

SUPPORT GROUPS

QUESTIONS ASKED, questions answered, and questions unanswered at International Polio Network's Support Group Leaders' Workshop in June of 1988 prompted the following series of articles. The thoughts and suggestions are not just for leaders but for all polio survivors who are seeking information about the late effects of polio or dealing with the consequences of the late effects of polio.

Support Groups: WHAT ARE THEY?

By Gini Laurie, St. Louis, MO

Polio support groups, like all other self-help groups, have a common health concern, govern themselves, provide emotional support, gather and share specialized information, increase public awareness and knowledge, are nonprofit and voluntary, charge small or no dues, and are constantly struggling to survive.

Sharing with other survivors in support groups is the essential psychological support needed to make lifestyle adjustments when dealing with the late effects of polio. The comfort in the togetherness that members extend to one another is essential in the aloneness of our mobile, urban society of small and scattered families.

Support groups are successful because they offer real relief from isolation and fear. They offer experiential knowledge and practical coping skills, not only for members but often for their spouses and families. They provide rare opportunities to learn from positive role models - those who have been there.

There is great variety in polio support groups. Some meetings are structured, others casual. Some

have achieved nonprofit status. Some meet in each other's home or by phone or mail; others meet in independent living centers, rehabilitation centers, churches, hospitals, senior centers, libraries, or local March of Dimes or Easter Seal Offices. Some have asked one or several of these organizations to provide photocopying or postage as well as meeting places; others are totally self-sustaining. Some have co-sponsored valuable local and regional conferences with their local organizations.

To seek help or not to seek help from local organizations is a dilemma for many support groups. If support groups work with local organizations, they must work out a collaboration that is mutually beneficial since all are part of the helping systems in a community.

If support groups work with local organizations, the groups must lead; the organizations must follow.

Total independence is the surest way to remain true to the purpose of a support group - to provide mutual support. Collaboration is an alternative if the support group maintains ownership and autonomy.

Gini Laurie is the Founder and Chairperson of Gazette International Networking Institute (G.I.N.I.).

Support Groups: WHY DO IT ALONE?

By Paul J. Rau, Greenville, NC

Many polio survivors who recovered from acute polio at an early age apparently learned a positive mental attitude. As a prerequisite to

accepting the pain of recovery, a positive attitude was part of the overcome philosophy - "I must do it alone."

Also, a special bond of trust was established between the polio survivor and the attending physician and between the survivor and family members who assisted in treatment.

When these pioneers in rehabilitation recovered from the initial paralysis and entered the mainstream of society as independent adults, many effectively hid or denied any residual effects.

Years later as reports on the late effects of polio began to appear, they were faced with many new problems and unanswered questions.

o Where can I find a physician who will be able to renew my original confidence in the physician/patient relationship?

o Am I at fault for my current problems by neglecting my health which was such an essential part of my early life?

o I have remained independent and have not asked anyone to do anything for me the past 30 to 40 years. How do I ask for help now?

o Can I get help from my family when the relationships have changed from parents and siblings to spouse and children?

Support groups can provide some of these answers. Meetings are a means of interacting with health care professionals, social service agencies, and most important, other polio survivors. All will benefit from the mutual exchange.

This first step towards the self-help movement will not be easy for someone taught to "do it alone." Some survivors may need to adjust their philosophy of life to "You alone can do it, but you can't do it alone."

Paul J. Rau is the Technical Coordinator for the Greenville Post Polio Support Group, 204 Great Glen Road, Greenville, SC 29615.

Support Groups: WHO NEEDS THEM?

By Mary Ann Hamilton, Denver, CO

Our support group had been meeting for several months before Will appeared. Trembling all over, he pulled up a chair and plopped a black notebook on the table in front of him. When he introduced himself, he told us (perhaps warned us), "My doctor told me that I have more information about post-polio syndrome in this notebook than any doctor can find!" As his bony finger jabbed at the fat book, it was obvious his courage was failing. That full notebook held no cure.

He looked around the circle of support and quietly said, "Before I came today I was contemplating suicide. Something happened recently that changed my mind and brought me to these meetings." Our personal fears were shelved. Will had our attention.

