

Post-Polio Support Group Philosophy, Guidelines and Resources

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POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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Post-Polio Support Group Philosophy, Guidelines and Resources

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 to assure the proper focus of the group.

A smorgasbord of purposes is listed below.

1. Exchange information, ideas and resources.
2. Foster self-help.
3. Provide knowledge from health professionals, social workers and lawyers.
4. Have a good time.
5. Supply non-judgmental people who want to support others.

6. Break down the feelings of isolation.
7. Become better health care consumers.
8. Advocate for the rights of people with disabilities.
9. Grow and change to meet the needs of all members.
10. Care about others.
11. Increase members' knowledge about the late effects of polio.
12. Offer a supportive environment for sharing common experiences and concerns.
13. Identify coping skills related to successful physical and psychological adjustment by polio survivors and their families and friends.
14. Identify community resources to address the needs of polio survivors.
15. Educate the general public and health care professionals about the late effects of polio and the needs of polio survivors.
16. Offer emotional support to polio survivors, their families and friends.
17. Identify and disseminate the newest information available on the late effects of polio to the public and professional communities.
18. Discuss the feelings and needs of the members.
19. Periodically invite guest speakers to address specific interests (physiological topics, psychological concerns, transportation and financial assistance).
20. Provide fellowship with moral support from other polio survivors.
21. Provide an exchange of information and ideas between polio survivors themselves; between polio survivors and others such as health care providers, legislators and the public on local, state and national levels.
22. Provide organized political "clout" with regard to post- polio issues.
23. Collect, compile, and disseminate information of specific or general interest to polio survivors.
24. Collect, compile, and distribute such information to the general public and the medical community.
25. Make polio survivors, the general public, and the medical community aware of the late effects of polio and the residual effects of polio in all its ramifications and manifestations.
26. Advocate for the rights of polio survivors (services, legislation, education and any other area of specific or general interest to polio survivors).
27. Cooperate with other organizations dedicated in whole, or in part, to similar objectives by which such cooperation will serve the needs of polio survivors.
28. Promote and assist research into the diagnosis and cause of the late effects of polio and to promote and assist research leading to a maximum rehabilitation of those having the late effects of polio.
29. Provide reassurance and emotional support to polio survivors and their families.

FIRST MEETING

All it takes is a phone call by one or more polio survivors for the initial meeting which could take place in a home. Others can be reached by arranging announcements on local TV and radio stations and notices and feature articles in local newspapers. 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.

One strategy is to start with a meeting on Saturday morning and suggest survivors bring a brown bag lunch. Interested persons will stay and form a core upon which the group will grow.

Set the pattern with name tags and a sign-in list for attendees to provide name, address and phone number. Open the meeting by asking each person to introduce him or herself and tell 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, as 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. Distribute a page listing of a choice of topics to be covered in future meetings: adjustment, aging, bracing, diminished function, equipment, exercise, fatigue, health maintenance, immunization, muscle weakness, nutrition, pain, resources, respiratory problems, stress, etc.

FUTURE MEETINGS AND SPIRIT

Keep the meeting informal, casual, friendly and small. A group larger than 30 people inhibits the ease of interchange. For large metropolitan groups, perhaps a solution would be a formal presentation to the whole group by a special speaker once every quarter or every other month. Smaller group meetings can be organized geographically by suburb and take place monthly. Remember that it takes time to establish a foundation of trust and cohesiveness among the attendees, time to feel at ease with one another.

Newcomers should be greeted with a sincere and friendly welcome. Do not threaten newcomers with excessive expectations of personal involvement. While a positive approach should be encouraged, negative aspects should not be denied, as both are a part of reality. Members should be made free to express and discuss feelings such as anger, fear and grief, as long as they do not become a burden to other members. Too much cheerfulness, as well as too much sadness, can be depressing.

Do not forget to plan time for fun that will include all family members. Organize monthly meetings with occasional social events such as a party during the holidays or a summer picnic.

