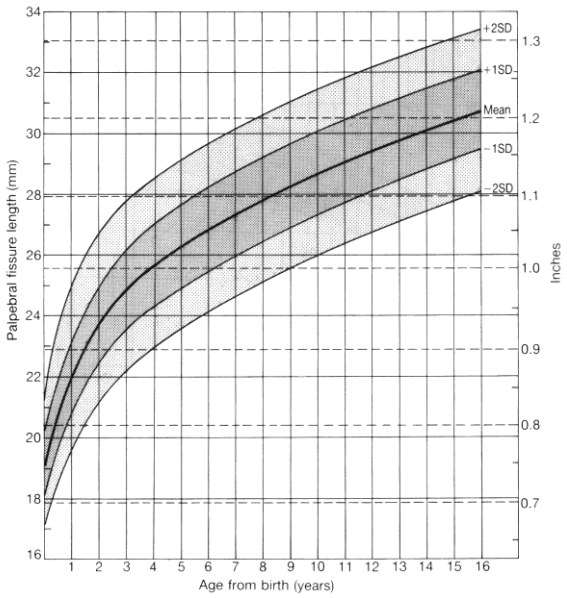
Palpebral Fissure Length



Measure from the endocanthion to the exocanthion.
Have patient look up, while holding head level, to standardize fissure measurement.



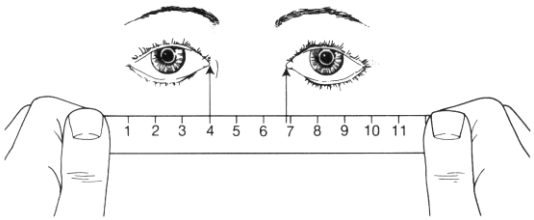
FEMALE and MALE (At Birth)



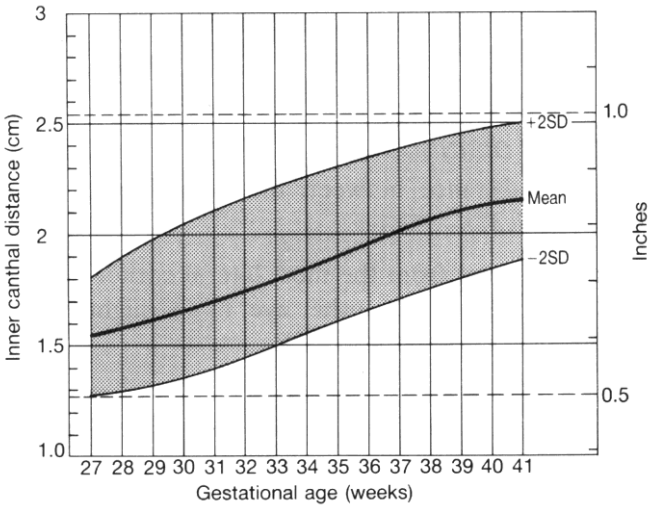
FEMALE and MALE (Birth to 16 years)

(Hall et. al., 1989, by permission)

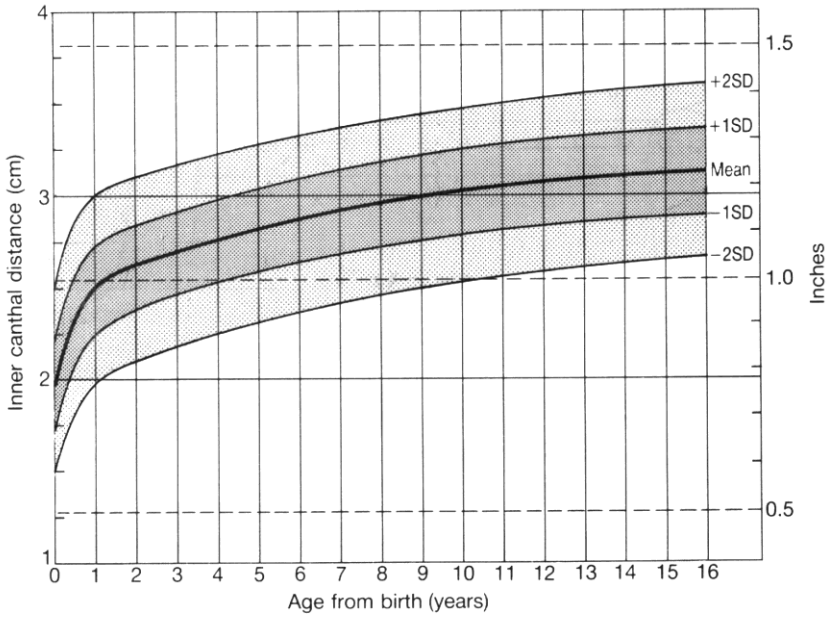
Inner Canthal Distance



Measure from the endocanthion of each eye, in a straight, line avoiding the curvature of the nose.



FEMALE and MALE (At Birth)

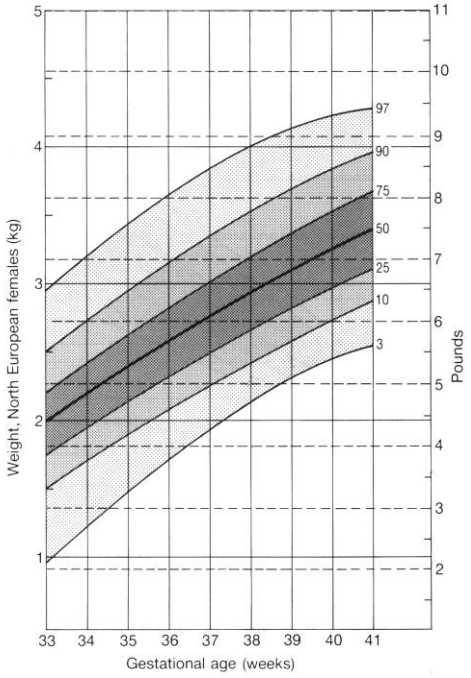


FEMALE and MALE (Birth to 16 years)

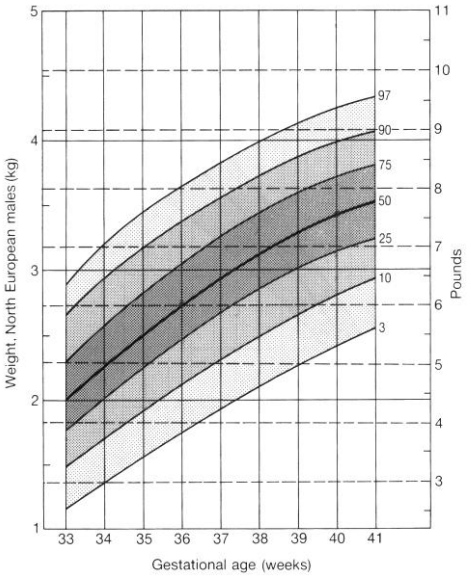
(Hall et. al., 1989, by permission)

