

# NOFAS

## 2015 Affiliate Network Guidelines



National Organization on Fetal Alcohol Syndrome



**National Organization on  
Fetal Alcohol Syndrome**

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Tom Donaldson

January 1, 2015

Dear Prospective NOFAS Affiliate,

On behalf of the National Organization on Fetal Alcohol Syndrome (NOFAS) thank you for your interest in the NOFAS Affiliate Network, and for all you have accomplished in your efforts to prevent Fetal Alcohol Spectrum Disorders (FASD) and care for individuals living with the disabilities. FASD is a tragic, unnecessary, and pervasive disorder that demands greater public and private attention and investment. NOFAS believes that the best way—likely the only way—to broadly fulfill the promise of prevention and meet the needs of all children and adults with FASD is to work collectively.

The NOFAS Affiliate Network was established 14 years ago to establish lines of communication among FASD colleagues and organizations, share resources, unify core values and messages, and turn up the volume on the appeal for attention and resources. There are numerous recent examples of success among other public health issues when like-minded groups collaborate. At the same time those in the FASD community continue to face significant challenges in overcoming misconceptions about the risk of alcohol use during pregnancy and a lack of adequate resources.

Fortunately, the international FASD field consists of many dedicated and effective advocates and organizations. By working together in pursuit of a few key but important goals our achievements can grow exponentially, while each affiliate member organization maintains its identity and autonomy. NOFAS believes that networks are the most effective way to disseminate a message when faced with limited resources, and to advance the cause within the medical, education, policy, and criminal justice communities, not to mention among the general public.

Thank you again for your interest in NOFAS and the affiliate network.

Sincerely,

Tom Donaldson  
President

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# **NOFAS Affiliate Network**

## Goal

The primary goal of the NOFAS Affiliate Network is to unite organizations, associations, tribes and other entities addressing FASD into an international network. The network functions as a coalition and each affiliate organization maintains its independence and identity.

## Objectives

The objectives of the network are to:

- ❖ share information and resources
- ❖ build the capacity of the FASD constituency and increase advocacy activity
- ❖ set common goals and messages
- ❖ seek consensus on the multi-faceted issues in the FASD arena
- ❖ collaborate on a range of public health and advocacy programs and services
- ❖ leverage resources
- ❖ strive to overcome the stigma and boundaries associated with the disorders

## Principles

NOFAS and each affiliate organization respects and does not directly or indirectly criticize or otherwise impugn:

- ❖ the identity, culture, policies and traditions of each member organization
- ❖ the image, reputation and public standing of each member organization
- ❖ individuals with FASD and their biological mothers and all family members and caregivers

## Benefits to Affiliates

- ❖ Free and discounted materials.
- ❖ Participation in the annual affiliate summit.
- ❖ Monthly affiliate conference call.
- ❖ Free access to the Foundation Center Online and NOFAS Affiliate Webinar Series
- ❖ Free or discounted attendance to NOFAS events and activities, including conferences, benefits and briefings.
- ❖ Opportunity to apply for a micro grant.
- ❖ Members only Facebook page.
- ❖ Opportunity to serve in leadership role with the affiliate network.
- ❖ Technical Assistance consisting of both strategic guidance and direct assistance with tasks such as developing a logic model (goal, objectives, outcomes), securing and maintaining non-profit status, grassroots advocacy, fundraising and proposal development, public awareness strategies, materials and website development, and nonprofit governance and administration including incorporation and IRS filings.
- ❖ Promotion of your organization and programs through the NOFAS website, *NOFAS Weekly Roundup* e-newsletter, and social media sites.

### Eligibility

Any organized entity worldwide with either a sole or significant focus or a specific, permanent program on FASD may be eligible to join the affiliate network.

### *Business Structure*

In the United States any incorporated non-profit organization, American Indian/Alaska Native Tribe, government entities or University program is eligible. Organizations must be incorporated and in good standing in their state. They must either have 501 (c)3 status or have an application seeking charitable status pending with the Internal Revenue Service. Non U.S. entities organized as charitable or public service organizations under the guidelines of their country may also join. Please contact NOFAS with any questions about eligible business structures.