"I was driving home from a doctor's appointment. It was snowing, one of those heavy spring storms. I stopped and watched the red signal light swing violently over the intersection, but my mind was recalling my visit with the doctor, who couldn't diagnose my fatigue, the feeling of weakness engulfing me."

Sensing we understood his fears, he continued, "Through the blinding snow I saw a bird huddled in a nest cupped in the light. I watched the bird through two turns of green as it clung to the nest while being whipped by blasts of blowing snow."

"I drove on and thought about that little bird which possessed the

(continued on next page)

Support Groups: WHO NEEDS THEM?

(continued from page 5)

will to survive, even in such a precarious perch. Perhaps I could find the will to fight - to hang on."

At a recent support group meeting we were going around the circle giving "Atta Boy, Atta Girl" reinforcements. Will told us, "I couldn't stop talking that first day. It was like a dam had burst and the words kept pouring and pouring out of my soul. You were listening and caring. I don't know what I would do without your support."

Who needs them? All of us who share the same fear of being out of control of our plans, our dreams, our quality of life. All of us who grow exhausted vainly trying to halt or reverse the changes brought on by this echo from the past.

We can learn from each other. Each of us has learned a valuable lesson we can share. With new support, the "Wills" of us can survive this confrontation with an old battle.

Mary Ann Hamilton, a polio survivor who uses a ventilator, is editor of the newsletter for the Post-Polio Connection, 1185 South Williams, Denver, CO 80210.

*Support Groups: WHO CAN BENEFIT?

By Margaret E. Backman, Ph.D., New York, NY

Leaders of post-polio support groups often feel frustrated that a large majority of those on their mailing lists do not come to the group meetings. More important, many leaders fear that these non-attenders are manifesting "serious denial" and may not be doing what is in their best interest. Although in many cases denial may be

operating, it is not necessarily self-destructive and often is an appropriate coping mechanism - putting aside disturbing thoughts and allowing one to move on with one's life.

The low level of participation in support groups is not endemic to the post-polio population. Research with those with other medical conditions suggests that a minority of people choose to attend group sessions.

REASONS

FOR LEAVING OR NOT JOINING A GROUP

"It depresses me being with people who are sick." "I prefer not to dwell on my illness." "It reminds me of when I was in the convalescent home; I've had enough of that." These are only some of the reasons given for not wanting to be in a group. Individuals have different coping strategies, and they differ in their capability and need for self-care and information.

A certain amount of support and information is needed; however, some people may be getting as much as they can handle. "Information overload" can be as stressful as not knowing what is going on. Some people prefer to be informed about the timing and the nature of an aversive event, while others prefer to be distracted from knowing, particularly if the information would be threatening.

Matching the amount of information given to a person's preferred coping style seems to be the best strategy. "Confronters" show less stress when given the requested information, and "avoiders" show less stress when given only the minimum information needed to take care of themselves. Generally speaking, the best guide would be to listen to a person's request for information and support.

Some support groups move from being supportive or educational to a more

psychodynamic mode, where participants are encouraged to talk about very disturbing feelings and memories. Many polio survivors would like to forget what happened to them. They also wish to delay thinking "prematurely" about the difficulties they may have to face in the future. Some are not ready to be confronted or to share their deepest fears - at least not "in public." They may be afraid that they will not be able to cope emotionally. Thus they avoid group meetings because they have no control over what might be said or asked of them. In such cases, avoidance or denial may be appropriate coping mechanisms.

Generally speaking, avoidance (or denial) is better than approach (or confrontation) if the situation is not in a person's control. If there is some possibility for control, however, a more direct approach strategy is better, because it allows the person to take advantage of opportunities.

Perception, however, plays a major role here. Polio survivors may feel that the present state of knowledge and treatment is uncertain and perceive their current situation as uncontrollable. They may feel that the help available is very limited, and discussion of their condition only stirs up what they consider to be unnecessary fear, anger, and frustration. By using avoidance and denial, they reduce their anxiety and possible depression.

For those who cannot tolerate group sessions, written material in the form of newsletters, educational pamphlets and books may be a preferred route for learning about the experiences of others and for obtaining information related to their condition. By this means they can have more control. They can choose to read it now, later, in small amounts, or never.