Birth Weight

FEMALE



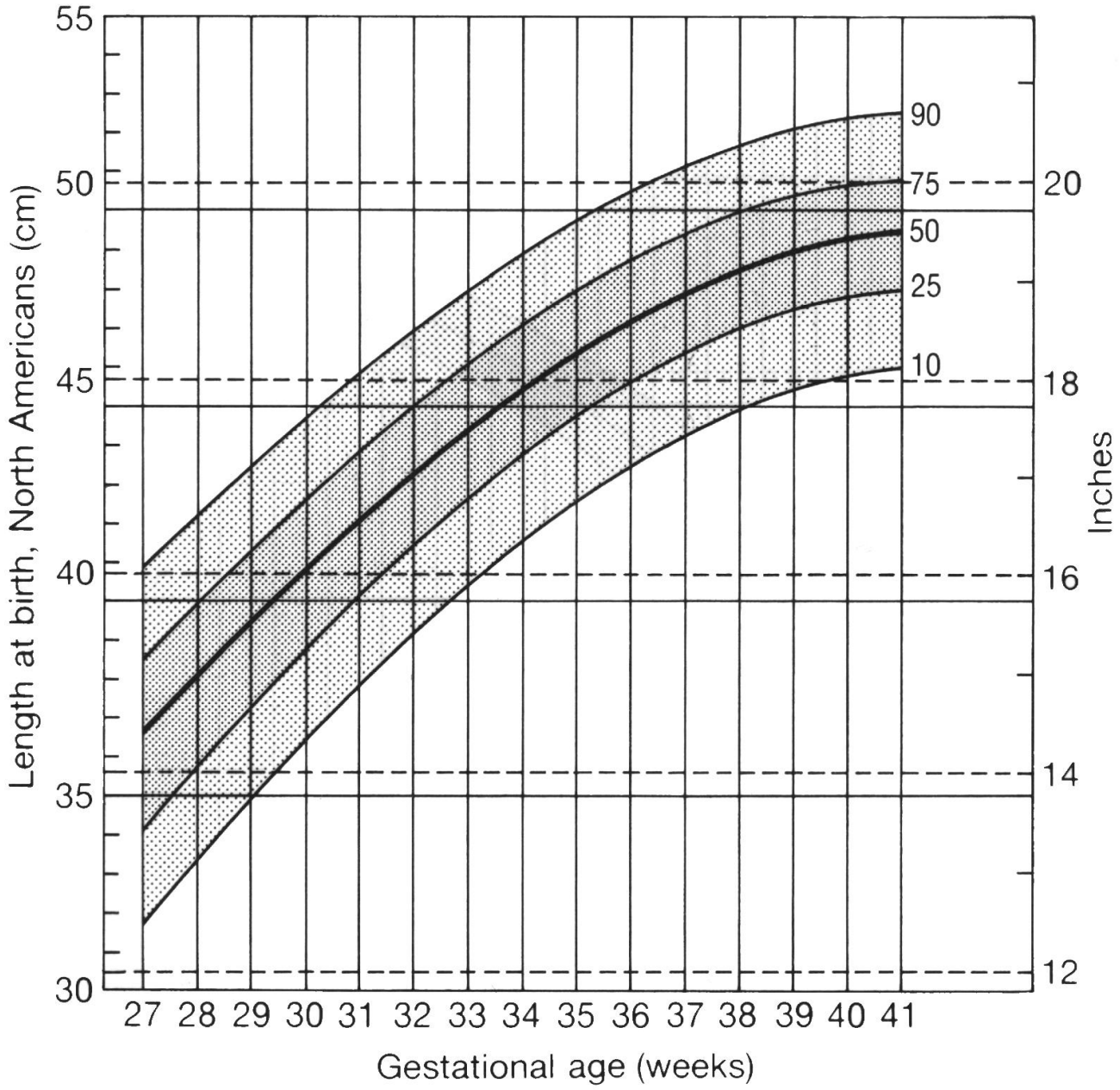
MALE



(Hall et. al., 1989, by permission)

Birth Length

FEMALE and MALE



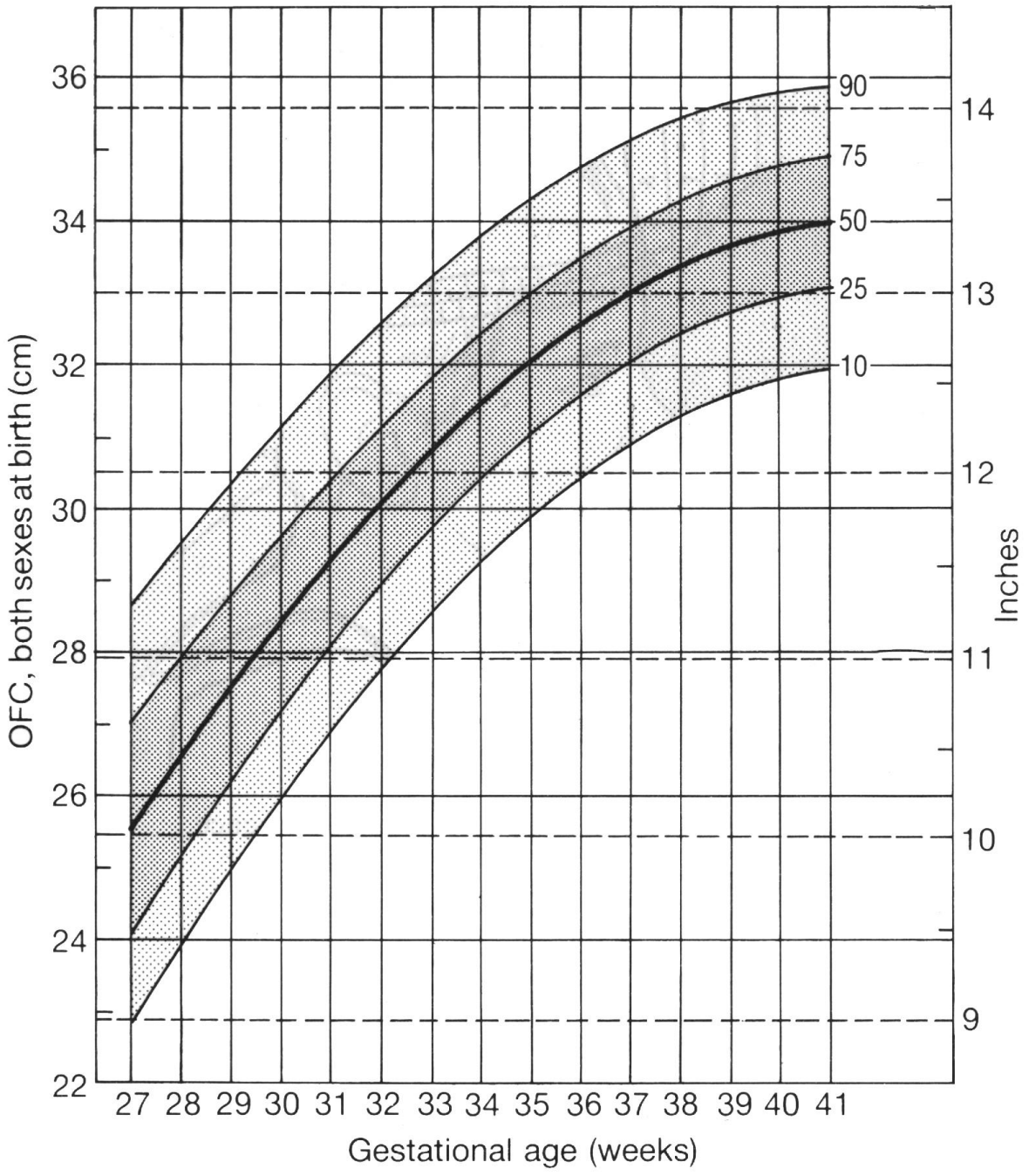
(Hall et. al., 1989, by permission)

.

