

**Summary of the First 1,500 Patients Diagnosed**

Using the Diagnostic Guide for FAS and Related Conditions: The 4-Digit Diagnostic Code (Astley &amp; Clarren, 1999)

**Description of Criteria Required to Receive an Evaluation in the FAS DPN Clinics**

In general:

The only criteria required to be seen in the FAS DPN is a confirmed prenatal alcohol history (Alcohol Rank 3 or 4). The presence of the full FAS facial phenotype (Face Rank 4) can be used in lieu of a confirmed prenatal alcohol history.

**OUTCOMES**

<b>Gender</b>	<b>n</b>	<b>(valid %)</b>
Female.....	647	(43.2)
Male .....	852	(56.8)

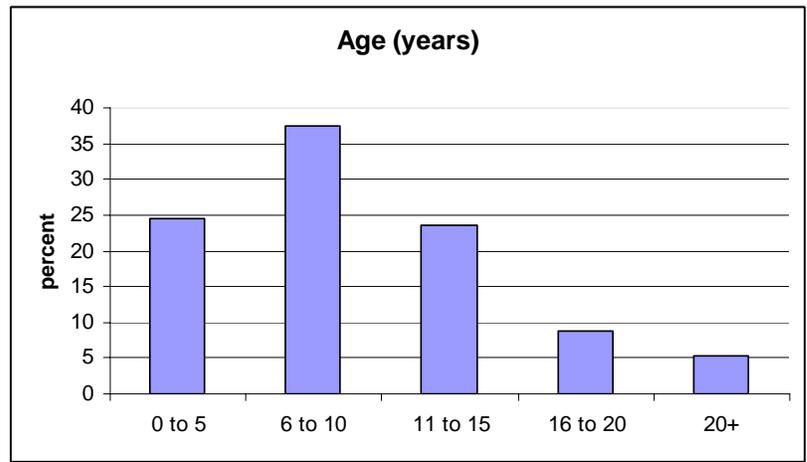
<b>Race</b>	<b>n</b>	<b>(valid %)</b>
Caucasian .....	764	(51.4)
Caucasian/Native American.....	109	(7.3)
Caucasian/Hispanic.....	78	(5.2)
Caucasian/Unknown .....	71	(4.8)
Caucasian/African American.....	59	(4.0)
Caucasian/Alaskan Native .....	24	(1.6)
African American.....	91	(6.1)
African American/Native American .....	16	(1.1)
African American/Hispanic .....	10	(0.7)
Native American .....	104	(7.0)
Native American/Hispanic.....	48	(3.2)
Native American/Unknown .....	18	(1.2)
Alaskan Native.....	4	(0.3)
Native American/Alaskan Native .....	4	(0.3)
Asian .....	0	(0.0)
Hispanic .....	15	(1.0)
Pacific Islander.....	1	(0.1)
Other Mixed Race .....	71	(4.8)

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<b>Age at Time of Diagnosis (years)</b>	<b>n</b>	<b>(valid %)</b>
0.0 - 0.9.....	26	(1.8)
1.0 - 1.9.....	68	(4.5)
2.0 - 2.9.....	67	(4.6)
3.0 - 3.9.....	88	(5.9)
4.0 - 4.9.....	119	(7.9)
5.0 - 5.9.....	113	(7.5)
6.0 - 6.9.....	136	(9.1)
7.0 - 7.9.....	111	(7.4)
8.0 - 8.9.....	110	(7.3)
9.0 - 9.9.....	91	(6.1)
10.0 - 10.9.....	80	(5.3)
11.0 - 11.9.....	81	(5.4)
12.0 - 12.9.....	64	(4.3)
13.0 - 13.9.....	72	(4.8)
14.0 - 14.9.....	57	(3.8)
15.0 - 15.9.....	43	(2.9)
16.0 - 16.9.....	38	(2.5)
17.0 - 17.9.....	26	(1.7)
18.0 - 18.9.....	20	(1.3)
19.0 - 19.9.....	8	(0.5)
20.0 - 29.9.....	53	(3.5)
30.0 + .....	29	(1.9)
	<b>mean</b>	<b>(SD)</b>
	9.5	(6.7)
	<b>minimum</b>	<b>maximum</b>
	0.2	50.8