Those who are dealing with strong emotional reactions and those who need to remain in some control may find individual psychotherapy preferable to group participation. In individual therapy they can have more control over the pace at which they confront their fears and frightening memories. They can also maintain their privacy, something dear to them after years of hospitalization and medical treatment.

There are other reasons that may cause people to avoid support groups. For one, they may be getting emotional support elsewhere, from family, friends, professionals, or religion.

Factors related to the group itself may play a role. Some may not feel comfortable with the leader or other group members. For example, there may be those who blame all their life problems on polio and attend group sessions for emotional support independent of polio. The enormity of their emotional problems and their extreme neediness may interfere with the group processes, alienating and frustrating other members and causing them eventually to leave the group.

People who had polio when they were infants have concerns that differ in some respects from those persons who contracted the disease when they were adolescents or adults. The former group may have a greater need to find out what happened to them, since they were too young to understand or to remember. Now they hope to learn through the experiences of others.

Those who were older have more vivid memories of contracting the illness, of stays in convalescent homes and hospitals, of unpleasant experiences with "helping" professionals and treatments. They may not be so eager to relive these memories by talking about them with others.

(continued on next page)

Support Groups: WHO CAN BENEFIT?

(continued from page 7)

The severity of disability resulting from polio may play a role in assimilation into a group. Some polio survivors were left with a less serious or less visible disability. They may feel they do not need the group support, whereas others may feel that those who are more disabled may not take their complaints seriously (and indeed this can happen in groups).

Also, being with those who are more disabled may be too frightening to those who have lived most of their lives with little or no disability and now are facing the possibility of becoming more seriously disabled.

ALTERNATIVES AND APPROACHES FOR SUPPORT GROUP LEADERS

- o Recognize the differing needs and coping styles of polio survivors. Periodically survey your membership for their ideas and evaluations of your services.

- o Be clear about the objectives of your group meetings. Remember group dynamics are not for everyone, and some may prefer one type of group format over another (support, educational, cognitive, behavioral, psychodynamic). Often the more homogeneous the group the better it functions.

- o Make referrals for individual psychotherapy when you feel people may be harming themselves through "serious denial" or have other serious emotional problems. Do not be afraid of losing control by making outside referrals or sharing information. You will be respected for being well-informed and responsible.

- o Conceive of the support group more broadly, perhaps as a network or a club with the support group being one part (including a speakers series, a newsletter, phone networking, a referral ser-

vice for medical and psychological care). Some may not need your help right now, but should their situation change, they will know that the services are there.

Margaret E. Backman, Ph.D. is a psychologist at Barnard College, a Clinical Instructor in Psychiatry at New York University Medical Center, and Associate Professor at New York University. Her address is Suite 902, 30 East 40th Street, New York, NY 10016.

*Support Groups: IS OUR GROUP NORMAL?

By Ruth Wilder Bell, Ph.D.,
Columbia, MD

When support group leaders share experiences and describe their support groups, it quickly becomes apparent that a separate and unique personality exists for each group. Group theorists use the term "syntality" to describe for a group what the term "personality" describes for an individual. And, just as individuals progress through relatively discrete developmental stages, each with its own growth-producing task to be accomplished, groups too pass through developmental stages on the way to becoming a mature group.

An awareness of the stages of group development and the work to be accomplished at each stage is useful to support group leaders as they facilitate effective group functioning.

OVERVIEW OF GROUP STAGES

Individuals are attracted to groups when they believe that they can meet their needs and achieve specific goals better in the group

than individually. However, to become involved with a group means a willingness to be identified with that group and to risk closeness with other group members.

Closeness, a central theme of group life, increases as a group progresses through the developmental stages. While there are multiple theories of group development, all theorists describe similar characteristics of a group as it deals with intimacy in progressing from a young to a mature group. The categories used by the Boston University School of Social Work (Bernstein 1965, 1973) are those used in the following discussion. The five stages of group development are: (1) pre-affiliation, (2) power and control, (3) intimacy, (4) differentiation, and (5) separation.

