

POLIO NETWORK NEWS

International Polio Network

4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

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Fall 1988 • Vol. 4, No. 4

Fifth International Polio & Independent Living Conference

Sheraton St. Louis, St. Louis, MO • May 31 – June 4, 1989

Wednesday, May 31.

INDEPENDENT LIVING WORLDWIDE.

Social policies around the world and how they affect persons with disabilities; existing limitations for persons with disabilities and ways of raising expectations.

Thursday & Friday, June 1-2.

LATE EFFECTS OF POLIOMYELITIS.

Symptoms, management, and latest research information on the late effects of polio; psychological and attitudinal adjustments for all persons involved.

Saturday, June 3 (A.M.).

ETHICAL CHALLENGES AND SOCIAL POLICIES OF DISABILITY AND AGING.

Ethical challenges facing persons with disabilities from birth to death with particular concern for involvement by persons with disabilities in all decision-making processes.

Saturday, June 3 (P.M.).

HOME MECHANICAL VENTILATION WORKSHOP.

Symptoms of underventilation, anesthesia in severe disability; medical, equipment, and support options for present and future ventilator users.

Sunday, June 4.

SPECIAL INTEREST WORKSHOPS.

For Men Only, For Women Only, Legal Rights and Legal Issues, Financial Planning, Support Group Leader's Role as a Peer Counselor, Computer Adaptations, Recreational Adaptations.

Friday - Sunday, June 2-4.

ABILITIES EXPO - MIDWEST.

Products for persons who are aging and for people with physical disabilities will be displayed at the Cervantes Convention Center across from the hotel by RCW Productions, Inc., Encinitas, CA.

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Fifth International Conference

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PURPOSE: To share medical, psychological, and experiential knowledge to assist polio survivors, ventilator users, and other persons with disabilities to live independently and productively in the community.

To inform polio survivors, ventilator users, and health professionals about the latest research, symptoms, and management of the late effects of polio.

PARTICIPANTS: Polio survivors, ventilator users, other persons with disabilities, their families and loved ones; general practitioners, physiatrists, pulmonologists, neurologists, orthopedists; rehabilitation psychologists, counselors, and nurses; orthotists, physical, respiratory, and occupational therapists; health service providers.

SITE: Meetings will be held at the Sheraton St. Louis Hotel, 910 North Seventh Street, St. Louis, MO 63101 (314/231-5100).

SPECIAL MEETINGS: Directors of post-polio clinics will meet for dinner Friday June 2 in the hotel. Support group leaders will meet for breakfast Sunday June 4.

FRIDAY NIGHT IN ST. LOUIS: Friday evening (June 2) dinner will not be included in the meal package. For advanced information about the city of St. Louis, scheduled events, accessible restaurants, etc., contact St. Louis Convention & Visitors Commission Tourism Information: 1-800-247-9791. For the brochure "Access St. Louis," contact Office on the Disabled, City Hall, Room 30, St. Louis, MO 63103 or call 314/622-3686.

TRAVEL: Trans World Airlines (TWA), the official conference carrier, will offer special fares to St. Louis. The following toll-free numbers are staffed between 7:15 A.M. and 7:00 P.M. (CT): United

States (except MO): 1-800-325-4933; Missouri (except St. Louis): 1-800-392-1673; St. Louis: 314-291-5589. Please refer to "profile number" 9914194 for domestic travel.

International travellers wishing to use TWA should contact Flying Wheels Travel, Owatonna, MN (1-800-533-0363) and ask for Sharon.

Also, contact Flying Wheels Travel, P.O. Box 382, Owatonna, MN 55060 (1-800-533-0363) for a travel agency with experience in making travel arrangements for persons with disabilities.

VENTILATOR SERVICE: LIFECARE will supply ventilators and service throughout the conference. Some of the service is gratis. For details contact Jack Craigs, LIFECARE, 408 NW Business Park Lane, Riverside, MO 64150 (816/741-7667).

EQUIPMENT RENTAL: Arrangements are being made for three-wheeler, etc., equipment rental.

REGISTRATION: The registration form and final details will be published in the Winter Polio Network News.

Abilities Expo-Midwest

Abilities Expo-Midwest, a consumer show benefiting persons with disabilities and seniors, will be joining the Fifth International Polio and Independent Living Conference in St. Louis.

The show will run from Friday June 2 to Sunday June 4 at the Cervantes Convention Center directly adjacent to the Sheraton St. Louis, the site of the Conference.

