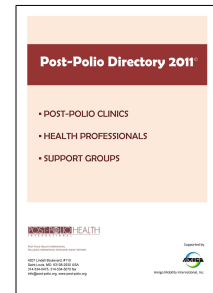


Post-Polio Support Group Philosophy and Guidelines

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Post-polio support groups sprang up in the 1980s after polio survivors attended the early [post-polio conferences](#) organized by Post-Polio Health International (then *Rehabilitation Gazette*). The organization's first [Post-Polio Directory](#) is dated 1985. In 1988, the organization developed "Post-Polio Support Group Philosophy, Guidelines and Resources" and has modified it over the years as needs and resources changed. Post-Polio Health International continues its role as the motivator for and connector of post-polio groups around the world.



PHILOSOPHY

The goal of a support group is to empower its members with the tools necessary to make adjustments needed to continue a life of dignity and independence.

Support group(s)...

- ... share a common health concern.*
- ... govern themselves and their agenda with success dependent on each member's feelings of ownership.*
- ... may use professionals as resource persons but not as leaders.*
- ... provide non-judgmental emotional support.*
- ... gather and share accurate and specialized information.*
- ... have membership which is fluid; newcomers are helped by veterans and become veterans who may outgrow the need for a group.*
- ... have a cause and actively promote that cause.*
- ... increase public awareness and knowledge by sharing their unique and relevant information.*
- ... charge small or no dues for involvement and typically struggle to survive.*

PURPOSES

The purposes of a support group should be clearly stated and reviewed periodically. PHI suggests several options below.

- Exchange information, ideas and resources.
- Foster self-help.
- Provide knowledge from health and other professionals.
- Have a good time.
- Educate to become better health care consumers.
- Identify and disseminate information on the late effects of polio.
- Offer a supportive environment for sharing common experiences and concerns.
- Provide reassurance and emotional support to polio survivors and their families.
- Discuss feelings and needs of the members.
- Provide fellowship with non-judgmental support from other polio survivors.
- Eliminate feelings of isolation.
- Identify community resources to address the needs of polio survivors.

- Provide an exchange of information and ideas between polio survivors and among polio survivors, health care providers, legislators on local, state and national levels and the public.
- Collect, compile and disseminate information of specific or general interest to polio survivors, the medical community and the general public.
- Advocate for the rights of polio survivors and all people with disabilities.
- Collaborate with other organizations dedicated to similar objectives.
- Promote research into the diagnosis and cause of the late effects of polio and post-polio syndrome.

FIRST MEETING

All it takes is a phone call or an email by one or more polio survivor(s) to initiate a meeting which could take place in a private residence. Others can be reached by arranging announcements on local TV and radio and by contacting local newspapers and disability-related organizations. Remember to contact Post-Polio Health International (PHI) when you start a group, and we will notify the readers of the *Post-Polio Health* and place the announcement on www.post-polio.org and Facebook.



One strategy is to start with meetings on Saturday morning especially if survivors are working, and suggest they bring a brown bag lunch. Interested persons will stay and form a core upon which the group will grow.

Set a pattern for future meetings with name tags and a sign-in list for attendees to provide name, address, phone number and email address.

Open the meeting by asking each person to introduce him or herself and tell one pre-selected fact about having had polio (e.g., the year polio was contracted and which hospital or respiratory or rehabilitation center where treatment was undergone). Immediate ties between survivors will be established. *A word of caution:* This invitation can “open the flood gates” for some survivors. Model how the introduction should be done and be prepared to insist on limited comments. Be sure to assure all that there will be time for telling their story later, because that is one purpose of the group.

All aspects of the polio experience need to be addressed in planning programs for meetings – the physical, emotional, spiritual, social, economic and political. At the first meeting, distribute a page of topics (see ideas on pp. 3-5) to be covered in future meetings and ask those in attendance to pick the ones that interests them most. Periodically, ask those in attendance and those who don't attend regularly what topics are important to them to be sure the group's programs meet their needs.

FUTURE MEETINGS AND SPIRIT

Keep the meeting informal, casual, friendly and small. A group larger than 30 people inhibits sharing of information and discussion. (Remember it takes time for polio survivors to feel at ease and to establish a foundation of trust.) For large metropolitan areas, a solution would be to offer a formal presentation by a special speaker once every quarter or every other month to the larger group. Then organize smaller group meetings by geographic location that meets during the other months.

Newcomers should be greeted with a sincere and friendly welcome. Do not “scare off” newcomers with excessive expectations of personal involvement. It can be very difficult for someone to attend the first meeting. While a positive atmosphere should be encouraged,

discussion of the negative aspects of having had polio should not be denied. It is reality and some survivors have never verbalized the past. Members should be free to express and discuss feelings such as anger, fear and grief. If the problems of one individual do not get resolved and his/her issues continue to overshadow those of others in the group, the leaders should consult a behavioral health professional for advice on how to handle the situation.