Pre-affiliation. This first phase is characterized by what psychologists term "approach-avoidance" behavior. That is, individuals at one moment seem involved and ready to make a commitment to the group and at the next moment, they withdraw and may not seem interested at all. Attendance may be sporadic, reflective of the general ambivalence regarding identification with other members of the group or with the goals and activities of the group. The role of the leader during this phase is to allow and support this "cautious arm's length" exploration while at the same time patiently inviting trust and involvement.

Power and Control. During this stage, members who have now resolved their ambivalence about involvement in the group begin to make arrangements to handle the work of the group. The leader is seen as the one holding the power and is still held responsible by the members for the group's success. Jockeying among the members for favor and attention from the leader is characteristic member behavior. An effective leader, how-

ever, does not respond to the competition for attention and treats all members as equals encouraging them to take increasing responsibility for the success of the group. As this stage closes, members have made a significant investment in the group and have accepted some responsibility for the group's outcomes.

Intimacy. Group cohesion and a sense of belonging flourish during the third stage. The group is now seen as a safe place in which feelings can be expressed and new experiences tried. The group looks less and less to the leader as a source of gratification or for solutions to problems. Members increasingly accept and share responsibility for group functioning and are able to carry out the work of the group.

Differentiation. During this stage, the growth of closeness and the level of intimacy between members that became apparent during the preceding stage continues. There is increasing recognition and acceptance of individual needs. A unique situation has been created in that while the group is cohesive with its own personality and expectations for members, the integrity of individual members is fully respected. The leader is needed less and less and the group increasingly runs itself.

Separation. Separation occurs when the group has met its purpose and the members are ready to move on, taking with them what they have learned from the group. As members prepare to leave the group they may revert to old behaviors, looking once again to the leader for direction. An appropriate role for the leader is to "let go," encouraging members to review both the group's accomplishments and what they as individuals have learned from the group. Particularly useful is a discussion of how experiences in the group can be transferred to new situations.

(continued on next page)

**Support Groups: IS OUR
GROUP NORMAL?** (continued from page 9)
IMPLICATIONS FOR POST-POLIO GROUPS

Guiding a support group through these stages, mobilizing the strengths that come with the cohesion and closeness of the later stages is no easy matter. A characteristic of support groups which makes the task more difficult is that while there may be a core of members who attend regularly and as such are the "culture bearers" of the group, there is also a pool of people who cycle in and out, perhaps not having been able to resolve their initial ambivalence about attending. They need to be caught up or reoriented each time they come. And at any meeting there are likely to be those who are attending for the first time and aren't sure what the group is about and whether they even want to participate.

These three groups, the core members, those who cycle in and out, and the newcomers, are in different places emotionally. It is the leader's task to respect their need to be close or not close and set the stage for an environment in which individual differences are respected and individual needs can be met.

A few suggestions to help create such an environment are:

- o Have someone available to greet newcomers, provide introductions and a brief orientation to the group.

- o Encourage core members to discuss what it was like for them when they first began attending. Hopefully, this will encourage sensitivity toward those who are not ready for the same level of intimacy they are.

- o Watch new members, or those who attend sporadically for signs of uncomfortableness if the discussion involves significant sharing.

At the end of the meeting the leader might speak privately to these folks, letting them know that they will not be pressured to share.

- o Respect the right of members to attend at intervals, depending on their need and readiness for the group. The leader can express interest in these members by making arrangements for another member to call periodically just to say "Hello." Delegating to another member conveys the notion that members share responsibility for the group. It is not the leader's job alone.

- o Begin each meeting with a "check in" time, a time when members catch up with each other since the last meeting. Because sharing is voluntary, it protects those who are not ready to participate, but also communicates that the meeting is a safe place for members to share with each other, should they desire to do so.

There are many other things that a leader and the members can do to provide for an environment in which needs can be met. It might be interesting to have a discussion with the entire group about ways the group can meet the needs of those who are at different levels of intimacy and identification with the group. Such a discussion communicates a sense of shared responsibility for the life of the group and, in fact, in and of itself facilitates the group's growth and development. Time spent nurturing the group as a whole, as well as the individuals in the group, is time well spent.