PLACE

Check out the location before the meeting to ensure both accessibility of the meeting room and adjacent restroom facilities, and accessibility of the garage for vehicles including vans with raised roofs.

Usually the setting is determined by the purpose of the meeting, but try to avoid an auditorium and a lectern. A circle is more inviting, but optional seating should be available.

Several possible meeting places are ...

Rehabilitation centers	Easter Seals
Recreation centers	Homes
Community centers or colleges	Churches
Wellness centers	Hospitals
Independent Living Centers	Restaurants
American Legion halls	Hotel/Motel conference Rooms

SPEAKERS/PROGRAMS

The speaker's warmth and concern are of the utmost importance. A physician, physical therapist, etc., who had polio would be ideal but other knowledgeable and caring persons are available. Find a professional person who will talk and listen, not pontificate. Plan for no more than approximately 15-20 minutes of opening remarks, then allow the speaker 45 minutes of questions and discussion.

Possible topics are ...

- Assistive technology/equipment
- Weight control and nutrition
- Consumerism and consumer protection
- Handling stress
- Exercise for polio survivors
- Pain management
- The many causes of fatigue
- Know your anatomy – Basic terms
- Social Security disability determination
- Collaboration with your physician
- Suggestions for making changes
- Architectural/environmental barriers
- Staying healthy
- Respiratory problems and treatment
- Arthritis and post-polio
- Coping strategies for people with disabilities
- Caring for your caregiver
- Wellness strategies
- The disability culture
- Furniture, fashion, and accessories for people with disabilities
- Medicare and Medicaid
- Motion economy – Saving energy
- Provisions of the Americans with Disabilities Act
- Living Wills and Durable Power of Attorney for Health Care

Speakers from ...

- An Independent Living Center
- A travel agency
- Weight Watchers
- A social security office
- A pain clinic
- State-funded agency
- Disability advocacy group
- Coordinator of educational programs at a health center
- Local hospital
- Vocational rehabilitation agency
- Local rehabilitation center
- An attorney's office
- A home health care company
- An area aging agency

Specialists ...

- Chiropractor
- Dietician/nutritionist
- Neurologist
- Occupational therapist
- Orthotist
- Physiatrist
- Physical therapist
- Podiatrist
- Psychologist
- Pulmonologist
- Respiratory therapist
- Rheumatologist
- Speech therapist
- Urologist

Etc. ...

- Salad social
- Free swim night
- Sweet Adelines
- Potluck
- Equipment show-and-tell
- An open forum of questions and answers
- Do-it-yourself aids
- Visit a retirement center/long-term facility

SPONSORS/FUNDS

The need for funds and sponsorship depends on the goals and sometimes the size of the support group. Requiring dues, requesting dues and requesting donations from members have all been successful means of financial support. If the group is not formally organized with membership dues, ask each attendee to contribute at least \$1 at every meeting to cover mailing notices and beverages. There are many disability-oriented organizations and health service providers that can be excellent facilitators, offering meeting space, speakers, printing facilities, bulk mailings and, in some cases, funding. Build as broad a local base as possible; form a consortium of sponsors.

Possible sponsors are ...

- Area Independent Living Center
- Local Rehabilitation Institute
- Local Hospital
- Local Easter Seals Society
- Local March of Dimes Birth Defects Foundation
- Local Service Organizations (Rotary, Jaycees, Sororities)

LIBRARY/RESOURCES

The library should contain the most recent information relating to the late effects of polio.

Post-Polio Health International (PHI), 4207 Lindell Boulevard, # 110, Saint Louis, Missouri 63108-2930, publishes the following:

The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (revised 1999) is available for \$11.50 USA; \$22.50 International Air. Contact PHI for bulk ordering information.

Post-Polio Health, formerly *Polio Network News*, published quarterly, is available with Membership. *Post-Polio Health* is copyrighted. To reprint articles, contact the publisher (PHI) for permission. The annual *Post-Polio Directory* (\$12 USA; \$14 Canada, Mexico; \$16 Overseas Air) is published by March 1st and is available at www.post-polio.org.

