

FASD Webinar Q&A's

Responses by Susan (Astley) Hemingway PhD

Q: Does fetal alcohol exposure result in increased genetic abnormalities, such as duplications or microdeletions?

Genetic abnormalities (duplications and microdeletions) are observed in individuals with prenatal alcohol exposure, but currently, there are no studies to date that confirm these abnormalities are observed more often in individuals with prenatal alcohol exposure than among individuals with no prenatal alcohol exposure. There are no studies to date that confirm prenatal alcohol exposure causes genetic abnormalities. Research in this arena is still relatively new, so it will be important to keep an eye on the literature.

Q: Is FASE still a term used?

I think you might be referring to the old term PFAE. Back in the 1990s, two diagnostic terms were used to define what we now call Fetal Alcohol Spectrum Disorder: FAS and PFAE (probable fetal alcohol effects). The term PFAE was abandoned shortly after it was coined because it was too broad and non-specific. It was however accurately conveying that prenatal alcohol exposure causes a spectrum of disorder, not just the syndrome FAS. When the 4-Digit Code was developed in 1997, it defined 4 diagnostic categories spanning the full continuum of FASD (FAS, Partial FAS, Static Encephalopathy/Alcohol Exposed and Neurobehavioral Disorder/Alcohol Exposed). Each diagnosis was specifically case-defined. In essence, the old diagnostic term PFAE has been replaced by 3 separate diagnostic terms: PFAS, SE/AE, and ND/AE.



FASD Umbrella

4 Diagnoses		Growth	Face	Brain	Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe	alc
2. PFAS	Partial FAS		face	severe	alc
3. SE/AE	Static Encephalopathy / Alc Exposed			severe	alc
4. ND/AE	Neurobehavioral Disorder / Alc Exposed			moderate	alc

Q: Does phenobarbital cause the same syndrome?

No. By virtue of the name assigned to the syndrome, only alcohol can cause fetal alcohol syndrome. Most all syndromes have individual features that overlap with other syndromes, but only alcohol causes the constellation of features that define FAS.

Q: Is there a recommended way to consider alcohol exposure in the context of other drug exposures?

Alcohol is a teratogen. Teratogens are substances that can produce physical or functional defects in the developing fetus. The adverse effects of prenatal alcohol exposure are often more severe than the adverse effects of prenatal exposure to illicit drugs. Thirty to 60% of our patient population with prenatal alcohol exposure has also been exposed prenatally to illicit drugs. 62% were exposed prenatally to tobacco. Alcohol is never the only risk factor contributing to an individual's disabilities. The 4-Digit Code ranks the severity of all the other prenatal (illicit drugs, tobacco, poor prenatal care, family genetics, etc) and postnatal (trauma,

multiple home placements, neglect, etc) adverse exposures and events that, in addition to alcohol, are adversely impacting the individual. In our [recent publication](#) we found that prenatal alcohol exposure was the dominant risk factor explaining the largest proportion of variance in regional brain size and brain function.

Q: What term do you use when speaking with the children themselves, and do you give them guidance on describing it to others, at school, for example?

With caregiver permission and involvement, we share results of the diagnosis with the child/adolescent in a way that is appropriate for their chronological and developmental age. We provide constructive feedback focusing on their positive qualities and strengths and acknowledging the areas that are more challenging for them. We rarely if ever feel compelled to use any of the diagnostic terms when speaking with the children/adolescents. Rather, we provide them with guidance for how they might share the challenges they experience with friends and teachers.

Q: Is there any guidance out there for working with adults who likely have FASD but were never diagnosed as children? Specifically working in behavioral health setting treating MH and SUDs?

In our experience, adults benefit greatly from an FASD diagnostic evaluation. Our oldest patient to date was 52 years old. A diagnosis can help qualify adults for services and provide them insight into their own strengths and weaknesses. One of the most compelling cases we had back in the 1990s was a young male adult living on the streets of Seattle. He was a kind soul that was struggling to survive on the streets. He had been in and out of jail not because he was a hardened criminal, but because he was often the victim of a crime perpetrated by other individuals who had duped him into being the one to enter the store and steal something. He blamed himself for his homelessness, sharing with us that he continually made poor decisions that landed him in trouble. His FASD diagnostic evaluation confirmed he met the criteria for full FAS. The diagnosis was a paradigm shift for him. For the first time he understood that his poor decision-making skills, impulsivity, cognitive limitations were brain-based and likely caused by his exposure to a teratogen during gestation. His homelessness was not his fault. He said receiving the diagnosis was like “having a burlap sack removed from his head”. He felt he could see more clearly why things in his life never went well. We connected him up with services. It was a memorable moment in clinic for both the patient and the clinical team.