### *Minimum Standards*

As of January 1, 2015, to become and remain a member of the affiliate network an organization or other entity must maintain the following minimum standards:

1. Incorporation – Organizations must be incorporated and in good standing. This requirement will not apply to university, state agency, or tribal-based entities.
2. Non-Profit Status – Organizations must, 1) have tax-exempt status, 2) have applied for their status, or 3) be working on the application seeking tax-exempt status (the application must be submitted by March 31, 2015). This requirement will not apply to university, state agency, or tribal-based entities.
3. Primary Contact – Each organization or other entity must name an individual as its authorized agent. This person will represent the entity in the affiliate network.
4. Telephone Number and/or Email Address – Organizations and other entities must have a publically accessible telephone number and/or email address (The email address must be on the organization's website domain. For example, the NOFAS domain is **nofas.org**; the NOFAS website's Internet address is **www.nofas.org**, and the primary email address is **information@nofas.org**). Calls may be answered by voice mail and emails may be responded to with an auto reply message. The telephone greeting and/or email response must identify the organization and provide instructions for submitting an inquiry. The organization must respond to all inquiries, OR refer requests to the NOFAS clearinghouse or other resource.
5. Bank Account – Organizations must have a corporate bank account. This requirement will not apply to university, state agency, or tribal-based entities.
6. Website and Domain – Organizations and other entities must maintain an Internet website on a web domain or address owned by the organization, consisting of at least: 1) a description of the mission, objectives, programs/activities, 2) internal or external link(s) to information and resources, 3) contact information, and 4) a merchant account. Social media pages, such as Facebook or Twitter are encouraged but are not required, and do not constitute a website.

7. Inquiries/Materials Fulfillment – Organizations and other entities must either respond to telephone, email, and/or website requests for information or materials, or refer requests to NOFAS or another resource.
8. Contact Database – Each organization must maintain a database of contacts, members, supporters, etc. The database can be as basic as an Excel file or other electronic format that stores information.
9. Affiliate Network Widget – Affiliate members must display the to-be-developed widget on their websites (it does not have to be on the homepage). The widget or icon will be linked to the list of affiliates and information about the network.
10. Each year, members must conduct at least one FASD-specific activity such as a support group meeting, public awareness event, briefing, training, fundraising event, etc.
11. Each year, members must participate in at least one affiliate activity such as attending the annual summit or participating on a conference call or one of the affiliate committees.
12. So that NOFAS may promote affiliate organizations and their work, annually provide NOFAS with:
  - ❖ Copies of all publicly distributed materials developed by your organization
  - ❖ A brief summary of all programs and activities
  - ❖ Photographs of your organization at work.

#### *Existing Affiliate Organizations*

Another consideration for eligibility is geographic vicinity to an existing affiliate organization. If an existing affiliate organization meets the minimum standards outlined above, **an applicant organization based in the same state must obtain the consent of the existing organization(s) to apply to the network.**

Before applying to the NOFAS Affiliate Network organizations or other entities should contact NOFAS to determine the status of any existing affiliate organization(s) in their state. If there is no existing affiliate organization in the state, or if an existing affiliate organization does not meet the minimum standards defined above, an applicant organization may apply directly to NOFAS without obtaining consent.

Member organizations that deny permission to other organizations or entities to apply to the network are encouraged to discuss potential collaborations with such organizations or entities.

These criteria shall also apply to organizations and other entities outside the United States.

#### *Mission Compatibility*

Although NOFAS affiliates are self-governing and autonomous, it is important that organizations joining the affiliate network have a mission that is compatible with NOFAS. The NOFAS mission includes the following key objectives:

- ❖ Raise awareness about the risk of alcohol use during pregnancy
- ❖ Prevent FASD
- ❖ Support anyone directly or indirectly affected by FASD
- ❖ Build and activate a constituency
- ❖ Reduce guilt and stigma

Any organization motivated by one or more of these principles, and who does not support goals or objectives contrary to these values, is an ideal candidate for affiliation with NOFAS. Affiliates do not need to adopt the NOFAS mission and they are not limited to the goals stated by NOFAS.

Organizations that meet the four eligibility criteria are encourage to apply to the network.

Application Process

The NOFAS Affiliate application and required attachments may be submitted to NOFAS at any time.

Name

Affiliate member organizations are autonomous and keep their own name and other branding mechanisms, including logos and messaging.