Dick Wooten, general manager of RCW Productions, Inc. reports the new Abilities Expo-Midwest has received a tremendous reception by both ex-

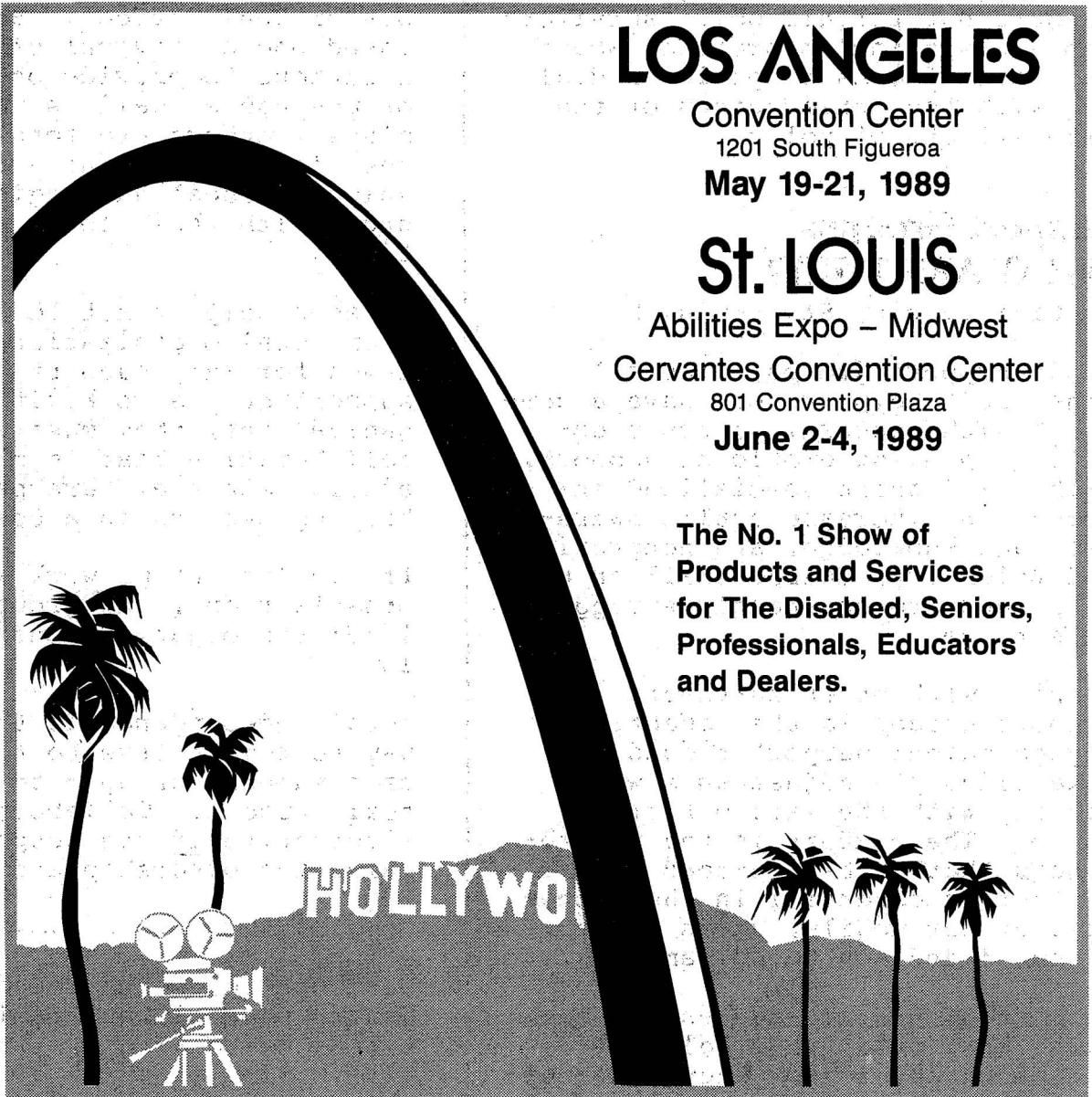
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ABILITIES EXPO '89

New 2nd Location!

Now Showing in St. Louis!

LOS ANGELES



LOS ANGELES

Convention Center
1201 South Figueroa

May 19-21, 1989

St. LOUIS

Abilities Expo - Midwest
Cervantes Convention Center
801 Convention Plaza

June 2-4, 1989

The No. 1 Show of
Products and Services
for The Disabled, Seniors,
Professionals, Educators
and Dealers.



St. LOUIS

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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

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Support Groups: WHO NEEDS THEM?

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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.

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Support Groups: WHO CAN BENEFIT?

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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.

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**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

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Support Groups: WHERE ARE THE SPOUSES?

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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.



What People with Disabilities Hope for from Other People

By Robert J. Ronald, SJ, Taiwan

PLEASE DON'T NOTICE ONLY OUR DISABILITIES.

They are the first thing that you see, but they are not the most important thing there is to know about us. We hope that when you see us you will say to yourself, "Here's somebody like me, who may have some abilities, interests, or aspirations similar to mine. I wonder if there is anything I can do to help keep the disability from standing in the way of their realizations."

PLEASE DON'T EXAGGERATE OUR DISABILITIES OR SUPPOSE WE'RE ALL ALIKE.

