

ORGANIZING A SELF-HELP GROUP

Starting a local amputee peer support program is not a easy thing to do. You will be competing with the larger charities for donations and generally speaking, the leader of a local support program is responsible for holding the group together and doing most of the work. However, the rewards are many and, if you are willing to volunteer many hours, the group might be successful and in a position to help a large number of amputees seeking guidance and direction. Most importantly, the group (and you) will become the information source for your community regarding services, funding sources, rehabilitation facilities, peer support, prosthetic services, and recreational activities.

The following is a suggested outline or road map on the steps necessary to begin an amputee (or any other) peer support group:

GETTING ORGANIZED:

- Set up a place for maintaining records, information, financial data, mail list, etc. Initially, this can be done from your home. But, as the group grows, you might be able to approach other disability organizations for a donation of office space. Hospitals, rehabilitation facilities, and independent living centers have an interest in the support group's success and may "donate" office space for the group, as well as a meeting room.
- Select a date, time, and place for the first meeting (a few months out) and put together flyers to hand out to prosthetic facilities, orthopedic surgeons' offices, hospital social work departments, and rehabilitation facilities to generate interest in the group.
- Remember, the meeting place must be accessible for wheelchairs and have enough handicap parking spaces to accommodate the group members.
- Organize a plan of action and set goals you would like to see accomplished to serve the needs of local amputees and the professionals who serve them. (Prepare this idea in a statement and outline what your plans are and how they might be a possible solution to the problem.)
- Have this outline prepared in a package which you can present to persons who might be willing to serve on your initial Board.
- Hold your first meeting.
- Consider initiating a Share-a-Ride program for those who will need assistance to attend.

DEVELOPING A BOARD OF DIRECTORS:

- Begin identifying possible board members. Approach the individuals and ask if they would be willing to serve at least one year. At the end of their term, the board members should be willing to find a replacement or continue serving.
- In the first board meeting, decide what the group's main priority is in serving the amputee. Are you primarily going to be a support group, an information center, provide hospital visitation, or what? Get a handle on what you are going to do and try to set some time frame on your goals.
- Elect group/board officers. Decide how the responsibilities are going to be delegated. The work should be delegated as evenly as possible. One of the main reasons support groups fail is

because of burnout on the part of one or two of the members trying to do everything.

- Host a social meeting of your contacts and amputees to begin educating the group of your direction, your goals, and what you need from them. At this time, try to get your well-adjusted amputees involved as volunteers.
- If the group has peer counseling as a goal, AAF has a training program and written workbooks to train individuals how to talk with new amputees (or any other disability). The course should be lead by a rehabilitation counselor or social worker and should take approximately three days. Social workers and rehabilitation counselors are well-versed in available local, state, and national resources, service agencies, transportation, housing, medical services, prosthetic facilities, etc.
- Approach a printer to donate the printing of business cards, letterhead, envelopes, brochures and newsletters. Locate a successful office supplier for supplies. Often these operations go hand-in-hand. Be sure to come up with an ingenious way to acknowledge their support/donation.

KEEPING THE GROUP ACTIVE

- As stated above, one of the biggest causes of support groups dissolving is burnout by the one or two people who do most of the work. To avoid this, the group should continuously recruit new members and enlist their help with projects.
- Ask local TV stations(s) and radio station(s) to run public service announcements about your group for public awareness.
- Think about printing a newsletter and placing advertising within to help cover the cost of distribution and printing, if necessary.
- Find a sponsor (a rehab facility, a prosthetic facility, etc.) that will help cover the cost of books, brochures, self-help guides and other materials. You will want to have a good supply of educational items to give the new amputees you encounter. Offer to place your sponsor's name on the back of all this material; have a stamp made which says:

"COMPLIMENTS OF:"

Sponsor Name

Address City & State Phone Number

"SUPPORTING THE SERVICES OF:"

Name of Your Local Group

- All materials and information in the AAF office is available to your group. This includes initial kits, which may be reproduced, letterhead, videotapes, self-help guides, etc. These items cost our foundation and we expect that after your initial package you will order these through us or directly through the supplier or publisher.
- At meetings, we suggest you " pass the basket " at the end of each meeting and request that everyone who can afford to, give a dollar or so to help cover the cost of cokes, coffee and the meeting space, if applicable.

NONPROFIT STATUS:

- If the group wants to raise money and be able to give a tax-deductible donation receipt, you must apply and be granted charitable foundation status by the IRS. This classification is known as a 501(c)(3) nonprofit organization as designated by the IRS. We suggest the group start out as self-supporting and, if the need arises after a year or so, then apply for nonprofit status with the IRS. If the group is peer lead and only provides information and peer support, nonprofit status may not be necessary. More information on how to apply for nonprofit status can be found on the IRS website: www.irs.gov.

CONCERNING FUND RAISING:

- Whether or not the group decides to apply for nonprofit status through the IRS, donations are only deductible after 501 (c)(3) status is granted. To be able to fund raise, the group must follow and meet the guidelines for charities and nonprofits as allowed by the IRS. Visit www.irs.gov/charities and investigate what your group needs to do in order to raise money.
- There are many resources in your community that can assist with your group and finding sponsors. The Chamber of Commerce should have a list of top local businesses which are in the area. Send the businesses your statement of goals and request that they assist you financially with this needed service.
- Selling advertising in your newsletter is a great way to offset the cost of printing and mailing.
- Look into grant opportunities. Contact the Grantsmanship Center for various helpful publications.
- Items such as desks, computers, chairs and other office furnishings can be donated and are tax deductible.
- Get the local newspaper to write an article about the formation of your support group and its purpose. It is best not to include your personal address or phone number, due to responses and attention you may receive which are undesirable.
- Offer to present your program to local clubs and organizations; this is an excellent opportunity to let the community know about the organization and recruit new members and donations. The more contacts made, the greater the exposure and chance for success.

- The group will need to locate an accountant or bookkeeper that can help with the annual IRS reporting and to help you with keeping your financial records straight. Nonprofits that raise less than \$25,000 in the fiscal year do not have to file form 990 (the nonprofit tax receipt) However, always consult with a tax advisor on a yearly basis. Also find out if there are any local and/or state filing requirements with your Secretary of State's office and the Attorney General's office.