Head Circumference

At Birth

FEMALE and MALE

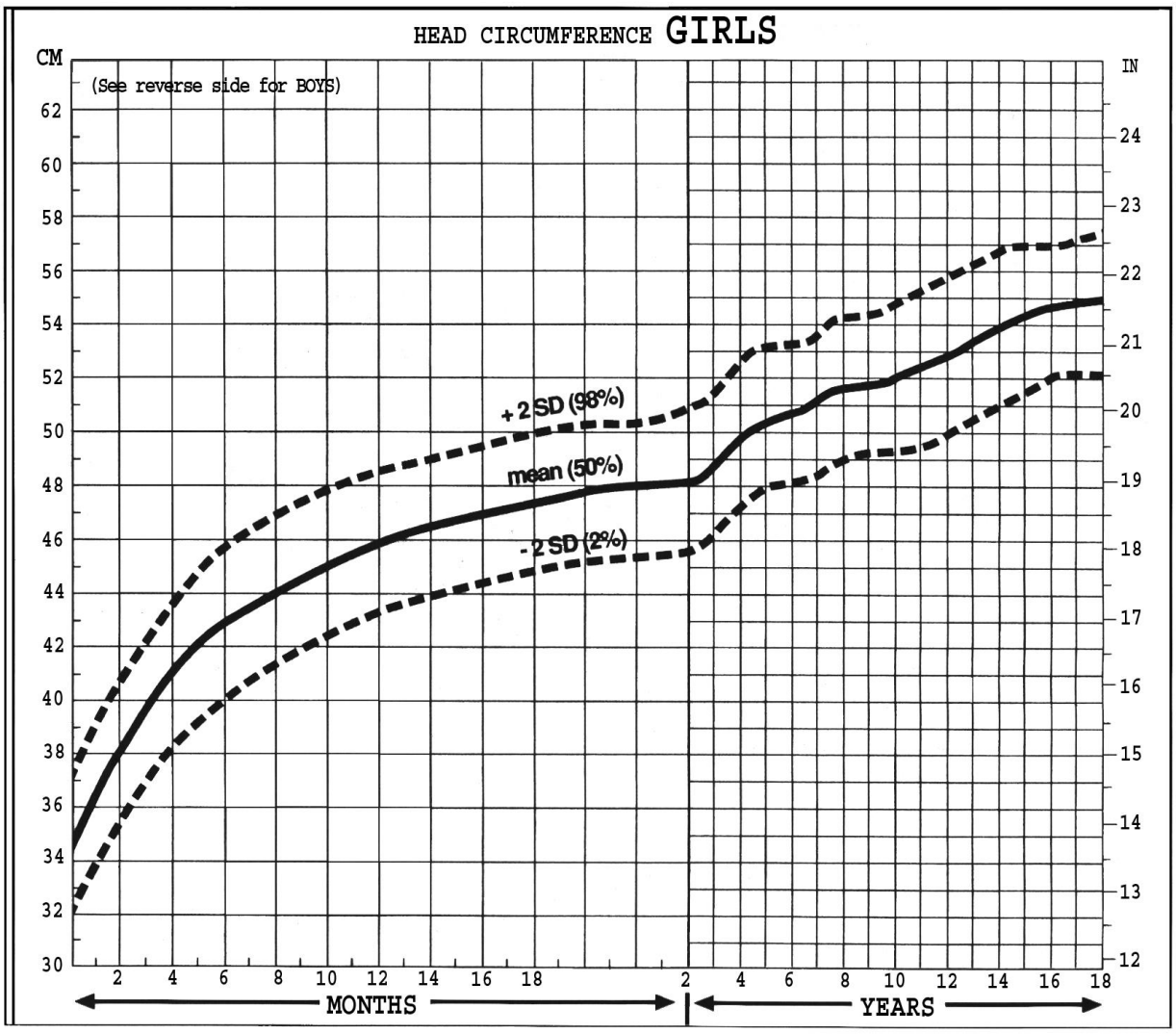


(Hall et. al., 1989, by permission)

Head Circumference

Birth to 18 years

FEMALE

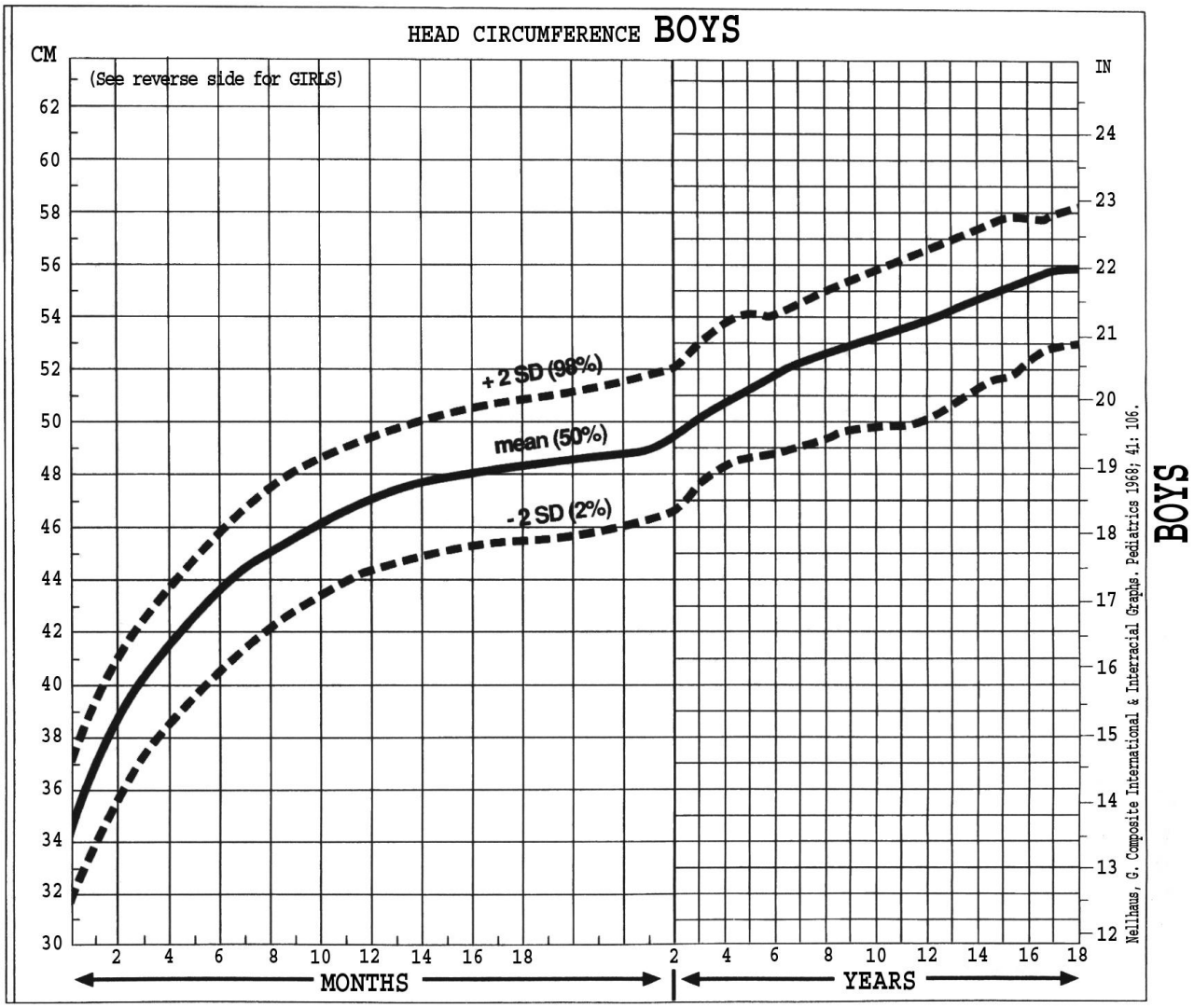


(Mead Johnson Nutritionals by permission, (Nellhaus, 1988)