PHI's website is www.post-polio.org. There is an abundance of information on the Internet and, as with all information, it should be screened.

Many groups around the country have compiled lists of the local physicians, physical therapists, orthotists, shoemakers and other health professionals whom the group members have found concerned and knowledgeable.

The following group has compiled a library with significant holdings.

- Michigan Polio Network Inc.
- 1156 Avon Manor Rd
- Rochester, MI 48307-5415
- 989-739-4065 tel & fax, Denilaur@sbcglobal.net, www.geocities.com/mi_polio_net

Post-Polio Health International (PHI) has an extensive website (www.post-polio.org) that is very useful in finding specialized information about polio and its late effects.

LEADERSHIP

PHI's Leadership Series by Nancy Baldwin Carter is online at www.post-polio.org/net/leadcol.html.

ORGANIZATION

Most groups confine their activities to 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 elect to organize.

Support groups should not take on more structure than needed. If your group takes on structure, let it be because you need it. 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.

Filing for non-profit status does involve 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 being a tax-exempt organization 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.

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.

NOTICES, MINUTES and NEWSLETTERS

Mail out notices two weeks before the meeting. The notice can be as simple as a single photocopied page or a postcard listing the speaker and his/her affiliation. Mailings should include the names of the sponsors.

Members could be notified by telephone rather than by mail. Having an organized and effective method of reaching members by phone could prove very beneficial.

For those who are unable to attend meetings, the group may decide to tape the session and make the tape or the transcript of the information available. The other alternative is finding a dependable and competent group member to serve as a recorder. This information may be mailed with the next notice. Keep in mind that for many members the only means of "support" may be the written communication.

More elaborate newsletters may develop as the group assumes its own peculiar nature and increases its sophistication. Producing a newsletter is time-consuming and costly. The group should consider these two factors before undertaking this major project. Editors of newsletters need to be vigilant in screening the information they print for accuracy.

To contact other support groups, log on to www.post-polio.org/net/pdir.pdf. Many produce newsletters and will be willing to exchange.

INTERNATIONAL

(Listed alphabetically by country)

Imprint

Marion Webb, Information Officer,
imprint@spinal.com.au
Spinal Injuries Association, Post-Polio Support
PO Box 5651, West End, Queensland 4101
Australia
www.spinal.com.au

Post-Polio Network WA Inc. Newsletter

Editor: Tessa Jupp, poliowa@upnaway.com.au
Post-Polio Network WA Inc.
45A Kirwin St, Floreat, Western Australia 6014
Australia

Post-Polio Network (NSW) Inc. Newsletter

Editor: Gillian Thomas,
editor@post-polionetwork.org.au
Post-Polio Network (NSW) Inc.
PO Box 888, Kensington,
New South Wales 1465 Australia

Polio SA

No editor given, poliosas@dodo.com.au
Post-Polio Support Group of South Australia, Inc.
11 Blacks Road, Gilles Plains,
South Australia 5086 Australia

Polio Perspectives

Editor: Mary-ann Liethof, polio@paraquad.asn.au
Polio Network - ParaQuad Victoria
208 Wellington Street, Collingwood,
Victoria 3066 Australia

PPASS News

Editor: Newsletter Team, ppass@ppass.bc.ca
Post-Polio Awareness and Support Society
of British Columbia
#214-10114 McDonald Park Rd, Sidney, British
Columbia V8L 5X8 Canada

Polio Post

Editor: Pat McNeill, No email given
Post-Polio Network (MB) Inc.
825 Sherbrook St, Winnipeg,
Manitoba R3A 1M5 Canada

Newsletter

Editor: Linda Muise, gerlyn@yar.eastlink.ca
Polio Nova Scotia
c/o Abilities Foundation of Nova Scotia
3670 Kempt Road, Halifax,
Nova Scotia B3K 4X8 Canada

