

## **Establishing a Support Group for Parents and Caregivers of Individuals with an FASD**

If you Google “starting a support group,” you will find many websites that give suggestions as to how to establish a support group in your community. The following suggestions are short to give you the impetus to get started without reading loads of websites!

### ***Getting the Word Out***

Start doing this at least 3 months before you actually plan on starting your group. Because of the lack of diagnosis for so many individuals, finding a minimum critical mass of 3 others takes time so do not disappoint yourself and try to get started as soon as you decide to start a group. It is not uncommon for a support group to take several years to be firmly established.

First, be clear about what you want to say in your PR materials and keep a template that you can adapt to various forms of media. One might be an email to organizations and another, a flyer. Think through what you want to say on a flyer and in emails for at least a week before sending out anything!

- Consistency across media forms is important
- Concise emails will be more likely to be read than long rambling ones!
- Spell out Fetal Alcohol Spectrum Disorder (don't just use the acronym) and use a phrase such as “those exposed to alcohol in utero” so people actually know what this means.
- Have a contact name, phone number, and email address
- Since you are just starting to get the word out, indicate that the date/time and place is TBA. You can change this after you have decided on a firm time and place for subsequent mailings and flyers after talking with those who will actually come to the group.
- Emails to professionals and others can have more substance (for example, by including your reason for starting the group), but flyers will get more attention if different bolding, italics, colors, etc. are used with few words. Colored paper will gain attention on a bulletin board.

### **Potential groups/individuals to contact**

- Diagnostic Clinics
- State Coordinators for FASD
- Health specialists
  - Pediatricians
  - Neurologists
  - Geneticists
  - Psychiatrists
  - Neuropsychologists
  - Psychologists
  - Counselors/therapists/social workers
  - Departments of health
  - Mental health association
  - Health department
  - Speech therapists

- Occupational therapists
- Physical therapists
- Department of Social Services  
(A large number of children in foster care have behaviors of those with an FASD even if they have not been diagnosed)
- Child Development Service Agencies
- Faith Centers
- Exceptional Children/Special Education Staff
- Online FASD groups, even if they are national or international
- NAMI
- The Arc
- Vocational Rehabilitation
- Adoption Agencies
- ECAC (through trainings, website, etc.) in NC
- International Adoption Groups
- Local newspaper through an article, letter to the editor, and/or calendar section
- Disability Rights

You will think of more contacts as you do your errands, take your children to school and appointments, etc., so save a list of contacts that you can add to over time. You will want to send out notices about every 3 months to keep the group on people's radar.

Work on sending emails and distributing flyers for a certain amount of time each day or week.

### ***Choosing a Meeting Place***

Consider potential charges for room usage, privacy and confidentiality, adjacent room for children, central location, etc. You may want to choose a location after you find out where those initially inquiring about the group live. Remember that you have no control over how long flyers are posted, so changing the location is not a good idea unless it is clear that the location you initially chose is not good for a specific reason.

Having child care during the meeting is a definite plus and will boost your attendance. Those 14 and older can gather together and play games or watch a movie together in an adjoining room. You can contact local day care centers to find a worker who would be interested in providing care to younger children during the meetings; the advantage of this, aside from experience with children, is that the person will have had a criminal background check. You will need to educate the person about FASD and about being firm and not allowing "things" to get out of hand! Currently, we pay someone \$20 for about a two hour span of time and the cost is shared by the families needing the care. Ask families to bring coloring books, games, videos (assuming you have a TV and VCR available), etc. to keep the children busy.

- Faith Center (this works great if you can use the nursery since there are some toys already there!)
- Public Library (many charge now)
- Community Center
- Community College Space

### ***Choosing a Day/Time***

The reality is that no one day and time period is good for everyone, but there are a few considerations to take into account:

- Wednesday evenings tend to be church nights! Avoid!!
- Thursday evenings are when people start winding down for the last day of the school and work week.
- Saturday mornings are often filled with sports.
- I have found that eventually those who are truly interested in the group will make it a standing commitment on their calendars. Nonetheless, there are always crises that interfere with attendance!

### ***Adding Group Activities***

This summer we planned a graduation picnic at a local lake for two of our “kids” who graduated from high school. It was fun, allowed us to get to know each other in another context, and was less hurried than our monthly meetings...so we had two more picnics. Now there has been the suggestion that we continue to get together in a social setting every couple of months.

Prepared by Kathy Hotelling, founder of the Triangle Area Support Group in North Carolina. For more information or to make suggestions for additions, please feel free contact her at [kathyhotelling@gmail.com](mailto:kathyhotelling@gmail.com) or at 919-265-3390

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