Q: What is the current composition of your multidisciplinary team doing these evaluations?

Since prenatal alcohol exposure can adversely impact growth, craniofacial structure and CNS function, we need a team trained to assess all these areas. The medical doctor’s role is to assess growth, facial anomalies and structural/neurological abnormalities of the brain. The Speech Language Pathologist assesses language skills. The Occupational Therapist assesses motor function and sensory issues. The psychologist assesses cognition, achievement, executive function, memory, attention, etc. Ideally, this team is working together on the same day (interdisciplinary) to conduct an evaluation, derive a diagnosis and generate intervention recommendations. It is also possible to work together but on different days (multidisciplinary) to achieve the same outcome. For example, the patient might be evaluated by each team member on different days. The team then comes together at the end of the process to derive the diagnosis and intervention plan.

Q: What is the lifelong impact of FASD?

The lifelong impact of FASD is different for each individual. The adverse impact can be substantially mitigated with an early accurate diagnosis, early intervention and a strong social support network. Historically, adults with undiagnosed FASD struggled to live independently, keep a job, make friends and not fall victim to crime. These outcomes can be avoided. Having provided FASD diagnostic services to individuals in WA State over 30

years, we have had the unique opportunity to reconnect with some of these children as adults. It is heartening to see how well many are doing (typically with some level of support), but doing well, nonetheless.

Q: Is there an impact on psychosis or major mental health?

There is a very high prevalence of psychosis and mental health disorders among individuals with FASD. There is also a very high prevalence of psychosis and mental health disorders among their birth parents. It remains unclear if the mental health disorders observed in individuals with prenatal alcohol exposure are caused by prenatal alcohol exposure or are familial in origin.

Astley SJ. [Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network](#). Canadian Journal of Clinical Pharmacology, Vol 17 (1) Winter 2010:e132-e164:March 26, 2010.

Astley SJ, Bailey D, Talbot T, Clarren SK [Fetal alcohol syndrome \(FAS\) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS](#). Alcohol & Alcoholism, 2000;35 (5):509-519.

Q: What kind of guidance or treatment would you say is effective for challenging behaviors?

Effective treatment starts with a comprehensive neuropsychological assessment that helps identify the patient's neurocognitive strengths and challenges. We want to construct interventions that play to the patient's strengths and work around their areas of challenge. For example, if a comprehensive assessment confirmed the individual has a significant language/communication disorder, talk therapy would not be an effective treatment approach. The comprehensive assessment may also reveal some of the root causes of the behavior challenges. Oftentimes our patients present with sensory abnormalities (over sensitivity to light, sound, touch) and ADHD, both of which can make it impossible for a child to sit still and pay attention in class. If these disabilities go unrecognized, their misbehavior can be misinterpreted by teachers and parents as volitional resulting in the child being removed from class or expelled from school, when to the contrary, they should be addressed with accommodations and interventions.

Q: Could you briefly discuss how your team diagnoses people with the behavioral issues but not the physical features?

FASD is defined by growth deficiency, a unique cluster of minor facial anomalies and structural/neurological/functional brain abnormalities in the presence of prenatal alcohol exposure. The only outcome that is specific to (caused only by) prenatal alcohol is the Rank 4 FAS facial phenotype as defined by the 4-Digit Code. All other outcomes that define FASD (growth deficiency, microcephaly, abnormal brain structure, seizure disorders and cognitive dysfunction) are not unique to (caused only by) prenatal alcohol exposure. Patients typically present with a plethora of other risk factors, in addition to their prenatal alcohol exposure, that could be causing their disabilities. When the FAS facial phenotype is present, one knows prenatal alcohol exposure had an adverse impact on that individual. In the absence of the FAS facial phenotype, it becomes less clear what role alcohol played, but our recent study found that prenatal alcohol exposure was the dominant risk factor explaining the largest proportion of variance in regional brain size and brain function.

Astley Hemingway SJ, Davies JK, Jirikowic T, Olson EM. [What proportion of the brain structural and functional abnormalities observed among children with fetal alcohol spectrum disorder is explained by their prenatal alcohol exposure and their other prenatal and postnatal risks?](#) Advances in Pediatric Research 7:41. doi:10.35248/2385-4529.20.7.41.