National Organization for Fetal Alcohol Syndrome


This report represents National Organization for Fetal Alcohol Syndrome's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

Mission:
NOFAS strives to prevent alcohol use during pregnancy and supports individuals and families living with Fetal Alcohol Spectrum Disorders (FASD). NOFAS educates the public, practitioners, and policymakers about the risk of alcohol use during pregnancy and FASD, the leading known preventable cause of brain damage, developmental disabilities, and birth defects, and a leading known cause of learning disabilities and behavioral problems in children, adolescents, and adults.
1. What are we aiming to accomplish?

NOFAS seeks to create a global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with Fetal Alcohol Spectrum Disorders (FASD). Founded in 1990, NOFAS is a public health advocacy, non-profit organization committed to preventing alcohol exposed pregnancies and supporting individuals, families and communities living with FASD.

2. What are our strategies for making this happen?

We have a variety of programs that help us achieve our objectives. Our informational clearinghouse develops and disseminates prevention messages and materials, responds to specific requests, and maintains a resource directory. NOFAS also develops print and electronic media regarding the dangers of drinking during pregnancy. NOFAS founded the Circle of Hope, an international peer mentoring birth mother’s network consisting of FASD birth mothers and women who used alcohol during pregnancy. NOFAS’s affiliate network allows them to share information, promote primary prevention, and further the policy agenda. NOFAS also reaches many thousands of professionals and advocates each year through a range of presentations and exhibits sponsored by NOFAS or as part of other conferences and meetings.

3. What are our organization's capabilities for doing this?

A small staff consisting of four multitalented permanent members, active and distinguished board and advisory members, and numerous student interns and professional volunteers face the complexities and challenges of the NOFAS mission with high morale and optimism. The largest government affairs legal firm in Washington, D.C., Patton Boggs LLP has provided pro bono services to NOFAS since 1998. The services are not limited to legal advice (in 25 years NOFAS has never faced a legal claim or grievance) but are focused on government affairs, court filings and briefs on behalf of individuals living with FASD, and other invaluable benefits that have enhanced NOFAS credibility. NOFAS also has an affiliate network with 40 members, helping to spread.

4. How will we know if we're making progress?

NOFAS maintains a dashboard of more than thirty quantitative, programmatic measures that are closely monitored, help determine programmatic direction, and monitor progress. From a qualitative standpoint, NOFAS contracts with an independent evaluator who assists in the development of surveys and the collection of outcomes data. The evaluator interviews NOFAS consumers and stakeholders and prepares outcome-based vignettes documenting specific results. Findings demonstrate that NOFAS meets its programmatic objectives and programs are efficient and effective. While assessment of NOFAS programs and activities is positive, measuring the progress of the organization’s overarching goals of reducing prenatal alcohol use and preventing FASD are mixed. Some of what we do know is: • More professionals are trained to diagnose and treat FASD (As a result, data shows an increasing prevalence of FASD over the past ten to 20 years.) • The proportion of women who drink any alcohol during pregnancy or who are heavy or binge drinkers has remained fairly constant through the past decade. • Fewer woman are receptive to guidance such as the Surgeon General’s advisories, preferring to gather information from multiple sources and reach their own conclusion.

5. What have and haven't we accomplished so far?

Since NOFAS was founded in 1990, it has responded to tens of thousands of specific requests for information and referrals.
NOFAS developed the first FASD curriculum for medical and allied health students, presented continuously since 1994. In addition to developing the first FASD affiliate network, with 40 members, NOFAS also founded the Circle of Hope, the first international birth mothers network. NOFAS has implemented alcohol and FASD Screening and Brief Intervention (SBI) in over 50 federally qualified community health centers in eight states. NOFAS has helped author and enact numerous pieces of federal and state legislation and has successfully advanced many policy initiatives including the expansion of diagnostic codes for the condition in the 10th edition of the International Statistical Classification of Diseases and Related Health Problems (ICD-10), the addition of FASD in the World Health Organization’s guidelines for pregnant and substance abusing women, and the provisional inclusion of Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5). NOFAS has also submitted friend of the court briefs on FASD-related issues including to the Supreme Court of the Unites States. There are several ongoing challenges to reducing alcohol consumption during pregnancy and ensuring that all affected individuals have access to appropriate diagnostic and treatment services. A lack of reliable and comprehensive incidence and economic data and untrained medical and behavioral health professionals are two considerable barriers that have yet to be overcome. Also, the role of alcohol as part of the lifestyle for many results in an instinctual resistance to messages recommending abstinence from alcohol in any circumstance among some.