Head Circumference

Birth to 18 years

MALE

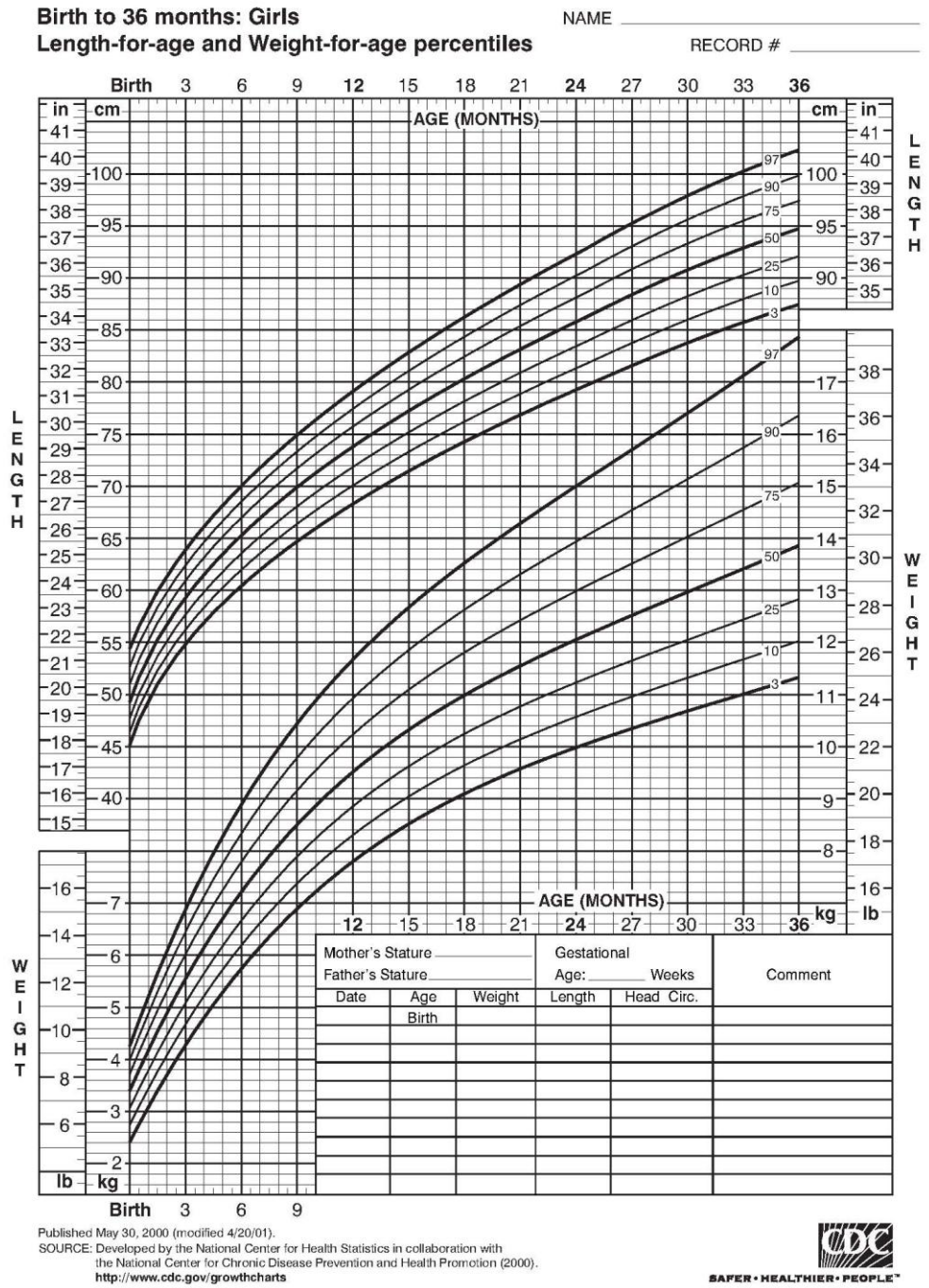


(Mead Johnson Nutritionals by permission, Nellhaus, 1988)

Height and Weight

Birth to 36 Months

FEMALE

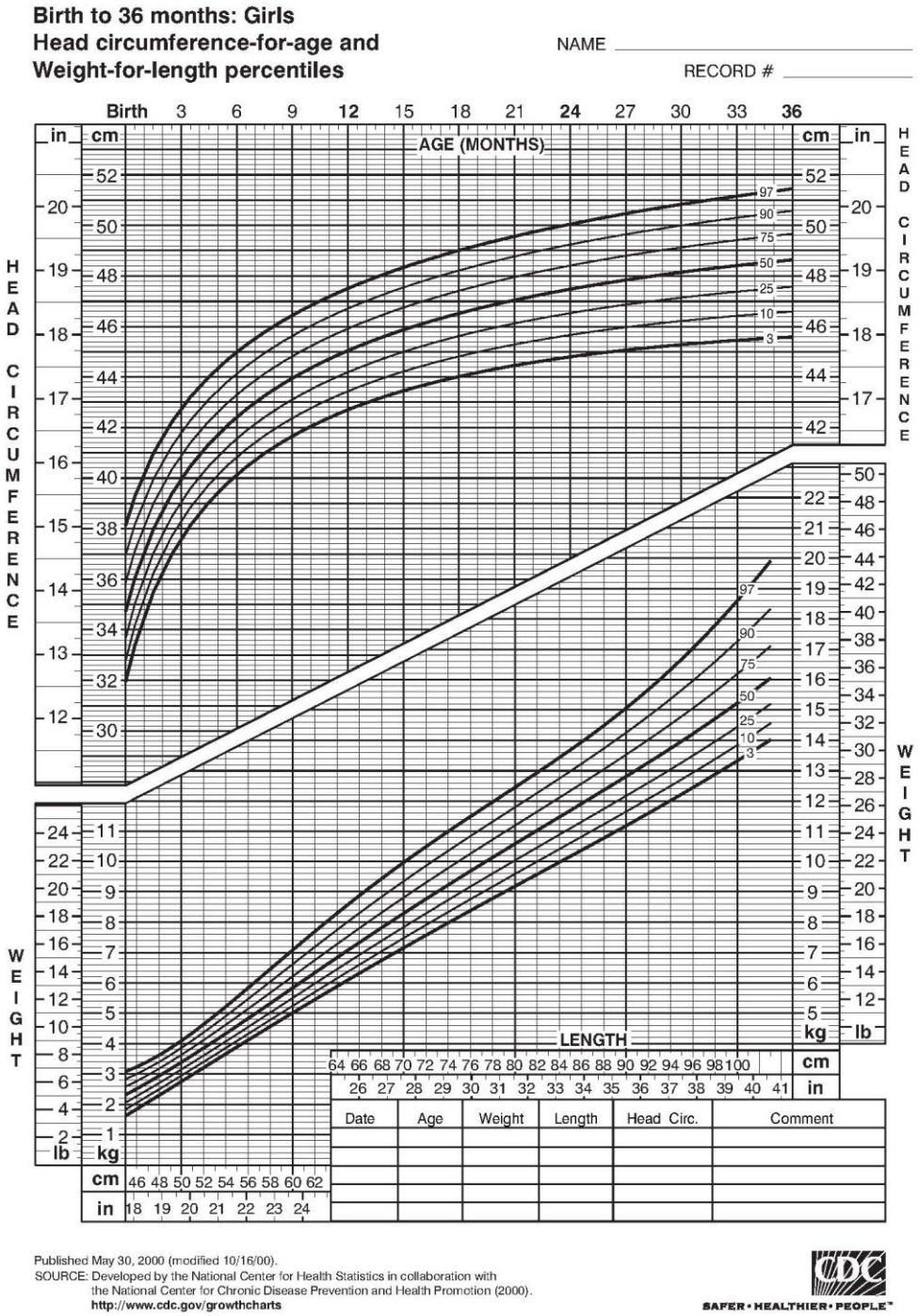


(CDC, 2000, http://cdc.gov/growthcharts)