Reference: Bernstein, S. (Ed.). (1976). Further explorations in group work. Boston: Charles River Books.

Ruth Wilder Bell, Ph.D. and polio survivor, is leader of the Polio

Society of Howard County, Columbia, MD and Assistant Professor at the School of Nursing, University of Maryland. Her address is Department of Nursing Education, Administration & Health Policy, University of Maryland, 655 West Lombard Street, Baltimore, MD 21201.

Support Groups: WHERE ARE THE SPOUSES?

By Jim Miller, Wichita Falls, TX

"You teach best what you most need to learn." I got that from Richard Bach's book, Illusions, some years ago, and it was the first thought I had when Joan Headley asked me to elaborate on a column I had written for our local group's newsletter following IPN's Support Group Leaders' Workshop last June.

I've been a writer most of my life, and part of that time I've even been a successful writer, but at no time had I been asked to submit to a respected publication of international scope. So it's not like I was feeling any kind of male-macho-ego desire-to-perform-and-to-please pressure to produce an intelligent piece on mixed marriages. Not the kind our folks whispered about when we were kids, but rather a close interpersonal relationship involving a nondisabled member and a physically disabled member.

I have lived with a polio survivor for five-going-on-six years now, an often intense learning experience for one whose former association with physical disability was watching "Ironsides" on TV. I still catch myself at odd moments - like when the cat, the dog and the 14-month-old grandson are playing King of the Mountain on her lap - looking at my wife, B.J., and wondering, "Why? Didn't she have enough problems without marrying an English major with two teenagers and a Judeo-Christian guilt complex?"

There must be others out there like me who married into the post-polio network. Most likely it wasn't planned that way, either. When I met B.J., she was a fully-employed professional in need of a full-time lover and part-time domestic manager who would write best sellers in his spare time. Within three years of the I Do's having been done, she was an early disability retiree and totally wheelchair dependent.

But, when it comes to independence, B.J. is typical of most polio survivors. I'm talking about a woman who mainstreamed the University of Dallas on crutches, braces, and a wheelchair before Section 504 legislation, graduating cum laude in biology just to prove to her father she could study with both the radio and TV on. Early retirement at age "fortysomething" wasn't exactly her life agenda.

By contrast, my picture features prominently in the unabridged dictionary under instant gratification. Excelling at impatience and procrastination, I think, is simply a manifestation of my hidden handicap (all we so-called "normals" have them whether we're ready to admit it or not) of being left-handed. Cruising in right through a left-brained world means for me that I struggle with another kind of PPS, namely the Peter Pan Syndrome.

Thus, that B.J. and I were attracted to one another is mysterious. That we're still together and both breathing after five-going-on-six years is stretching the bubble of credibility. I can only attribute the fact that our relationship works, albeit not always well, to there being a God, and B.J.'s ultimate sense of humor.

Part of our adjustment to B.J.'s post-polio syndrome began while she was in physical therapy. She started a survivors' support group, the first between Dallas-Ft. Worth

(continued on next page)

Support Groups: WHERE ARE THE SPOUSES?

(continued from page 11)

and Oklahoma City. Response was staggering. Monthly meetings drew good crowds to hear excellent speakers. Within six months our first real newsletter went out to nearly two hundred addressees in a half a dozen states. For the better part of that first year, B.J. was running this one-woman show with support from the North Texas Easter Seal Rehabilitation Center and the North Texas Division of March of Dimes.

B.J. and I celebrated the first anniversary of the group's founding by attending the group leaders' workshop in St. Louis at March of Dimes' expense.

As I told the others, I was there because I had heard that St. Louis had a decent zoo and somebody had to drive. Feeling indebted to the March of Dimes for picking up the tab on our first vacation since marrying, I wrote a column for our group's newsletter about my workshop experience.

The piece concerned the invisibility of survivor spouses within the network. The piece caught Joan's attention and after agreeing to send her something expanding on the column, I dug the piece out of the files and re-read it. No doubt I thought it good when I wrote it. However, from the perspective of two months later, although it still read well, I didn't have the foggiest notion of what I had been trying to say. Joan allowed a speculative tack.