Toronto Peel Polio Survivors' Newsletter

No editor given, dlavinge@dimes.on.ca
Ontario March of Dimes York Region,
Post-Polio Chapter
10 Overlea Blvd, Toronto, Ontario
M4H 1A4 Canada

Folio Polio

No editor nor email given
Polio Quebec Association
3500 Blvd Decarie, Ste 263, Montreal,
Quebec H4A 3J5 Canada

Polio Postbox

Editors: Blenda and Fred Ramsay,
fbramsay@sasktel.net
Polio Regina Incorporated
825 McDonald St, Regina,
Saskatchewan S4N 2X5 Canada

Sapplings

No editor given, msjohnson@sasktel.net
2310 Louise Ave, Saskatoon
Saskatchewan S7J 2C7 Canada

The Survivor Irish Polio News

Editor: Paula Lahiff, info@ppsg.ie
Post-Polio Support Group Ireland
The Carmichael Centre, North Brunswick St,
Dublin 7, Ireland

Polio News

Editor: Jim Webber, ferris.webber@paradise.net.nz
Post-Polio Support Society NZ Inc.
103 Amohia Street, Paraparamu (Wellington)
5032, New Zealand

Polio Happenings

Editors: D&R, auckpostpolio@clear.net.nz
36 Eastern Beach Road, Bucklands Beach,
Manukau, Aola, 2012 New Zealand

The LincPIN

Editor: Hilary Boone,
hilary.boone@lincolnshirepostpolio.org.uk
Lincolnshire Post-Polio Network
PO Box 954, Lincoln LN5 5ER, United Kingdom

Bulletin

Editor: Nicola Hill, No email given
The British Polio Fellowship
Eagle Office Centre, The Runway
South Ruislip, Middlesex HA4 6SE, United Kingdom

UNITED STATES

(Listed alphabetically by state)

Polio Echo News

Editor: Jane Crawford, janwec94@earthlink.net
Polio Echo Inc.
PO Box 61024, Phoenix, AZ 85082-1024

Polio Epic Newsletter

Editor: Micki Minner, mickiminner@msn.com
Southern Arizona Post-Polio Support Group
PO Box 17556, Tucson, AZ 85731-7556
www.polioepic.org

Central Arkansas Polio Survivors Newsletter

Editor: Paula Sporn, pdsphd@suddenlink.net
Central Arkansas Polio Survivors (CAPS)
3220 Case Ford Rd, Heber Springs, AR 72543

PPS Group of Bakersfield

Editor: Mary T. Correia, No email given
PPS Group of Bakersfield
3709 Kennedy Ave, Bakersfield, CA 93309

Sacramento Post-Polio Support Group

Editor: Evelyn Crain, crain.e@sbcglobal.net
PO Box 3043, Citrus Heights, CA 95611-3043

Rancho Los Amigos Post-Polio Support Group Newsletter

Editor: Richard Daggett, Ranchoppsg@hotmail.com
Rancho Los Amigos Post-Polio Support Group
12720 La Reina Ave, Downey, CA 90242

Newsletter of The Post Polio Support Group of Orange County

Editor: Baldwin Keenan, keenanwhelan@cox.net
Post Polio Support Group of Orange County
15231 Marne Circle, Irvine, CA 92604

The PPS Manager

Editor: Richard Van Der Linden, PPSman@aol.com
Hemet Area Polio Survivors (HAPS)
34711 Lyn Ave, Hemet, CA 92545

Post-Polio Group – California North Coast

Editors: Jean Kreger, Dee MacKinney,
ppsgsonoma@yahoo.com
Post-Polio Group – California North Coast
PO Box 9397, Santa Rosa, CA 95405-1397

Colorado Post-Polio Connections

Editor: Margaret C. Hinman,
mhinman12@comcast.net,
post-poliocolo@comcast.net
Colorado Post-Polio Connections
10180-C Green Ct, Westminster, CO 80031