Do not forget to plan time for fun! Include family members, health professionals and volunteers. Organize occasional social events such as a party during the holidays or a summer picnic.

PLACE

Select a location that is completely accessible. Check the accessibility of the meeting room, restroom facilities and the garage so that it accommodates vans with raised roofs and with side entrances.

The purpose of the meeting can determine the setting, but try to avoid an auditorium and a lectern. A circle is more inviting, but optional seating should be available for those who want to observe. Remember to make space for wheelchairs and scooters by removing chairs throughout the room. Don't seat them all up front or all in the back, but offer them choices of places to "park."

Several possible meeting places are listed below. Many are offered free of charge.

- Community centers/libraries
- Condominium public meeting space
- Independent living centers
- Places of worship
- Private homes
- Recreation/wellness centers/YMCA
- Rehabilitation centers
- Restaurants

SPEAKERS/PROGRAMS

Sharing meetings are very important to individual survivors so they can tell their story and ask questions. These meetings also offer others an opportunity to describe what has worked for them. Support groups are the place people can ask for help, receive help and offer help.

Sharing meetings help develop the group's *esprit de corps*. It is helpful to have these meetings that are an open discussion facilitated by a caring but strong person, who can "enforce" the "rules of discussion" established by the group.

The speaker's warmth and concern and knowledge are of the utmost importance. A physician, physical therapist, etc., who had polio is an ideal presenter. Invite speakers who will talk *and* listen, and not only pontificate. Plan for approximately 20 minutes of opening remarks and then allow 45 minutes of questions and discussion. Don't forget that many of the polio survivor attendees will have excellent abilities and talents and can be speakers, too.

Possible topics are ...

- Aging with a disability
- Architectural/attitudinal barriers to being independent

- Assistive technology/equipment (visit a home health company, i.e., vans, wheelchairs)
- Body work (massage, adapted Tai Chi and yoga, etc.)
- Coping strategies for people with disabilities
- Caring for your caregiver and/or family members
- Collaboration with your physicians and among your physicians
- Causes and treatment of fatigue/weakness/pain
- Disability culture and identity
- Do-it-yourself aids
- Educational options
- Energy conservation, pacing
- Equipment show-and-tell
- Exercise for polio survivors
- Falls and prevention of falls
- Furniture, fashion, and accessories for people with disabilities
- Governmental programs (e.g., Medicare and Medicaid) provisions in your country, state
- Handling stress, distress
- Housing options
- Know your anatomy – basic terms
- Living Wills and Durable Power of Attorney for Health Care
- Potluck of healthy foods
- Post-polio syndrome
- Provisions of the Convention on the Rights of Persons with Disabilities
- Provisions of the Americans with Disabilities Act
- Respiratory problems and treatment
- Sharing time
- Social Security disability determination
- Spirituality discussion
- Staying healthy advice
- Suggestions for making changes
- Swallowing problems and treatment
- Telling polio stories
- Travel in a wheelchair, with a ventilator
- Visit a retirement center/assisted living/long-term facility
- Visit a pool
- Work options
- Wellness and health strategies
- Weight control and nutrition

Speakers from ...

- Aging agencies
- Attorney's office
- Disability advocacy group (ILC, DPI)
- Health/wellness center
- Home health care/equipment company
- Pain clinic
- Post-polio clinic staff
- Rehabilitation center
- State-funded agencies
- Social security office
- Travel agency
- Vocational rehabilitation agency

Medical Specialists ...

- Anesthesiologist
- Cardiologist
- Chiropractor
- Neurologist
- Nutritionist/dietician
- Occupational therapist
- Orthotist (brace maker)
- Psychiatrist
- Physical therapist
- Podiatrist
- Psychiatrist
- Psychologist
- Pulmonologist
- Respiratory therapist
- Rheumatologist
- Speech therapist
- Urologist

SPONSORS/FUNDS

With access to the internet and the ability to email meeting notices, many groups function without any funds. The need for funds and sponsorship depends on the purposes and sometimes the size of the support group. Requiring or requesting dues from members have been successful means of gaining financial support. If the group is not formally organized with membership dues, suggest that each attendee contributes as they are able and/or "pass the hat." There are many disability-oriented organizations and health service providers that can be excellent support of the group's efforts by offering meeting space, finding speakers, sending mass emails, etc. Build a broad local base by connecting with as many local supporters as possible.

Possible sponsors are ...

- Area independent living centers
- Rehabilitation centers/hospitals that have a "post-polio clinic."
- Disability-related non-profits or non-governmental organizations
- Service organizations (Rotary, Jaycees, Sororities)

NOTICES, MINUTES and NEWSLETTERS

Mail or email notices two weeks before the meeting. It is easy to send reminders when using email. The notice should include the date, time, location, the speaker and his/her affiliation or the focus of the program, i.e., discussion of the polio experience, family relationships, etc. Mailings should include the names of the sponsors and a phone number or email in case there are questions. There may be times that you will request an RSVP.