Head Circumference

Birth to 36 Months

FEMALE

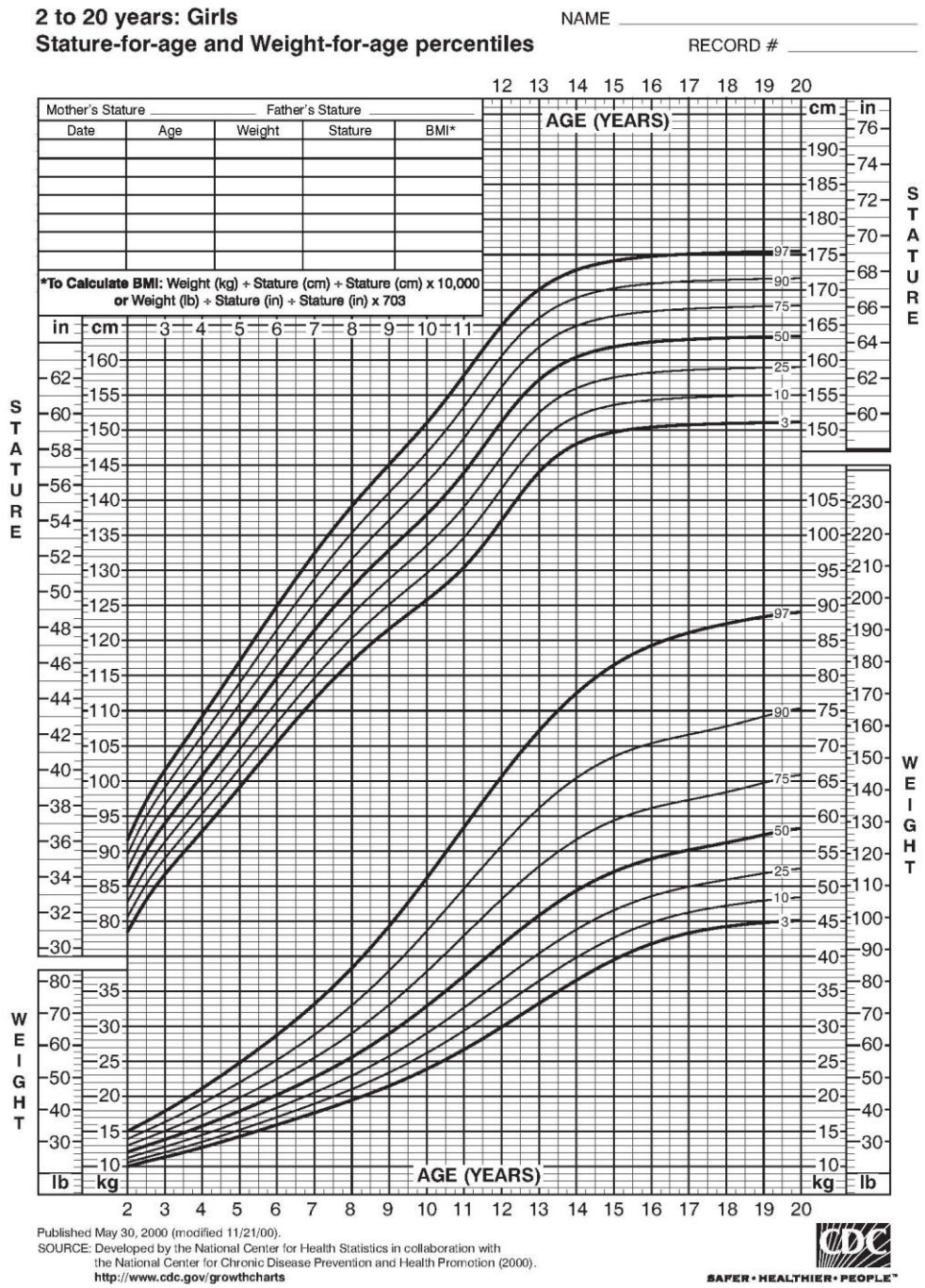


(CDC, 2000, http://cdc.gov/growthcharts)

Height and Weight

2 to 20 Years

FEMALE

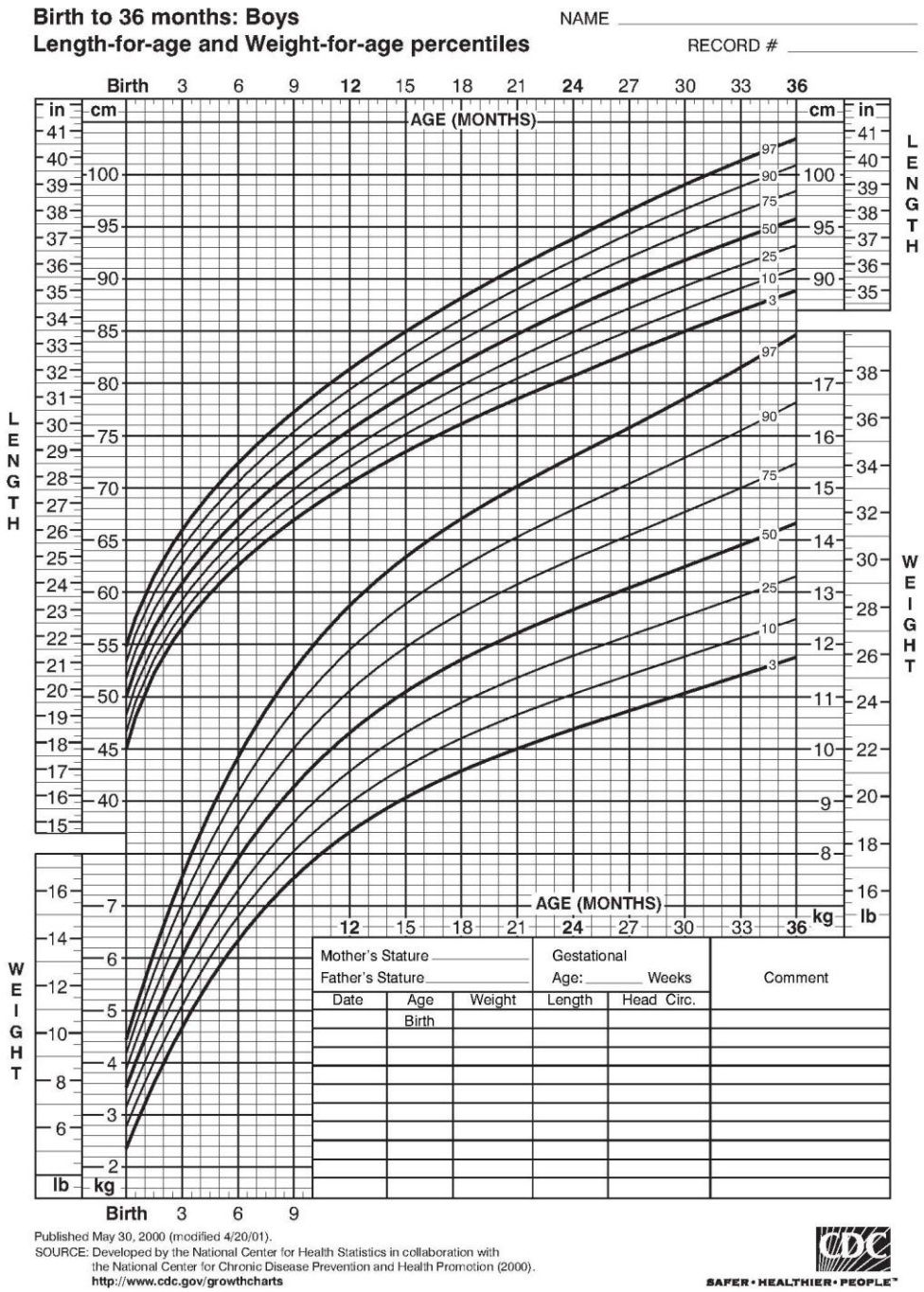


(CDC, 2000, http://cdc.gov/growthcharts)