The Polio Messenger

Editor: Linda Wheeler Donahue,
LinOnnLine@aol.com, PolioOutreach@aol.com
The Polio Outreach of Connecticut
75 Tallwood Rd, Southbury, CT 06488

Options

Editor: Jessica Scheer, No email given
The Polio Society
4200 Wisconsin Ave NW, PMB # 106-273,
Washington, DC 20016

PPSSG Newsletter

Editor: Dick Thamm, RCThamm@comcast.net
Easter Seals Society of Delaware and
Maryland's Eastern Shore
61 Corporation Circle, New Castle DE 19720

Second Time Around

Editors: Carolyn DeMasi and Maureen Sinkule,
bappg@aol.com
Boca Area Post-Polio Group
11660 Timbers Way, Boca Raton, FL 33428

Post Scripts (temporarily discontinued)

Editor: Carol Norris Vincent, wavcnv@yahoo.com
2515 Langtree Ct, Sun City Center, FL 33573

Polio Post News

Editor: Carolyn Raville,
Carolyn@postpoliosupport.com
7180 SW 182nd Ct, Dunnellon, FL 34432

Forward Motion

Editor: J. Ann Singleton,
postpolioresource@mac.com
Post-Polio Resource Group of Central Florida
481 Meadowood Blvd, Fern Park FL 32730

PPASF Newsletter

Editor: Barbara Gratzke, ppsouthfl@aol.com
Post-Polio Association of South Florida
2660 SE 7th Pl, Homestead, FL 33033

First Coast Post-Polio News

Editor: Janice Askwith,
firstcoastpostpolio@yahoo.com, 904-333-3457
First Coast Post-Polio Support Group
13119 Blackhawk Trail Ct, Jacksonville, FL 32225

Florida East Coast Post-Polio Support Group

Editor: Barbara Goldstein, bgold@iag.net
Florida East Coast Post-Polio Support Group
12 Eclipse Trail, Ormond Beach, FL 32174-4936

Post-Polio Voice

Editor: Kathy Suchareski,
ksuchareski@webcomet.com
5601 Duncan Rd #191, Punta Gorda, FL 33982

Post-Polio Support Group of Brevard

Editor: Cathy Casabianca, casabiaf@bellsouth.net
Post-Polio Support Group of Brevard
266 Harvey Ave NE, Palm Bay FL 32907

FDR PPS Foundation

Editor: Harold Roupe, FDRPPS@yahoo.com
231 Cedar Drive, Sparta, GA 31087

The Lighthouse

Editor: Sandra Bath, sbath@comcast.net
Coastal Empire Polio Survivors Inc.
112 Van Nuys Blvd, Savannah, GA 31419

APPA News

Editor: Linda Priest, lpriest@comcast.net
APPA, PO Box 50566, Atlanta GA 30325

Hawaii Post-Polio Network

Editor: Theo Hufen, hufent001@hawaii.rr.com
Hawaii Post-Polio Network
c/o March of Dimes Birth Defects Foundation
1451 S King St Ste 504, Honolulu, HI 96814

Bringing Forth a Positive Attitude

Editor: Janice Hawkins, jhintmw@gowebway.com
Iowa Polio Survivors Inc.
402 N K St, Indianola IA 50125

The Polio Pacesetter

No editor nor email given
WCIPPSG
PO Box 184, Kiron, IA 51448

Polio Update

Editor: Ann Crocker, abcrocker@roadrunner.com,
www.ppsgm.org
The Post-Polio Support Group of Maine
674 Hallowell-Litchfield Rd,
West Gardiner, ME 04345

The Band-Aid Newsletter

No editor given, Cbudwyer@aol.com
P.O.L.I.O. Polio Outreach Links &
Information Organization
PO Box 683, Longfellow MA 01028-0683

Triumph

Editor: Norma Markson, njmarkson@verizon.net
Greater Boston Post-Polio Association
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Wellesley, MA 02181-0024