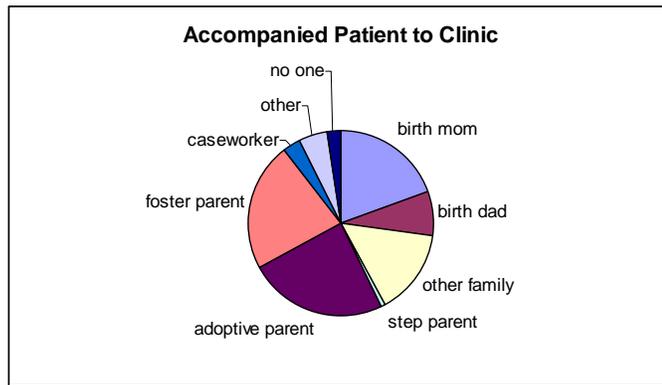


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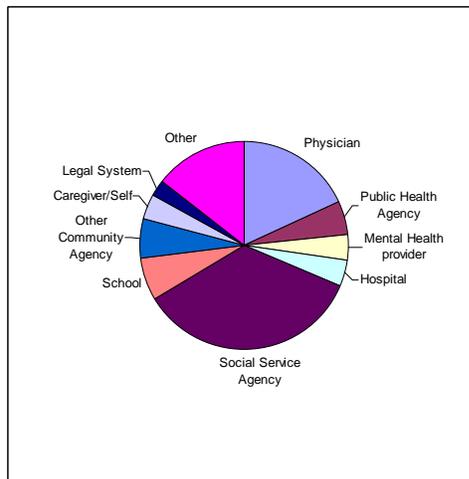
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<b>Closest Relation Accompanying Patient to Clinic .....</b>	<b>n</b>	<b>(valid %)</b>
Birth mother .....	281	(19.4)
Birth father .....	111	(7.7)
Other biological family member .....	214	(14.8)
Step parent .....	12	(0.8)
Adoptive parent.....	352	(24.3)
Foster parent.....	326	(22.5)
Social or caseworker .....	42	(2.9)
Other .....	73	(5.0)
No one.....	38	(2.6)



<b>Who Referred Patient for a Diagnostic Evaluation .....</b>	<b>n</b>	<b>(valid %)</b>
Physician .....	148	(17.9)
Public Health Agency .....	44	(5.3)
Mental Health provider .....	33	(4.0)
Hospital .....	34	(4.1)
Social Service Agency .....	288	(34.9)
School .....	57	(6.9)
Other Community Agency .....	49	(5.9)
Caregiver/Self .....	32	(3.9)
Legal System.....	22	(2.7)
Other .....	118	(14.3)