Height and Weight

Birth to 36 Months

MALE

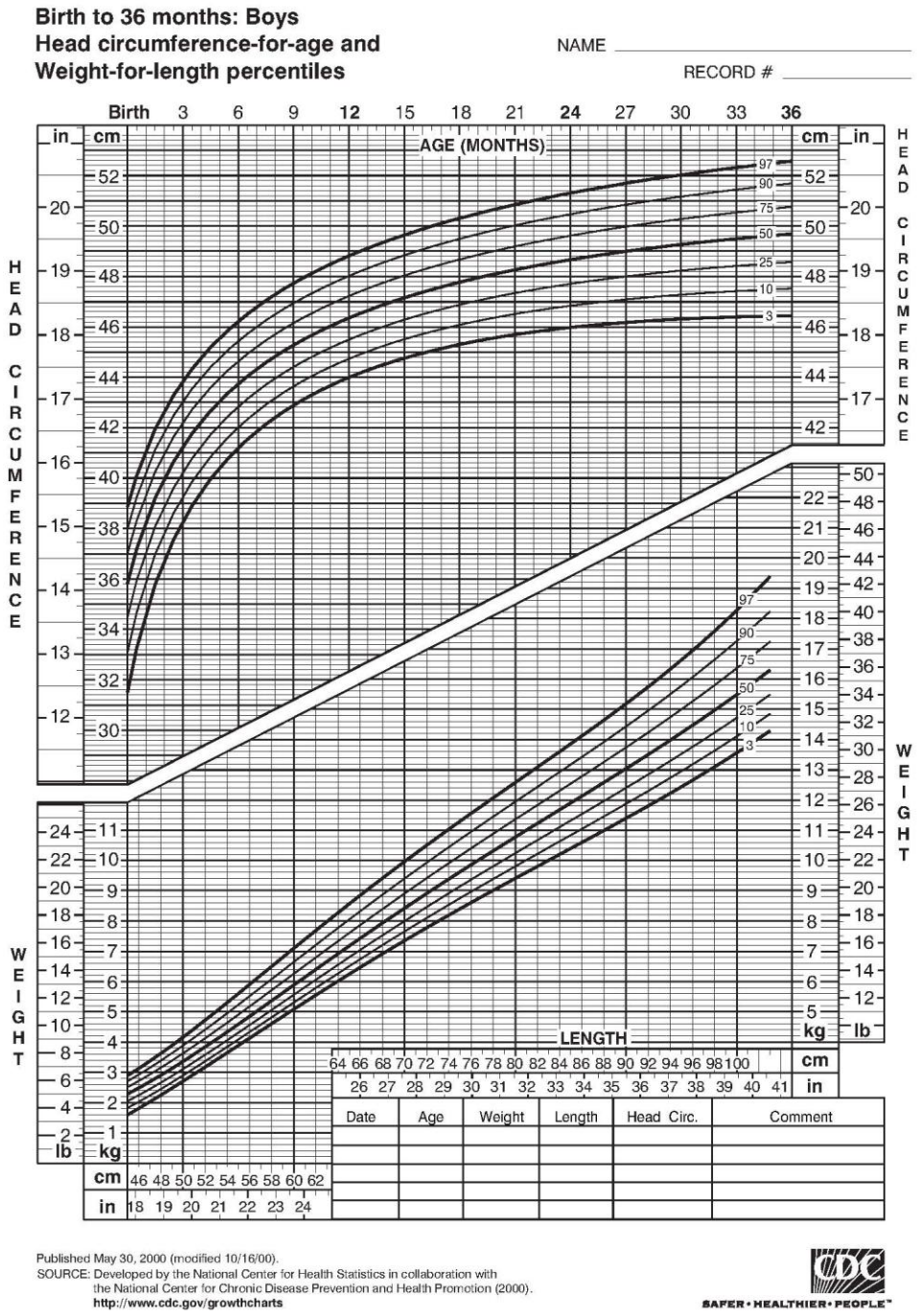


(CDC, 2000, http://cdc.gov/growthcharts)

Head Circumference

Birth to 36 Months

MALE

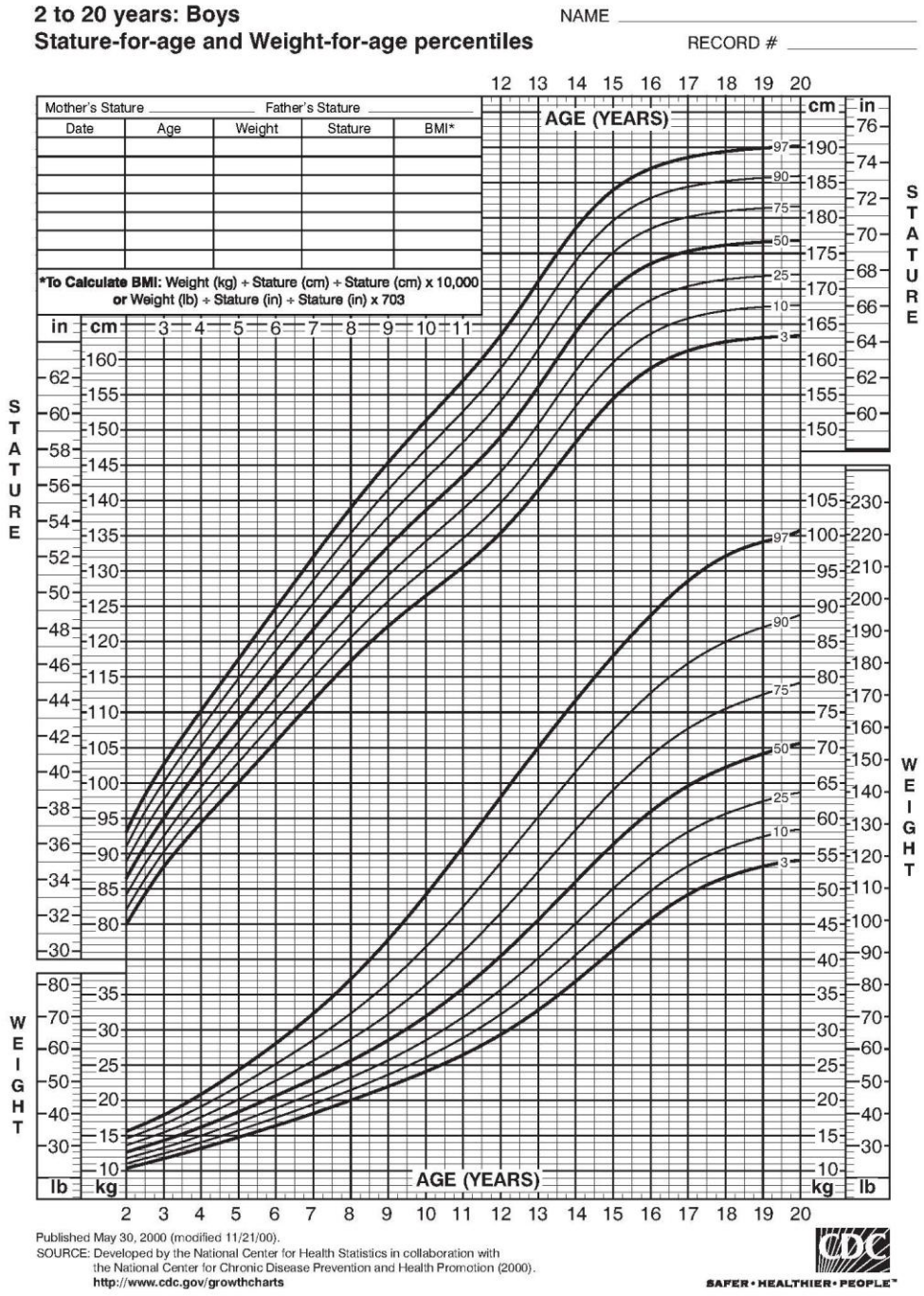


(CDC, 2000, http://cdc.gov/growthcharts)

Height and Weight

2 to 20 Years

MALE



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X. Appendices

1. FAS DPN WEBSITE http://depts.washington.edu/fasdpn/index.htm

The University of Washington FAS DPN website provides a comprehensive overview of all clinical, research, and training activities conducted by the FAS DPN. Included are all publications, order forms for diagnostic tools, and registration forms for the training programs.

