

SELF-HELP Philosophy*

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

Self-help 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 the 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.

*International Polio Network, 4207 Lindell Blvd., #110, Saint Louis, Missouri 63108-2915

SUPPORT GROUP SUCCESS

"Many support groups are extremely empowering and valuable; unfortunately, others promote victimization. When considering a support group, be sure to evaluate what the support group is supporting."

Excerpted from *Five Steps to Selecting the Best Alternative Medicine: A Guide to Complementary and Integrative Health Care* by Mary and Michael Morton. First published in December 1996, this book is divided into two parts, Part I: The Steps — How to Make Alternative Medicine Work for You, and Part II: The Five Licensed Systems of Alternative Medicine — the Terrain of Alternative Medicine, is a very readable, logical, and balanced treatment of the subject. (ISBN-10880032-94-5; New World Library, Novato, California; \$16.95 at your local bookstore.)

The secret to our success is ...

Planning a meeting that is worthwhile to come to with both a time for sharing and a time for education.

Over the years we have learned ...

To quit fighting the late effects of polio and to concentrate on helping ourselves adjust to the changes.

MID-WILLAMETTE SUPPORT CHAPTER, OREGON

The secret to our success is ...

Offering a variety of activities; drawing each person present into the meeting, making him or her feel that they have contributed; having lots of laughter.

Over the years we have learned ...

That knowledge is our power; sharing is caring; and our success is 80% our attitude.

THE WEST VIRGINIA CHAPTER OF POLIO SURVIVORS

The secret to our success is ...

The fact that we have a very faithful core group who likes to keep in touch with each other, even when we do not get together for meetings. We meet four times a year, so we call just to check on each other in between.

Over the years we have learned ...

That there are always new people who do not know about post-polio and our support group. We have found that meetings with speakers draw more of a crowd, so we plan two meetings with speakers and the other two are luncheon meetings just for us.

TOPEKA POST-POLIO SUPPORT GROUP, KANSAS

The secret to our success is ...

Combining structure and flexibility. We decided early to have elected board members who, in turn, elect officers and committee chairs (these elections yearly); we put together and mail a monthly newsletter to members and their physicians; and we have informative and relevant monthly programs, as well as two luncheon meetings a year. This structure has allowed us to obtain local grants for state-wide forums, for buying books and videos, and for sending interested members to out-of-state meetings. We have been functioning now for over six years, which indicates that we're meeting somebody's needs!

Over the years we have learned ...

That different polio survivors need different things from a support group. Some are searching for information and once they find it, they remove themselves from the group, sometimes returning with new needs. Others are looking for social interaction or a need to rehearse their polio history. Others need a place to



Some board members of the Birmingham Post-Polio Support Group starting work on the group's 1998 Forum: (l to r) James Jarrell (president), Danny Junkins, Faye Perkins, and Dave White.

vent their fear or anger. Occasionally, a family member needs help in coping, and always the community needs education about polio issues. Our support group organized with the purpose to educate, but we provide a little of everything for those who want to learn.

BIRMINGHAM POST-POLIO SUPPORT GROUP,
ALABAMA

The secret to our success is ...

Listening ... because many polio survivors have not talked about their polio in decades. We put more emphasis on our mailings than meetings and try to network information so a person with any level of education finds it understandable. Our meetings are informative, informal, and friendly with time to answer questions. We maintain a file of knowledgeable resources — social security, teacher disability, etc., in each county so our resources are close to home. We take advantage of the community resources already in place.

Over the years we have learned ...

That polio survivors must become the experts in their own condition and be active, assertive managers of their own healthcare, keeping a file of polio materials. Polio survivors should find a good quarterback physician who will take care of the whole person and coordinate information from specialists. Polio survivors need to know that it is okay to say "I hurt;" to get angry, depressed, frustrated, and grieve; to know that they are not imagining their symptoms; and to realize that they are not alone. Polio survivors should view canes, braces, scooters, wheelchairs, etc. as friends and realize that there is no magic pill or shot.

POLIO HEROES OF TENNESSEE

The secret to our success is ...

Our cumulative assessing of the needs and wants of our membership and addressing them accordingly. Our key word is support, and we work hard to ensure that we provide any and all aspects of our needs which make post-polios unique unto themselves. Good organization, a viable leader, volunteerism, all contribute to making our support group thrive. To help meet needs, we call upon our members with special professional skills — psychology, geriatric social services, nursing, financial advising, legal advice, etc. The establishment of a post-polio clinic formed three years ago at the University of Miami School of Medicine, staffed with a physiatrist from the Department of Orthopedics and Rehabilitation, a physical therapist from the graduate School of Physical Therapy and an orthotist — has benefited our group. Other specialties to enhance total well-being are easily assessed and utilized. Brochures were developed, printed, and are being distributed. Flyers are being developed in English and Spanish.