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4-Digit Diagnostic Category		Prevalence		Age (years)		
		n	(valid %)	mean	(SD)	
A.	FAS	(alcohol exposed)	36	(2.4)	6.7	(9.1)
B.	AFAS	(alcohol exposed)	7	(0.5)	13.4	(5.0)
C.	FAS	(alcohol unknown)	56	(3.7)	9.5	(7.7)
D.	FAS Phenocopy	(no alcohol exposure)	0	(0.0)	(--)	(--)
E.	Sentinel physical findings / static encephalopathy	(alcohol exposed)	120	(8.0)	8.4	(6.8)
F.	Static encephalopathy	(alcohol exposed)	298	(19.9)	10.6	(6.3)
G.	Sentinel physical findings / neurobehavioral disorder	(alcohol exposed)	116	(7.7)	7.7	(5.9)
H.	Neurobehavioral disorder	(alcohol exposed)	498	(33.2)	9.4	(5.8)
I.	Sentinel physical findings	(alcohol exposed)	17	(1.1)	8.3	(11.5)
J.	No cognitive/behavioral or sentinel physical findings	(alcohol exposed)	101	(6.7)	6.3	(6.3)
K.	Sentinel physical findings / static encephalopathy	(alcohol unknown)	20	(1.3)	11.9	(8.5)
L.	Static encephalopathy	(alcohol unknown)	66	(4.4)	11.7	(4.9)
M.	Sentinel physical findings / neurobehavioral disorder	(alcohol unknown)	34	(2.3)	12.7	(10.2)
N.	Neurobehavioral disorder	(alcohol unknown)	107	(7.1)	11.3	(7.1)
O.	Sentinel physical findings	(alcohol unknown)	1	(0.1)	6.3	(--)
P.	No cognitive/behavioral or sentinel physical findings	(alcohol unknown)	19	(1.3)	8.3	(10.6)
Q.	Sentinel physical findings / static encephalopathy	(no alcohol exposure)	0	(0.0)	(--)	(--)
R.	Static encephalopathy	(no alcohol exposure)	2	(0.1)	6.6	(3.2)
S.	Sentinel physical findings / neurobehavioral disorder	(no alcohol exposure)	1	(0.1)	5.3	(--)
T.	Neurobehavioral disorder	(no alcohol exposure)	1	(0.1)	6.8	(--)
U.	Sentinel physical findings	(no alcohol exposure)	0	(0.0)	(--)	(--)
V.	No cognitive/behavioral or sentinel physical findings	(no alcohol exposure)	0	(0.0)	(--)	(--)

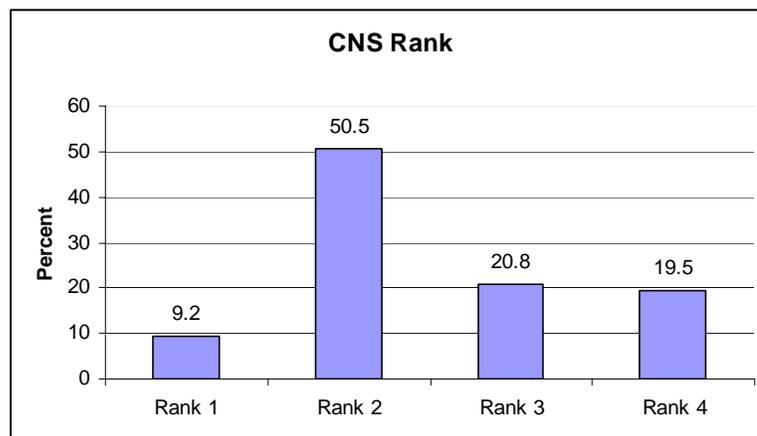
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<b>Evidence of Organic Brain Damage</b>	<b>n</b>	<b>(valid %)</b>
Static encephalopathy (FAS or AFAS).....	99	(6.6)
Static encephalopathy (not FAS or AFAS).....	506	(33.7)
Neurobehavioral disorder.....	757	(50.5)
No evidence of organic brain damage .....	138	(9.2)

<b>Microcephaly (2 or more standard deviations below the norm)</b>	<b>n</b>	<b>(valid %)</b>
At time of diagnosis.....	189	(12.6)

<b>CNS Rank: (Likelihood of CNS Damage)</b>	<b>n</b>	<b>(valid %)</b>
Rank 1: No evidence of CNS damage/dysfunction.....	138	(9.2)
Rank 2: Possible, (neurobehavioral disorder), .....	757	(50.5)
Rank 3: Probable (static encephalopathy).....	312	(20.8)
Proportion of Rank 3 that are also Rank 4.....	83	(26.6)
Rank 4: Definite (static encephalopathy.....	293	(19.5)
Proportion of Rank 4 that are also Rank 3.....	83	(28.3)
Proportion of Rank 4 that are also Rank 2.....	77	(26.3)