A. Frequently Asked Questions, Updates and Sample Forms.
Posted on the FAS DPN website are answers to frequently asked questions regarding the 4-Digit Code. Also posted are updates, support information and pdf versions of the FASD Diagnostic Form and NPIF. Examples of completed FASD Diagnostic Forms for selected 4-Digit Codes are also posted to further illustrate how to use the 4-Digit Code.

B. TRAINING PROGRAMS AND COURSES

i. Two-Day Interdisciplinary Clinical Training Program. This training program is offered at the University of Washington. Interdisciplinary clinical teams are taught how to use the 4-Digit Diagnostic Code in an interdisciplinary clinical setting.

ii. Online Training Course. This accredited course will provide healthcare, educational, and social service professionals with detailed instruction on the use of the 4-Digit Diagnostic Code in an interdisciplinary clinical setting.

iii. One-Day Clinical Observational Training Program. This training provides healthcare, social service, and educational professionals with insight into their role in the community for screening, referral, diagnosis, prevention, and intervention of FASD.

C. DIAGNOSTIC TOOLS AND SOFTWARE

i. FAS Facial Photographic Analysis Software (2003). This software is intended for use by healthcare and research professionals. The software allows one to measure the magnitude of expression of the key facial features of FAS from a digital facial photograph using the method derived by Astley & Clarren, (2001).

ii. FAS TUTOR ™ CD (1999). A compact disk entitled Fetal Alcohol Syndrome Tutor™ has been created by the University of Washington FAS DPN to instruct healthcare professionals, through video, computer animation, and photographic examples, on how to screen and diagnose FASD.

iii. Diagnostic Guide and Lip-Philtrum Guides (2004) Additional copies of the "*Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, 2004*" and the laminated, *Lip-Philtrum Guides* can be ordered from the FAS DPN website.

2. NEW PATIENT INFORMATION FORM (See form below).
This form is sent to families requesting a diagnostic evaluation at the University of Washington FAS DPN clinic. The form allows the family to share with the clinic why they are seeking a diagnostic evaluation, what they hope to gain from the evaluation and what they currently know about the patient's exposure(s) and outcomes. This form serves as a clinical intake form.

New Patient Information Form FASD Clinic

Office Use: Date received ___/___/___ Deadline ___/___/___ ASAP ____ Response Let. ___/___/___ Photo ___ Screen Code _____
G _____ F _____ B _____ A _____ M _____: 1 2 3 4

Patient Identification

Patient's Social Security Number *(optional)* _____ ❑ Female ❑ Male Race _____

Patient's Name _____ Birth date _____ Age _____
First Middle Last

Patient's Address _____

City _____ County _____ State _____ zip code _____

Patient's Telephone Home ( ) _____ Work ( ) _____

Caretaker Identification

Name of patient's primary caretaker(s) _____

Relationship to patient: ❑ birth, ❑ adoptive, or ❑ foster parent ❑ other (specify _____)

Caretaker's Address

City _____ County _____ State _____ zip code _____

Telephone Home ( ) _____ Work ( ) _____

Name of patient's legal guardian(s) _____

Person Completing the Form

Name of person completing this form _____ Date _____

Relationship to patient: ❑ birth, ❑ adoptive, or ❑ foster parent, ❑ caseworker, ❑ medical care provider

❑ other relationship (please specify _____)

Referred by (e.g., who or what organization told you about the clinic ?) _____

Who Should Correspondence be Sent To?

Name _____

Relationship to patient: ❑ birth, ❑ adoptive, or ❑ foster parent ❑ other (specify _____)

Address _____

City _____ County _____ State _____ zip code _____

Telephone Home ( ) _____ Work ( ) _____

Please complete this form to the best of your ability. We realize you will not have the answers to all questions. All information requested in this form is important in allowing us to provide you with the most accurate diagnosis and most appropriate referrals for care. Thank you for taking the time to complete it.

Reasons for Evaluation What are the patient's primary problems? Please be specific.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

What do you hope to gain from the evaluation?

_____

_____

_____

_____

_____

_____

_____

Growth

Birth Measures

1. Birth weight: lbs / oz _____ or gms _____

   Birth length: inches _____ or cm _____

   Birth head circumference: inches _____ or cm _____

   Gestational age *(length of pregnancy)*: weeks _____ or months _____

Please provide additional height, weight and head measures if available*

2. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

3. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

4. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

5. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

Birth Parents' Heights: Birth Mother: inches _____ or cm _____

Birth Father: inches _____ or cm _____

* This information may be available from the patient's physician or school nurse. If growth charts are available and can be photocopied and attached to this form, you need not fill out this section.

Physical Appearance and Health

1. Photographs of the patient's face are very helpful to us. The best photos are ones where the face fills the photo and the patient is not smiling. Pictures between ages 1 and 12 years are best.

- Are such photographs available? ____ yes ____ no
- Are one or two included with this form? ____ yes ____ no
- Can others be brought to the clinic? ____ yes ____ no

Please staple photo(s) here:

Photo may be bigger than this space

2. Was the patient born with (or later discovered to have) any birth defects (things like cleft lip, congenital heart defects, club foot, etc.)? ____ yes ____ no _____ unknown

If yes, please describe: _____

_____

3. Has this patient ever had:

	yes	no	unknown		yes	no	unknown
Allergies	_____	_____	_____	Chronic illness of the heart	_____	_____	_____
Multiple ear infections	_____	_____	_____	Chronic illness of the kidneys	_____	_____	_____
Chronic sinusitis	_____	_____	_____	Chronic illness of the joints/limbs	_____	_____	_____
Chronic hearing loss	_____	_____	_____	Chronic illness of the stomach/ bowels	_____	_____	_____
Visual problems	_____	_____	_____				

4. Has this patient ever had:

A. Operations (since birth) ____ yes ____ no ____ unknown

Describe Operation	Surgeon's Name	Patient's Age

B. Any other hospitalizations ____ yes ____ no ____ unknown

Reason for Hospitalization	Hospital/Doctor	Patient's Age

C. Physical abuse ____ yes ____ no ____ unknown Age(s): _____

Was this evaluated by a physician? ____ yes ____ no ____ unknown

D. Sexual abuse ____ yes ____ no ____ unknown Age(s): _____

Was this evaluated by a physician? ____ yes ____ no ____ unknown

Neurological Issues

1. Has this patient ever had:

A. Seizures

____ yes ____ no ____ suspected ____ unknown

Type: _____

Age when seizure(s) started: _____

Name(s) of medication(s) given? _____

B. Loss of specific motor skills such as standing, walking, running, etc.

____ yes ____ no ____ unknown

If yes, please describe _____

C. Bed wetting or soiling after 8 years of age.

____ yes ____ no ____ unknown ___ not 8 years old yet

2. Has this patient ever had a head injury leading to unconsciousness or evaluation by a doctor?

____ yes ____ no ____ unknown

If yes, please describe _____

3. Has the patient ever had a CT scan or MRI scan of the brain

____ yes ____ no ____ unknown

If yes, was it described to be abnormal? ____ yes ____ no ____ unknown

Attention Deficit and Hyperactivity

1. Has the patient ever been evaluated for attention deficit/hyperactivity disorder (ADD / ADHD)

____ yes ____ no ____ unknown

If yes:

When was the evaluation done? Age: _____ Date: _____

Was the patient diagnosed with ADD or ADHD? ____ yes ____ no ____ unknown

Was the patient ever treated for ADD or ADHD? ____ yes ____ no ____ unknown

What medications have been tried?