Dues

Beginning in 2015, the affiliate network is instituting a progressive, annual dues structure based on the member organization’s FASD-related revenue:

<u>FASD-Related Revenue</u>	<u>Annual Dues</u>
\$0 - \$50,000	\$25
\$50,001 - \$100,000	\$50
\$100,001 - \$250,000	\$100
\$250,000 and above	\$200

The annual dues will be payable by March 31.

Leadership

The affiliate network is governed by an eight-member Executive Committee. Committee members serve two-year terms, except for the charter members of the committee who are serving staggered one, two, and three year terms. Members may serve as many as three consecutive terms. NOFAS maintains a permanent seat on the Committee. The current leadership is:

<u>Member</u>	<u>Affiliate</u>	<u>Term</u>
Leigh Tenkku Lepper	NOFAS-Missouri	2016
Eileen Bisgard	NOFAS Colorado	2017
Ajeet Charate	Trinity Services, Inc.	2015
Peggy Combs-Way	SoCal NOFAS	2016
Sr. Suzette Fisher	Double Arc	2017
Amy Hendricks	NC Fetal Alcohol Prevention Program	2015
Jerome Romero	FAS Prevention Program, University of NM	2016
To Be Determined	NOFAS	Permanent

The Executive Committee election and term years begin in June. Nominations to be included on the slate of candidates for the June election should be submitted to NOFAS from May 1 - 31. Nominees must be either a staff or board member of a member organization. Self nominations are allowed. Members are elected by a vote of the full affiliate network membership with each member in good standing having one vote.

The powers vested in the Executive Committee include:

- ❖ Determining the eligibility of applicants
- ❖ Voting on applications to join the network
- ❖ Ruling on member compliance with guidelines
- ❖ Revising the affiliate network guidelines
- ❖ Planning the annual affiliate summit
- ❖ Determining the use of funds from dues or other sources
- ❖ Establishing and prioritizing programmatic and legislative/policy initiatives

#### Authorized Agent and Address

Each affiliate will name a board or executive staff member to serve as their authorized agent. This person will conduct all official correspondence with NOFAS. Tom Donaldson is the authorized agent for NOFAS. The authorized affiliate address should be the official address of the organization. Each affiliate organization is expected to have its own authorized agent and address.

#### Annual Meeting

NOFAS hosts an annual affiliate summit. Affiliates are strongly encouraged to send at least one member to the summit.

#### Policies and Position Statements

NOFAS realizes that although affiliate organizations have compatible missions and programs our policies may not always be in agreement. NOFAS periodically releases organizational policy statements on issues such as the acceptance of funds, the composition of the board of directors and the NOFAS position on various federal, state and other legislation and policies. As the legal authority of NOFAS, the Executive Committee of the Board of Directors is responsible for governing the organization and ratifying all policies.

NOFAS will share all organizational statements with affiliates. Affiliates are under no obligation to adopt, sponsor, or consider any NOFAS statement. However, affiliates are welcome to adopt any or all NOFAS policies, position statements, and guidelines.

NOFAS encourages affiliate organizations to share their position statements and policies with members of the network, as well as to thoughtfully and appropriately share their thoughts or questions with NOFAS about any of its policies.

### Donors

NOFAS and affiliate organizations have a range of corporate, foundation, individual, government, and other donors. Neither NOFAS nor affiliate organizations should knowingly solicit another organization's donor(s) without first discussing the donor with the organization receiving funding. NOFAS lists its current donors on its website.

Donors give funds for a variety of reasons, most often because of a personal relationship. Some donors give to NOFAS or an affiliate organization and they would not consider giving to another member of the affiliate network. Other donors may specifically focus on FASD or for other reasons would contribute to multiple members of the network. It is imperative that organizations communicate before approaching other organization's donors so as not to interfere with existing relationships and to determine if it is appropriate for multiple organizations to approach a common donor. Generally, if an entity has previously cultivated a specific funding source, it should be reserved for that entity until such time as the relationship is no longer valid. Organizations should respect other organization's wishes regarding donors.

Often, there are many funding sources within a single corporation or other entity. By communicating, organizations can help each other identify a donor in their geographic region or who may be interested in their specific program.

### Ending Affiliation

The relationship between NOFAS and each affiliate organization is considered to be permanent until terminated by one or both parties or superseded by a subsequent agreement. Either NOFAS or the affiliate organization may terminate the affiliate agreement at any time by submitting a written notice to the subject organization's authorized agent.