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## Spotlight On: National Organization on Fetal Alcohol Syndrome

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*Spotlight On:*  
**National Organization on Fetal Alcohol Syndrome**

*By: Joanna Pawlowska*

The key to a child's healthy development begins well before birth, with proper prenatal care. Described by some as the "cornerstone of a healthy pregnancy, labor, and baby," prenatal care is crucial to ensuring that a child's development progresses well, while also promoting healthy lifestyles that benefit both the expecting mother and the unborn child. Though the development of a child continues throughout each trimester, research has revealed that the child's most dramatic development takes place during the first trimester, thus making it the most vital period of a child's development. It is at this point in time when the child's brain, spinal cord, heart, organs, and various systems begin to develop. As such, this is also the time in which the child is most vulnerable to external dangers.

Though the importance of proper prenatal care is well established, a significant problem remains prevalent in contemporary society: the consumption of alcohol by mothers during pregnancy. According to most recent statistics from 2013, 1 in 10 women reported alcohol use during pregnancy, and 1 in 33 women reported binge drinking during pregnancy. Any amount of alcohol consumed by the mother during pregnancy passes easily through the placenta from the mother to the developing baby. However, developing babies lack the ability to process or metabolize the alcohol. Consequently, a baby in utero will absorb the alcohol at the same alcohol concentration as their mother.

Consumption of alcohol during pregnancy increases the risk of miscarriage and may lead to a number of diagnosed conditions, the broad spectrum of which are referred to as Fetal Alcohol Spectrum Disorders (FASD). FASDs range from neurodevelopmental disorders such as Alcohol-Related Neurodevelopmental Disorder (ARND), to birth defects like Alcohol-Related Birth Defects (ARBD), while the most severe disorder related to prenatal alcohol intake is Fetal Alcohol Syndrome (FAS). While the prevalence of FASD varies due to different criteria being measured, it is estimated that FASD affects between 2% to 5% of people in the United States and Western Europe. FAS is estimated to occur in between 0.2 and 9 per 1,000 live births in the United States.

Depending on the time and frequency in which alcohol was consumed during pregnancy, a child may develop a number of symptoms later in life. Further, while drinking a small amount of alcohol during pregnancy is not likely to cause physical abnormalities, it may cause a child to have future behavioral problems. Increased consumption of alcohol during pregnancy can lead to birth defects, including facial abnormalities and defects in the heart, kidneys, and bones. Children with ARND may have difficulty focusing, making judgments, controlling their impulses and could develop intellectual and learning disabilities. It is no surprise that children with the most severe form of FASD, FAS, may develop both birth defects as well as neurodevelopmental issues. Frequently, children with FAS develop issues with their central nervous system, such as problems with attention span and hyperactivity. Problems with vision, hearing and memory, learning disabilities, and difficulties with judgment and reasoning are also other potential side effects of FAS.

The National Organization on Fetal Alcohol Syndrome (NOFAS) was formed in 1990 to address the continuing existence of FASD occurring in society. This non-profit, international organization was founded by advocates seeking to help create a “global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with FASD.” NOFAS’s motto: “Alcohol and Pregnancy. No safe amount. No safe time. No safe alcohol. Period.” demonstrates the organization’s stance on the consumption of alcohol. While some organizations may claim that a glass of wine at dinner during pregnancy is acceptable, NOFAS endorses that any amount of alcohol poses a substantial risk because the alcohol passes from the mother to the developing baby.

The organization’s underlying methodology is based on three basic premises. First, the organization promulgates that FASD is a national health crisis, as it affects nearly 100,000 newborns in the United States alone. Secondly, the organization believes that society does not understand the magnitude of FASD due to the myths and misconceptions about the risk of alcohol use during pregnancy that remain in today’s society. Thirdly, NOFAS believes that in order for there to be a significant change in society, the stigma involving shaming and punishing mothers for consuming alcohol during pregnancy must be eliminated. Instead, the stigma must be replaced with the understanding that alcohol dependence is a chronic, progressive disease for which appropriate treatment must be sought.

NOFAS hopes to accomplish its mission through achieving twelve objectives, described by the organization as “prevent, educate, support, advocate, communicate, associate, fundraise, evaluate, overcome, lead, respect, and inspire.” To attain its goal of prevention, NOFAS seeks to reduce the incidence of FASD by implementing national, statewide, and community-based prevention campaigns. The organization also wishes to accomplish this goal by implementing alcohol screenings, intervention practices, and other prevention strategies into clinical practice at health care delivery sites.

NOFAS also seeks to increase public awareness regarding the significant risk and potential harm of prenatal alcohol exposure through education. NOFAS hopes to educate the public, practitioners, and policymakers about the risk of alcohol use during pregnancy and the resulting consequences. To achieve these goals, NOFAS promotes its message to the public through traditional, social, and entertainment media by disseminating news, information, and resources regarding FASD. Additionally, NOFAS seeks to implement the organization’s curricula by presenting practicums and providing informational trainings on FASD and best approaches for addressing the disorder for doctors, mental health service providers, and other public health professionals.

Commingled with the organization’s goal of education is NOFAS’s goal to advocate for those individuals affected by FASD. The organization has a network of 40 affiliates around the United States and works in collaboration with several U.S. governmental agencies. In partnering with various organizations, NOFAS hopes to cultivate relationships with federal, state, and local decision makers and policymakers in an effort to maintain NOFAS’s legislative and non-legislative policy agenda. NOFAS has even been successful in forming a Congressional Caucus focused on FASD. By reporting to the various constituents of the Caucus, NOFAS endeavors to advance FASD-related policies and legislation by promoting common legislative objectives.

Furthermore, NOFAS hopes to provide resources to people living with FASD and their caregivers. By maintaining a variety of traditional and social media outlets, the organization is able to expand its reach and provide materials to those seeking assistance. The organization provides referrals to various affiliate organizations, treatment facilities, and outreach programs. Additionally, through various campaigns such as the *Circle of Hope* and *Stamp Out Stigma* campaigns, the organization hopes to create a network that can support mothers, families, and individuals living with FASD.

Finally, NOFAS seeks to overcome the stigmatization surrounding FASD, particularly the shaming of women who drink alcohol while pregnant. NOFAS hopes to raise awareness that addiction and alcohol dependence are chronic issues that are at the core of FASD disorders, and that in order to prevent FASD, these principal issues must first be addressed through therapeutic intervention.

FASD is an unfortunate, global phenomenon that affects the lives of thousands of newborn children yearly, and continues to affect those newborns, mothers, and families throughout the remainder of their lives. However, through the extensive efforts of NOFAS and its wide reach into the public, health, and legislative spheres, raising public awareness of FASD and advocating for the implementation of preventative measures will undoubtedly decrease the prevalence of this tragic occurrence.

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