What I had noticed in St. Louis was the same phenomenon I've been observing in our local group for two years. Survivor spouses are conspicuously absent. When we do attend meetings, we're the invisible people.

How come?

Surely we don't believe that PPS only affects our partners. Do we?

Being married to a wheelie is much like being left-handed. At times it seems the whole world and half your close kin are conspiring against you over a stupid physicality. A mixed marriage affects the kind of car you drive, the social functions you do or do not attend, which theaters you can or cannot get into, and how the furnishings in your home are arranged. Vital issues for other couples, such as the proper rest position for a com-mode seat, pale in comparison to which shelf the peanut butter lives on.

I cannot believe we survivor spouses believe PPS is our partner's problem. I'd much sooner believe that a survivor spouse has yet to stand up and say, "Hi, my name is Jim, and what about us?" I'm asking now because we survivor spouses need to be involved, and I'm not talking simply setting up and taking down chairs. I realized this need early on when I heard a polio survivor say about her husband, "He says I wasn't having any (physical) problems until I started coming to these 'damn meetings.'"

Clearly, we survivor spouses need to talk just as our polio partners have been doing for some years now. And if it's so that we're not quite comfortable yet with talking with our spouses, we at least need to be talking to each other. We need some kind of dialogue to help us realize our roles as the relatively able-bodied members - arthritis, bursitis, middle-age spread, and various other late effects of ill-spent youth notwithstanding - of this far-flung network team.

That this need for dialogue is legitimate is attested to, I believe, by the fact we survivor spouses have been placed on the agenda of the 1989 Fifth International Polio and Independent Living Conference. We need to start talking now if one

hopes to be in St. Louis with worthwhile questions.

You may write to me, Jim Miller, in care of PSSG-WF, 4503 Allison Drive, Wichita Falls, TX 76308. I admit here and now that I have no answers. I'm still looking for the questions. But who better to teach us what we need to know than ourselves with the help of our polio partners? Who better to learn from than one another?

You see, we really do teach best what we most need to learn.

Jim's wife, Barbara, and the Post-Polio Support Group of Wichita Falls, TX are busy organizing the Texas-Oklahoma Post-Polio Symposium scheduled for April 29-30, 1989 in Wichita Falls.

Program Ideas

International Polio Network (IPN) receives many requests for program ideas. Below is a listing of possible programs. Remember, it is not necessary to have a speaker at every meeting. If a speaker is invited, try to find a professional who will talk and listen and not pontificate. Plan for no more than 10 minutes of speaking time and allow plenty of additional time for questions and discussion.

Titles:

- "Bridging the Gap from Dependence to Independence"
- "Motor Control and Muscle Imbalance"
- "Pain Management"
- "Know Your Anatomy - Basic Terms"
- "Social Security Disability Determination"
- "The Psychology of the Late Effects of Polio"
- "Environmental Barriers"
- "Stress Management"

- "Breathing Obstacles"
- "Arthritis and Post-Polio"
- "Coping Strategies for the Disabled"
- "The Disability Culture"
- "Accessibility Issues"
- "Furniture, Fashion, and Accessories for Special Needs"
- "Sharing Time"
- "Motion Economy - Saving Energy"

Speakers from:

- state funded agencies
- disability advocacy groups
- coordinator of educational programs at a health center
- local hospital
- area post-polio clinic
- vocational rehabilitation agency
- local rehabilitation center

Specialists:

- chiropractor
- dietician
- occupational therapist
- orthotist
- psychologist
- pulmonologist
- respiratory therapist
- rheumatologist
- speech therapist

IPN Membership Renewal Notices

In October, IPN mailed renewal notices to individuals whose memberships are due this quarter. Renew by returning the card with a check for \$8.00 so you will receive the Winter Polio Network News (Vol. 5, No. 1) and the 1989 Post-Polio Directory.

Post-Polio Directory

The 1989 Post-Polio Directory will be updated this quarter and published in February 1989. Please check the 1988 Post-Polio Directory and the Supplement for additions, deletions, and corrections. Mail any changes to IPN, 4502 Maryland Avenue, St. Louis, MO 63108 or call Joan Headley at 314/361-0475.