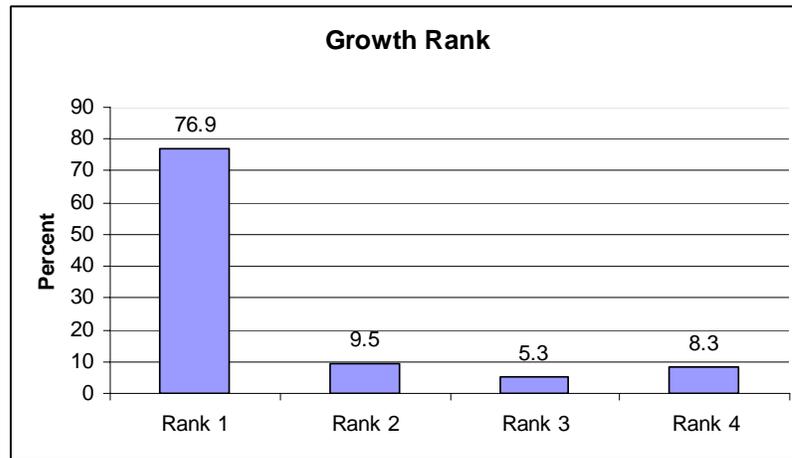


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**Growth Deficiency Rank**

	<b>n</b>	<b>(valid %)</b>
Rank 1: None (height and weight > 10 <sup>th</sup> percentile) .....	1154	(76.9)
Rank 2: Mild (height and weight between 5 <sup>th</sup> and 10 <sup>th</sup> percentile) .....	142	(9.5)
Rank 3: Moderate (height and weight between 3 <sup>rd</sup> and 5 <sup>th</sup> percentile).....	79	(5.3)
Rank 4: Severe (height and weight ≤ 3 <sup>rd</sup> percentile) .....	125	(8.3)

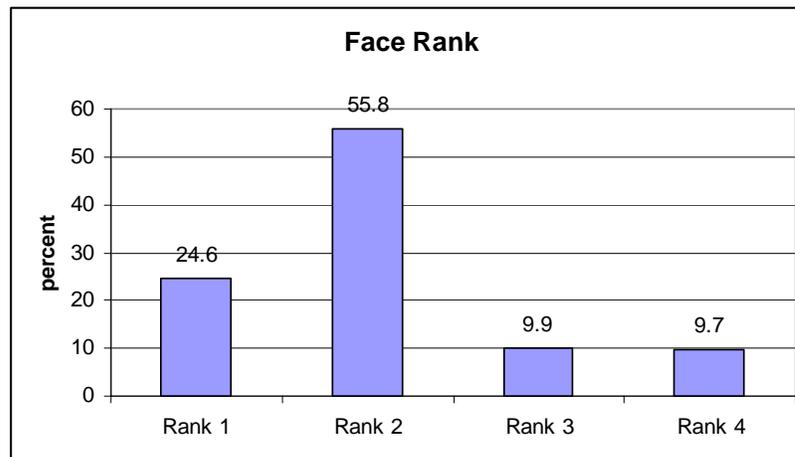


**FAS Facial Phenotype Rank**

*The three diagnostic features include*

1. palpebral fissure lengths two or more SDs below the norm,
2. smooth philtrum (Rank 4 or 5 on the Lip-Philtrum Guide) and
3. thin upper lip (Rank 4 or 5 on the Lip-Philtrum Guide)

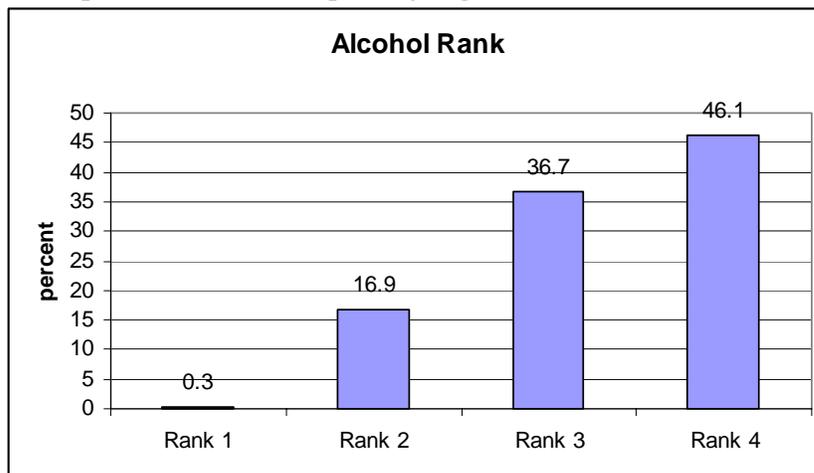
	<b>n</b>	<b>(valid %)</b>
Rank 1: Normal, none of the three FAS facial features .....	369	(24.6)
Rank 2: Mild, one of the three FAS facial features .....	837	(55.8)
Rank 3: Moderate, two of the three FAS facial features .....	149	(9.9)
Rank 4: Severe, all three of the three FAS facial features.....	145	(9.7)