Lansing Area Post-Polio Support Group Newsletter

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Lansing Area Post-Polio Support Group
2518 Lake Lansing Rd Apt 1, Lansing MI 48912

Polio Perspectives

Editor: Vera Hazel, jerryhazel@aol.com
Michigan Polio Network, Inc.
1156 Avon Manor Rd, Rochester Hills, MI
48307-5415

PPASS Times

Editor: Larry Kohout, larrykohout@comcast.net
Post-Polio Awareness & Support Society of Minnesota
7720 York Ave S # 520, Edina MN 55435-4461

Gleanings

Editor: Marian Barnett, mjbarnett@att.net
Nebraska Polio Survivors Association
PO Box 45139, Omaha, NE 68145-0139

*New Hampshire Network Post-Polio
Support Group Newsletter*
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The New Hampshire Network Post-Polio
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c/o Jan Alperin, 204 S Main St,
New Market, NH 03857

Current Tides
Editors: Marge and Steve Disbrow,
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Atlantic County Post-Polio Support Group
38 Rosewood Ln, Mays Landing, NJ 08330-8900

Raritan Valley PPSG Newslines
Editor: Joan Swain, jsvain@patmedia.net
Raritan Valley Post-Polio Support Group
PO Box 537, Martinsville, NJ 08836

Polio Network of New Jersey Newsletter
Editor: Joan Swain, NJPN10@patmedia.net
Polio Network of New Jersey (PNNJ)
PO Box 537, Martinsville, NJ 08836,
www.njpolio.org

The Seagull
Editor: Sharon Bowden, TriadPPG@yahoo.com
Triad Post-Polio Support Group
4830-C Tower Rd, Greensboro, NC 27410

Ohio Polio Network Newsletter
Editors: Joyce M. Metheny and Alice Sporar,
ranger91@core.com
Ohio Polio Network
9179 Manorford Dr, Parma Hts OH 44130-3231

Polio Connection
No editor nor email given
PO Box 9575, Cincinnati, OH 45209

Delaware Valley Polio Survivors Association
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Delaware Valley Polio Survivors Association
Box 190, Abington, PA 19001

Polio Heroes News
Editor: Nickie Lancaster, No email given
Polio Heroes of Tennessee
529 Albany Dr, Hermitage, TN 37076-1422

Top of Texas Post-Polio Support Group
Editor: Aldine Manning, No email given
Top of Texas Post-Polio Support Group (TTPPSG)
2200 W 7th St # 417, Amarillo, TX 79106-6789

The Phoenix
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Blueangel7131@sbcglobal.net
San Antonio Polio Survivors Association
c/o The Warm Springs Resource Center for
People with Disabilities
5101 Medical Drive, San Antonio, TX 78229-4801

Post-Polio Partners
No editor given, pauljr@hiline.net
Post-Polio Partners
PO Box 606, Donna, TX 78537

Polio Deja View
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Central Virginia Post-Polio Support Group
1803 Aston Ln, Richmond, VA 23236-3066

Polio Outreach of Washington
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Polio Outreach of Washington
4704 235th St E, Spanaway, WA 98387-6162

Spirit
Judith Pipher, Together@PPRG.org, www.pprg.org
Post-Polio Resource Group of Southeastern Wisconsin
Independence First, 600 W Virginia St Ste 401,
Milwaukee WI 53204-1516
(newsletter available in pdf on website)

Mid-Ohio Valley Post-Polio Support Group Newsletter
Editor: Becky White, myridin1@juno.com
Mid-Ohio Valley Post-Polio Support Group
2807 11th Ave, Vienna, WV 26105

POLIO CLINICS and CONFERENCES

If the group has involved a broad range of sponsors and has reached the local medical community, a clinic will evolve naturally in due course. Ideally, the support group and clinic should work in tandem, sharing, exchanging, and reinforcing. Some people have been instrumental in establishing a clinic or working with physicians in their area.