Drug	Dose	Ages	Response

Mental Health Issues

1. Has the patient ever been evaluated by a psychiatrist, psychologist, or MH counselor?

____ yes ____ no ____ unknown

If yes, please list each psychiatrist, psychologist and/or counselor.

A. Type of professional: _____

Reason for assessment: _____

Type of therapy (i.e., behavioral, individual counseling, group counseling, family counseling, medicine): _____

_____

Age at the time of therapy: _____ Did the therapy help? ____ yes ____ no ____ unknown

If yes, how did it help? _____

_____

_____

B. Type of professional: _____

Reason for assessment: _____

Type of therapy (i.e., behavioral, individual counseling, group counseling, family counseling, medicine): _____

_____

Age at the time of therapy: _____ Did the therapy help? ____ yes ____ no ____ unknown

If yes, how did it help?_____

_____

_____

2. Has the patient ever been evaluated for mood problems (depression, anxiety, etc.) or phobia?

____ yes ____ no ____ unknown

If yes:

When was the evaluation(s) done? Age(s): _____ Date(s): _____

3. What medications have ever been tried and how well did they work?

Drug	Dose	Response	Currently Using?

School Issues

1. List <u>ALL</u> schools the patient has attended and the grades of attendance:

School	**City**	**Grades Attended**	**Received Special Education, Resource Room, Tutoring, etc.** yes	no	unknown

2. What <u>learning</u> problems does the patient have?

3. What <u>behavioral</u> problems does the patient have?

Alcohol Exposure

Please fill in this information as completely as possible.
This information is critical to the evaluation of the patient.

Alcohol use by the birth mother

- **Before pregnancy**: average number of drinks per drinking occasion: _____
  maximum number of drinks per occasion: _____
  average number of drinking days per week: _____
  Type(s) of alcohol: ___wine, ___beer, ___ liquor, ___ unknown, ___ other (specify) _____

- **During pregnancy:** average number of drinks per drinking occasion: _____
  maximum number of drinks per occasion: _____
  average number of drinking days per week: _____
  Type(s) of alcohol: ___wine, ___beer, ___ liquor, ___ unknown, ___ other (specify) _____

Which trimester(s) did the mother drink alcohol? ____ 1st ____2nd ____3rd ___unknown

	No	Yes	Unknown
Was the birth mother ever reported to have a problem with alcohol?	____	____	_____
Was the birth mother ever diagnosed with alcoholism?	____	____	_____
Did the birth mother ever receive treatment for alcohol addiction?	____	____	_____

If the above information is unknown, please provide any information that might help describe the mother's level of alcohol use DURING pregnancy _____

_____

_____

What is the source(s) of this information on alcohol use? _____

_____

Did the birth mother use any of the following substances during pregnancy?

Yes	No	Unknown	Type	Please List Specific Substance(s)	Month(s) of Pregnancy
___	___	___	Drugs	_____	_____
___	___	___	Tobacco	_____	_____
___	___	___	Medications	_____	_____
___	___	___	X-rays	_____	_____

Information about the Patient's Biological Parents

Birth mother's name_____ Birth date _____
First Middle Last

Mother's Race ❑ White ❑ Black ❑ American Indian ❑ Alaskan Native ❑ Hispanic
❑ Asian ❑ unknown ❑ other (specify) _____

Education level attained (last year of school completed) _____ Age at birth of patient ____

Does she have a history of learning problems? _____

Birth mother's Address _____
Street City State Zip

When was the last contact with the birth mother? _____

Birth father's name_____ Birth date _____
First Middle Last

Father's Race ❑ White ❑ Black ❑ American Indian ❑ Alaskan Native ❑ Hispanic
❑ Asian ❑ unknown ❑ other (specify) _____

Education level attained (last year of school completed) _____ Age at birth of patient _____

Does he have a history of learning problems? _____

When was the last contact with the birth father? _____

Medical History of the Biological Family

Has anyone in this patient's biological family ever had any of these conditions? *Check all that apply*.

	Birth Mother	Birth Father	Mother's Family	Father's Family	Siblings of patient
Alcoholism					
Birth Defects					
Stillbirths					
Miscarriages					
Mental retardation					
Other developmental disabilities					
Learning disorders					
Attention deficit					
Hyperactivity					
Epilepsy					
Neurological disease					
Child abuse					
Sexual abuse					
Depression					
Suicide					
Mental illness					
Vision problems					
Hearing problems					
Chronic illnesses					
Tourette syndrome					
Delinquency					
Any specific genetic condition					
Other					

Pregnancies of Birth Mother

1. Please list **all** of the birth mother's pregnancies including miscarriages, abortions, in the order of their occurrence:

Year	Length of Pregnancy	First name of child if applicable	Live born Child yes	Live born Child no	Normally Developed yes	Normally Developed no	If not normal, please explain *Include FAS / FAE diagnosis, if known*
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________

Office Use:	Total Parity	Total Gravity	Patient Parity	Patient Gravity	FASD diagnoses

Pregnancy, Labor, and Delivery of this Patient

1. **Did the birth mother experience any difficulties during pregnancy?** __ Yes ___ No ___ Unk.
   If yes, please describe: ____
2. **Did the birth mother receive prenatal care?** ___ Yes ___ No ___ Unknown
3. **Were there complications during the labor or delivery?** ___ Yes ___ No ___ Unknown
   If yes, please explain:____
4. **Was the delivery:** _______ Natural ________ By C-section _______ Unknown
   Reason for C-Section, if performed ______________________________________
5. **Where was the patient born?** Hospital __________ City State _________________
6. **Apgar scores** ______________ at 5 minutes _____________ at 10 minutes
7. **How many days did the infant stay in the birth hospital?** ______________________
8. **Did the patient have any of the following problems while still in the birth hospital?**

	Yes	No	Unknown		Yes	No	Unknown
Feeding problems	____	____	____	Infections	_____	_____	_____
Apnea / breathing difficulties	____	____	____	Jaundice	_____	_____	_____
Supplemental oxygen required	____	____	____	Convulsions	_____	_____	_____

List of Professionals Currently Involved in Patient's Care

Primary Physician Name: _____ Phone: _____

Address: _____

Other Physicians Name: _____ Phone: _____

Specialty: _____

Address: _____

Name: _____ Phone: _____

Specialty: _____

Address: _____

Name: _____ Phone: _____

Specialty: _____

Address: _____

Mental Health Consultants *(includes Psychiatrists Psychologists, and Counselors)* Name: _____ Phone: _____

Specialty: _____

Address: _____

Name: _____ Phone: _____

Specialty: _____

Address: _____

School Name: _____ Phone: _____

Address: _____

Contact Person *(teacher, nurse, counselor, etc.)*:

_____

Other Name: _____ Phone: _____

Profession: _____

Address: _____

Placements

1. List all of the placements the patient has had from birth through today.

Type of placement (i.e., foster, adoptive, etc.)	Duration of placement	Age of patient when placement started
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Office Use:	Total	First	Last

A. How long has the patient been in your care? _____

What to bring to Clinic

If the patient has had any of the following assessments, please bring them to Clinic on the day of your appointment. This information is very important to the patient's diagnostic evaluation.

_____ Facial photographs of the patient from birth to 12 years of age, without a smile.

_____ Medical records which document the problems you have reported above.

_____ School Assessments including:
- Achievement tests
- IQ tests
- Language assessments
- Social Skills assessments
- Behavior assessments

_____ Psychological Assessments

_____ Developmental Assessments including:
- Motor Development (fine and gross motor)
- Occupational Therapy assessments
- Mental (cognitive) assessments