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<b>Prenatal Alcohol Exposure Rank</b>	<b>n</b>	<b>(valid %)</b>
Rank 1: Confirmed absence of exposure from conception to birth.....	4	(0.3)
Rank 2: Unknown exposure .....	254	(16.9)
Rank 3: Alcohol exposure confirmed, quantity moderate or unknown.....	551	(36.7)
Rank 4: Alcohol exposure confirmed, quantity high.....	691	(46.1)



<b>Other Prenatal Exposures / Adverse Events:</b>	<b>n</b>	<b>(valid %)</b>
Rank 1: None reported.....	14	(0.9)
Rank 2: Unknown.....	279	(18.8)
Rank 3: Some risk (poor prenatal care, other drug exposure, etc) .....	1043	(70.3)
Rank 4: High risk (exposure to known teratogen, known genetic risk factor(s))..	148	(10.0)

<b>Other Postnatal Exposures / Adverse Events</b>	<b>n</b>	<b>(valid %)</b>
Rank 1: None reported.....	55	(3.7)
Rank 2: Unknown .....	253	(17.1)
Rank 3: Some risk (neglect, multiple placements).....	573	(38.7)
Rank 4: High risk (physical / sexual abuse, severe neglect) .....	601	(40.6)

<b>Physical Abuse</b>	<b>n</b>	<b>(valid %)</b>
None reported.....	703	(47.4)
Suspected .....	88	(5.9)
Yes .....	447	(30.1)
Unknown.....	246	(16.6)

<b>Sexual Abuse</b>	<b>n</b>	<b>(valid %)</b>
None reported.....	753	(50.8)
Suspected .....	153	(10.3)
Yes .....	279	(18.8)
Unknown.....	298	(20.1)

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<b>Birth Mother's Age (years) at Time of Child's Diagnosis</b>	<b>n</b>	<b>(valid %)</b>
15 to 19.9 .....	11	(1.0)
20 to 29.9 .....	305	(27.5)
30 to 39.9 .....	554	(50.0)
40 to 49.9 .....	180	(16.2)
50 to 59.9 .....	36	(3.2)
60 or greater .....	23	(2.1)
	<b>mean</b>	<b>(SD)</b>
	35.3	(9.2)
	<b>minimum</b>	<b>maximum</b>
	16.1	81.2

<b>Birth Mother's Age (years) at Child's Birth</b>	<b>n</b>	<b>(valid %)</b>
< 15 .....	3	(0.3)
15 to 19.9 .....	203	(18.3)
20 to 29.9 .....	619	(55.9)
30 to 39.9 .....	265	(23.9)
40 to 49.9 .....	16	(1.4)
50 to 59.9 .....	1	(0.1)
	<b>mean</b>	<b>(SD)</b>
	26.0	(6.1)
	<b>minimum</b>	<b>maximum</b>
	14.2	51.2

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<b>Reported Maternal Alcohol Use Before Pregnancy</b>	<b>mean</b>	<b>(SD)</b>
Average number of drinks per occasion (n = 532) .....	9.7	(10.6)
Maximum number of drinks per occasion (n = 489) .....	14.5	(13.7)
Number of days of drinking per week (n = 672) .....	4.9	(3.6)

<b>Reported Maternal Alcohol Use During Pregnancy</b>	<b>mean</b>	<b>(SD)</b>
Average number of drinks per occasion (n = 571) .....	8.4	(10.3)
Maximum number of drinks per occasion (n = 515) .....	12.5	(11.7)
Number of days of drinking per week (n = 733) .....	4.7	(3.5)