## How To Start A Support Group

It is not the size or frequency of the meetings that makes a support group effective. What makes them effective is that they exist. Our message boards are just an internet support group. However, support groups that allow us to meet people and make eye contact and have real-time conversations are different. We need these connections, we crave these connections. Let's make those connections.

If you decide to move ahead and make a group, please let me know. We do have a yahoogroup for support groups, though I am thinking that a newsletter might work better. So please email me your name and location, so I can direct others to you. Also, please email me (claudia@ubpn.org) what you have decided to do. Any ideas you use, can help others.

If you want to start the support group, here are some things to consider:

- 1. How often do you want to meet?
  - a. often- monthly, weekly, quarterly
  - b. not so often once a year

if it is once, then perhaps you want to tie it into an event: awareness week, Halloween, a spring fling...

- 2. What style of meeting do you want?
  - a. potluck at someone's house

whose house?

indoor or outdoor bring food or buy food assign food and supply duties

- b. park or community center
  - get permits, if necessary

bring food or buy food

are there rules regarding food at that location?

c. big gathering, that costs per person, a certain amount decide on location: museum, gym center, pool talk to caterers

where will you eat at the location?
in groups or all at once
will there be other people at that location or
just your group?

## 3. Who is coming?

a. families

how many people
activities for kids
sand art
coloring
"camival games" (can be rented)
pool or kiddie pool
seating for kids (rent kid sized tables and
chairs or borrow
arts and crafts
field day-type games (three legged races, etc)

b. just adultsparents of bpiadults with bpic. obpi or tbpi or both

- 4. Do you want a speaker(s)?
  - a. doctor
  - b. lawyer
  - c. therapist
  - d. toy reps (discovery toys)
  - e. psychologist
  - f. financial planner
- 5. How do you plan on financing?
  - a. potluck means that the cost is only for mailings and whatever you are bringing
  - b. a big event inevitably means more out of pocket costs for the organizer

finding the location money for securing location paying for food, tickets etc. before event getting a dedicated checking account (money must go in to start the account)

will recoup these costs (mostly) in the end

c. fundraising is not really an option, unless you are 501(c)3.

your friends and family can "pay" for things, though

- 6. Do I have to register as a non-profit in my state to be a support group?
  - a. no, you do not need to be a non-profit or 501(c)3 to be a support group. However, if you are not a non-profit organization, you can't do fundraising. You can, however, re-coup any costs for an event
  - b. if you want to become a non-profit, contact and attorney and accountant to do this
- 7. Does ubpn have charter organizations?
  - a. no, ubpn looked into Chartering and decided that a more informal style of support group was more in keeping with our mission
  - b. you will be a support group unto yourself, but we will help you as much as we can
  - c. once you decide you want to become a support group, let Claudia know (claudia@ubpn.org) and she will help you out
- 8. How do I find other families in the bpi world?
  - a. ubpn's registry
  - b. ubpn's message board and events site
  - c. give flyers to your ot, pt, aquatherapist, speech therapist, bpi specialist and anyone else who helps your child and might come in contact with other bpi families
  - d. ask your therapist if they would give flyers to their therapist friends, to spread the word
  - e. use the phone book-call ot and pt offices and ask if they would put up flyers
  - f. take out an ad through local newspapers (smaller newspapers are now usually owned by large companies, you can often pay one price to put the ad in several local

## papers

## 9. Ask for help

a. don't be afraid to ask someone to help you, even if they are not bpi-related. Your non-bpi friends probably want to do something to help you and would be happy to stuff envelopes, make their special 3-layer dip or decorate your house.

b. there are always people who want to help and be involved, but don't want to be in charge. Use them. Give them jobs to do. And give them deadlines.

c. ask places of business to help

bagel stores bakeries restaurants community centers places of worship small toy stores

anywhere you "do business"-ask them to *give back.* Since your group is local, you give them recognition for their donation (this increases their business)

Remember, you can always contact me if you have any questions.

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