Contact the following people for information:

Barbara Duryea, RN
Conemaugh Health System's
Post-Polio Clinic
1450 Scalp Ave Ste 2100
Johnstown, PA 15904-3374
814-534-5700, 814-534-5150 fax
bduryea@conemaugh.org
www.conemaugh.org

Anna G. Rubin
International Rehabilitation Ctr for Polio (IRCP)
at Spaulding-Framingham
570 Worcester Rd
Framingham, MA 01702-5311
508-872-2200 ext 241, 508-872-1205 fax
agrubin@partners.org
www.polioclinic.org

Similarly, a well-established group may consider planning and coordinating a conference. Include all medical fields as well as the other support groups in your region of the country. Credibility and attendance is enhanced when an association is made with a hospital or a rehabilitation center.

Contact the following support groups that recently have coordinated successful conferences:

Gerald J. DeLeeuw
Post-Polio Resource Group
of Southeastern Wisconsin
PO Box 13841
Milwaukee, WI 53213-0841
414-454-9093
together@pprg.org, www.pprg.org

Jean Fox Csaposs
New Jersey Polio Network (NJPN)
PO Box 537
Martinsville, NJ 08836-0537
201-845-6860, 201-843-2903 fax
jjcsaposs@msn.com, www.njpolio.org

ADVOCACY

The problems facing polio survivors, along with many of the solutions, are not unique to polio survivors but totally intertwined with the other 43 million Americans with disabilities. There are numerous disability issues at the national level that need scrutiny and support, but perhaps your group would rather start with local accessibility problems for persons with disabilities. The knowledge, solutions, and excellent support systems developed by your group could then easily be incorporated into the nationwide effort on behalf of all persons with disabilities.

www.post-polio.org

Post-Polio Health PHI's quarterly newsletter includes current information about the late effects of polio, related research and networking among the post-polio community worldwide.

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors

Contains 90 entries in dictionary format, the compilation of the research and experience of more than 40 experts; describes the late effects of poliomyelitis, its evaluation and its appropriate management, and is designed to be useful both for the survivors of polio and their families, as well as health care professionals.

www.ventusers.org PHI's affiliate, International Ventilator Users Network (IVUN) has its own comprehensive website that includes past issues of Ventilator-Assisted Living, the Home Ventilator Guide and much more.

Ventilator-Assisted Living IVUN's quarterly newsletter provides information and networking for ventilator users, their families, and health professionals committed to home mechanical ventilation.

Resource Directory for Ventilator-Assisted Living IVUN's networking tool for health professionals and both long-term and new ventilator users that includes health professionals, ventilator users, manufacturers of ventilator equipment and aids, and related organizations, associations and foundations.

Information about Ventilator-Assisted Living IVUN's new 16-page brochure is an introduction to mechanical/assisted ventilation: what is it? who uses it? what types of ventilators? what types of interfaces? and more.

Not already a Member?

Join PHI!

Support Post-Polio Health International's educational, research, advocacy and networking mission.

Rates Effective July 2007

PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Or join PHI online at www.post-polio.org. Memberships are 100 percent tax-deductible.

- \$30 Subscriber**
Quarterly newsletter of your choice:
 Post-Polio Health OR *Ventilator-Assisted Living*
- \$55 Subscriber Plus**
Both quarterly newsletters:
Post-Polio Health AND Ventilator-Assisted Living
- \$100 Contributor**
ALL the benefits of Subscriber Plus AND
Post-Polio Directory AND
Resource Directory for Ventilator-Assisted Living;
discounts on special publications
and meetings sponsored by PHI
- \$150 Sustainer**
ALL the benefits of Contributor AND
One additional complimentary gift membership to:
 Person of your choice (include name and address) or
 Person who has expressed financial need to PHI

Membership at the following levels includes ALL benefits PLUS special recognition in PHI publications:

- \$250 Bronze Level Sustainer**
- \$500 Silver Level Sustainer**
- \$1,000 Gold Level Sustainer**
- \$5,000 Platinum Level Sustainer**
- \$10,000 Gini Laurie Advocate**

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I am enclosing a check for \$ _____ made payable to "Post-Polio Health International." (USD only)

Please charge \$ _____ to this credit card:

- VISA MasterCard Discover

Card No. _____

Exp. Date _____ Card Verification # (3 digits on back of card) _____

Name on Card _____

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Send this form to: Post-Polio Health International
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
314-534-0475 314-534-5070 fax



Post-Polio Health International
Iniciativa Internacional Voluntarios Usas Network

*PHI is inviting your group to become an
Association Member ...*



Post-Polio Health International
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www.post-polio.org

Because of your commitment to polio survivors – and to providing them with useful information and emotional support – we are happy to share exciting news with you.

Post-Polio Health (PHI) has created a new membership category called Association Membership. Association Membership is open to consumer-led self-help groups or associations whose mission complements that of PHI. You will recall that our mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

The purpose of this new membership category is to strengthen our partnership with support groups and other post-polio organizations, to maximize the power of our numbers through networking and to improve the quantity and quality of communication among the Association Members.

As you know, PHI has always been available for counsel and advice, and many of you have taken advantage of our knowledge base and connections. Groups have regularly accessed our online resources about the philosophy and basics of coordinating a support group (www.post-polio.org/net/supgrps.html).

Why are we creating this new membership category now?

We have observed a decline in the number of post-polio support groups and in some, a decline in their vitality. In a perfect world, all support groups would disappear because all the problems were solved! But PHI believes there is more work to be done – more education of polio survivors and health professionals, more emphasis on research and solutions and stronger advocacy on issues that affect polio survivors.

We see some groups celebrating 20 years of operation, while others appear to be struggling. While all groups, no matter how successful, struggle at times, we think that all groups benefit from re-evaluating, evolving and networking with others.

That's why we think it's an ideal time to capitalize on our network and leverage the "power of numbers."

There will be immediate benefits for Association Members. PHI will:

- Distribute *Post-Polio Health* and the annual *Post-Polio Directory* in print.
- Create a special area on www.post-polio.org recognizing Association Members and their groups' work.
- Continue to provide current services, such as permission to reprint PHI copyrighted articles, discount on PHI brochures, etc.
- Communicate with Association Members for consultation and for opinions to be sure polio survivors are heard and counted in advocacy efforts.
- Facilitate a monthly e-communication (in English for now) so that Association Members can more systematically share support group successes and candidly discuss issues related to lingering post-polio issues as well as develop plans to meet future needs.

PHI will also assist and encourage Association Members as they:

- More systematically communicate information about their groups to PHI so these activities can be promoted more broadly.
- Disseminate information about PHI and its activities.
- Promptly respond to advocacy requests and calls-to-action.
- Participate in discussions related to post-polio support groups and polio survivors via e-communication.

Will you join us to maximize the "power of numbers?" The power of our network benefits all of us. We want to help strengthen and support your group. And we want to help meet your members' needs with greater impact and relevance than ever.

Our fee structure is based on the number of members in your group. And it's only **\$1.00 per member per year!** The minimum fee is \$35. The maximum fee is \$250.

Please complete and return the enclosed card today.

Sincerely,
The Volunteer Board of PHI
and
Joan L. Headley, Executive Director

Yes, we want to join with Post-Polio Health International (PHI) as an Association Member!

Group Name _____
Mission _____
Year group was formed _____ Number of members you represent _____
Contact Person _____ ID No. (if known) _____
Phone number (include country code or area code) _____
Street address _____
City _____ State/Province _____
Zip/Postal Code _____ Country (if outside USA) _____

Email (To ensure that you receive messages, set your spam filters to accept email from info@post-polio.org.)

Month membership to begin _____ Membership fee for one year \$ _____



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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