Over the years we have learned ...

That we must make ourselves available to those in need of our support and that we still have much to learn and are open to any and all information provided to us. Even though we feel we are unique, we know that we are just a part of the whole and we are not alone. Like most such groups, we have no paid staff. It is important that the officers have time to devote to fulfilling their responsibilities, be enthusiastic, and have their hearts in what they are doing. Since everyone is a volunteer, it is sometimes easy for one to leave the completion of important tasks and the meeting of deadlines to the president. The location and time of meetings are important. We now meet at the Metro-Dade Center for Disability Services and Independent Living, centrally located with gener-



Annual picnic of the Post-Polio Association of South Florida — Social events are essential to a support group.

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ous parking in a lot adjacent to an all-ramped building. The facility provides a large meeting room with kitchen and space for our library. Audio-visual equipment is also available for our use. We meet every third Saturday of the month at 10:30 a.m., a day best suited to our members' schedules since many are still gainfully employed.

Communication is vital and accomplished by a monthly newsletter and a telephone committee which has not only increased meeting attendance, but has served to enhance support. Close friendships have developed between members with pleasurable socialization. Our members are becoming increasingly involved in community activities. Following intensive training, they are certified as handicapped parking enforcement specialists. Committees, standing and ad hoc, do not lack volunteers. Members join eagerly and participate actively.

POST-POLIO ASSOCIATION OF SOUTH FLORIDA

New Groups Meet **SACRAMENTO** The Sacramento Post-Polio Group meets at 11:00 am on the first Saturday of each month January-April and September-November at the Fairvale Baptist Church on Madison Avenue in Fair Oaks. The group plans social events for the months of May and December. For more information, contact Alice Basco, 3510 Cheri Court, Rocklin, California 95677 (916/624-0448).

SAVANNAH The first official meeting of the Coastal Empire Polio Survivors in April had 25 people in attendance. Future meetings will be held the fourth Tuesday of each month at 7:00 pm at Candler Hospital in the GI waiting room, just off the lobby of the Candler Professional Building. Shirley Carnell, a retired RN, began the group with the assistance of Cheryl Brackin and Lorraine Poling. For further information about the group, call 912/927-8332 or 912/355-7341.

Videos on Loan Michigan Polio Collection Library is located at 4291 Squires Road, Quincy, Michigan 49082 (near Coldwater and Hillsdale) and has a collection of books, periodicals, audio tapes, video tapes, etc. Contact Nancy Miller, Librarian at 517/869-2996 or 517/869-2611 FAX, for a listing of materials and borrowing information which usually just requires return postage. International Polio Network has donated the video *My Body Is Not Who I Am*, in which polio survivor Jeanne Putnam interviews individuals with disabilities who share their thoughts and feelings. The video would instigate discussion in any support group meeting. If you have new polio-related materials you wish to donate to the library, send them to Miller for review. ❧

THE POST-POLIO TASK FORCE

WHAT AND WHO

In early 1997, the Post-Polio Task Force was formed to help promote awareness and advance medical knowledge of post-polio syndrome. The task force is chaired by Neil R. Cashman, MD, associate professor of Neurology at the Montreal Neurological Institute and Hospital at McGill University in Montreal, Canada. It includes two groups: clinicians and researchers who specialize in diagnosing and treating polio survivors with symptoms of post-polio syndrome, and advocates for survivors of polio.

Other members include: Lauro Halstead, MD, director of the Post-Polio Program at National Rehabilitation Hospital in Washington, DC; Joan L. Headley, executive director of the International Polio Network, headquartered in St. Louis, Missouri; Burk Jubelt, MD, a neurologist at the SUNY Health Sciences Center in Syracuse, New York; Frederick M. Maynard, MD, medical director of the MetroHealth Center for Rehabilitation in Cleveland, Ohio; Robert Miller, MD, chairman of the Department of Neurology at California Pacific Medical Center in San Francisco, California; Dorothy Woods Smith, RN, PhD, associate professor at the University of Southern Maine College of Nursing in Portland, Maine; and Daria A. Trojan, MD, MSc, assistant professor at the Montreal Neurological Institute and Hospital at McGill University in Montreal, Canada.

WHY AND HOW

Mission Statement

The Post-Polio Task Force is dedicated to improving the care and quality of life for people with post-polio syndrome.

Objectives

- ◆ To raise awareness of issues surrounding the diagnosis and management of post-polio syndrome through education and the promotion of research;
- ◆ To develop educational tools and events that raise awareness of post-polio syndrome and its clinical significance;
- ◆ To facilitate the definition of standards of care for people with post-polio syndrome.

ACCOMPLISHMENTS TO DATE

Prior to the opening of the April, 1997 American Academy of Neurology (AAN) meeting in Boston, the task force conducted a roundtable discussion during which members gave presentations aimed