Members can be notified by telephone rather than by mail. Having an organized and effective method of reaching members by phone could prove very beneficial if the meeting is cancelled or if the group has other important messages to relay.

For those who are unable to attend meetings, the group may decide to tape the meeting and make the tape available. The other alternative is finding a dependable and competent group member to serve as a note taker. This information may be mailed with the next notice. Keep in mind that for many members the only means of post-polio support may be the written communication they receive from the group.

More elaborate newsletters may develop as the group grows. Producing a newsletter is a major project that can be time-consuming, but rewarding. Editors of newsletters need to be vigilant in screening the information they print for accuracy. PHI [lists newsletters](#) it receives. Contact the editors and ask if they would like to exchange newsletters.

RESOURCES

Local resources: Ask the group to suggest names for a list of local physicians, physical therapists, orthotists, shoemakers and other health professionals, as well as home care companies and businesses selling medical/disability-related equipment. The individual who takes phone calls should have this list for reference. It also could be placed on the group's website.

The internet has replaced the need for a physical library in many places. Post-Polio Health International (PHI) maintains three comprehensive websites.



The information on [post-polio.org](#) is organized around PHI's mission of education, advocacy, networking and research. The site includes PHI's newsletter, *Post-Polio Health* and its *Post-Polio Directory*. It also contains a section for [Support group leaders](#) that features PHI's [Leadership Series](#). The fifteen columns answer questions commonly asked by support groups and their leaders. Become a [PHI Association Member](#) and receive a monthly e-Communiqué.



[Polio Place](#) explores the past, the present, and helps build a promising future for the world's polio survivors. The past includes not only the story of the disease, but the story of its survivors. Presently, survivors are living with the effects of poliomyelitis in such diverse places as Cuba, Democratic Republic of Congo, Ireland and the United States and are creating their individual stories each day. Their future is influenced by their access to health care, social and governmental support, and medical and practical information from other survivors.



The information on [ventusers.org](#) is organized around International Ventilator Users Network's (IVUN) mission of education, advocacy, networking and research. It includes IVUN's newsletter, *Ventilator-Assisted Living* and its *Resource Directory for Ventilator-Assisted Living*. Established in 1986, International Ventilator Users Network (IVUN) meets the information needs of polio survivors experiencing new respiratory problems and chronicles long-term ventilator use in people with other neuromuscular conditions, such as ALS, DMD, SMA, CCHS and SCI.

ORGANIZATION

Most groups focus their activities on mutual support and sharing. Officers, by-laws, dues and non-profit tax-exempt status are not necessary for a successful support group, but a few will decide to formally organize.

Support groups should not take on more structure than needed. Many people enjoy self-help groups because of the lack of bureaucracy and the opportunity to share leadership

duties. Newly established groups need time to develop a sense of identity, by getting to know each other and having shared experiences and successes.

Filing for non-profit status in the United States involves some paperwork, but it is not an especially difficult process. Filing for tax-exempt status is more involved, and may not require legal assistance. In most cases, obtaining legal advice would be an important safeguard.

Some support groups will find that achieving federal tax-exempt status is worth the time and effort, because it adds to the legitimacy of their organization. It allows them to apply to foundations and corporations for grants.

Several questions should be answered by the group before making a decision.

What are the purposes of the group?

Is the structure in place to accomplish those purposes? Is it working?

Are there other activities that the group would like to initiate?

Would having tax-exempt status help accomplish these new goals?

What is the procedure for filing for non-profit status? Tax-exempt status?

Is legal advice necessary? Does a member have this expertise?

Will the time of some members need to be reallocated to complete the process?

Discussion of these questions will reveal the tasks involved and assist members in making a decision.

In the US, contact your Secretary of State to obtain information on non-profit status.

To obtain tax-exempt status, start by contacting your District Director, Department of the Treasury, Internal Revenue Service. Request information and forms needed by an organization wanting federal tax-exempt status as described in Section 501(c)(3) of the Internal Revenue Code.

For information on exemption from your state's sales/use tax, contact the Department of Revenue of your state.

Consult established non-profits or non-governmental organizations (NGOs) for guidance and advice.

ADVOCACY

The problems facing polio survivors, along with many of the solutions, are not unique to polio survivors but totally intertwined with others with disabilities. There are numerous disability issues at the national level that need scrutiny and support. There are many local issues that need to be addressed, too. Seek out the disability advocates in your area to stay abreast of the issues and to help educate the members of the group, the public and policymakers.



PHI encourages support groups to become involved in the annual October WE'RE STILL HERE! campaign. Each year groups are encouraged to focus on one issue to let the public know WE'RE STILL HERE! and to help change the world to make it better for all people with disabilities.