People have shouted at me as though I were also deaf and talked to me like a child as though I had never grown up. Or because I'm in a wheelchair like their grandfather who just died, they think they know all about me. We hope that you will think when you see us, "Here is somebody who has something interesting to say if I will stop and listen. And something interesting to do if I'll give him or her the chance."

PLEASE DON'T THINK OF US ONLY AS PEOPLE WHO CANNOT DO THINGS.

We are just people who cannot do some things the regular way. I cannot walk from here to there, but with a good wheelchair I can still go from here to there. A blind person cannot see the words in a book, but with braille can read the book. We hope that when you see us you will not say to yourself, "How sad that this person can't do the things I like to do or go the places I like to go or work where I do." We hope you will think instead, "Too bad about the limitations, but no matter. What kind of training or special equipment or ramps are needed, so that he or she can also do the things I like to do

or go the places I like to go or work where I work?"

PLEASE DON'T DENY OUR DISABILITIES OR TREAT THEM LIGHTLY.

They are something very real to us with serious, permanent effects on our lives. We hope that you too will acknowledge the difficulties we face and pitch in to help us remove the barriers and problems. If we are discouraged, encourage us not by distracting us to think of something else but by showing us practical ways of coping.

PLEASE FEEL WITH US OUR GRIEF AND ANGER AND FRUSTRATION.

Often the best way of handling such feelings is to get them out in the open where they can dissipate. Don't take as personal insult or rejection what we might say or do in your presence on such occasions. Instead of just telling us to shut up or to cool it, show us you understand and empathize with our point of view. But if we persist in bemoaning our losses, make your encouragement practical. Point out to us all the things we can do. Help us find a goal for our lives that appeals to us and which we can attain even with our disabilities. Then as our friend show us how to reach that goal.

PLEASE DON'T THINK THAT WE ARE ALL INFERIOR AND DEPRESSED AND WOULD RATHER STAY WITH OUR OWN KIND.

Sometimes this is true, but if we manifest fear or hesitation or distrust or believe that we cannot do a lot of things, it is usually the result of bitter experience. Some people stare at us, avoid us, laugh at us, pity us, overprotect us. Everywhere we meet barriers. We have learned inferiority from being relegated to inferior status. What we hope for from you, therefore, is positive regard and feedback. We will more readily learn to value ourselves the more we experience you valuing us, accepting us as

friends and associates, and providing us opportunities for participation, self-expression, growing, and giving.

PLEASE DON'T PITY US.

Disclosing horror or sadness at our situation only makes us feel worse. We need solutions not commiseration. Show us you believe these obstacles can be overcome. Show confidence that we can still lead wonderful, full lives. Don't deny the hard work or the difficulties that lie ahead of us, just help us move forward.

PLEASE DON'T BE AFRAID TO NOTICE OUR DISABILITIES OR ASK QUESTIONS, BUT DO IT RIGHT.

Curiosity is not always bad, since asking each other questions is one of the best ways that friends have of getting to know each other. So look at us, ask all the questions you want, but just don't treat us like animals in a zoo without feelings. It is degrading when people pay all their attention to our wheelchairs, caring nothing about us. When you look and speak, do so in a way that shows respect for us as persons and interest in us as potential friends. And don't forget to give us a chance to know something about you, too.

PLEASE DON'T MAKE DECISIONS FOR US OR TELL US WHAT WE SHOULD DO.

What we are and wish to do should not be defined by our disabilities but by the nature of our particular abilities, interests, aptitudes and ambitions. We may need your suggestions and advice for which we will be grateful. We may even need to be cautioned if we want to bite off more than we can chew, but remember, it is the size of my mouth and not yours that determines how much I can chew.

PLEASE OFFER US HELP, IF YOU SEE THAT WE NEED IT.

Please ask first whether the assistance is wanted; then ask how the help should be given. Do it as inconspicuously as possible. You may

want the whole world to see that you are doing your good deed for the day, but we would rather no one noticed that we could not do things for ourselves.

PLEASE BE PATIENT WITH US AND FAIR.

We people with disabilities are not perfect, nor always on our best behavior. In this, unfortunately, we are all too normal. Like everyone else, we are sometimes in the dumps and sometimes on cloud nine; sometimes lazy, demanding help we really don't need; sometimes stubborn, refusing even the assistance we do need; sometimes friendly, sometimes hostile; sometimes placid, sometimes angry. We do not ask you to ignore our faults. We should be accountable for our actions like everyone else. But at least show us as much tolerance for our short-comings as you show your other friends and colleagues for theirs.

PLEASE DON'T TELL US HOW WONDERFUL WE ARE BECAUSE WE SMILE SO BRAVELY OR TRY SO HARD.

In the first place, we already know it, having been told so a million times before. In the second place, this is actually rather discouraging. Here we are just trying to do the ordinary things every one else does all the time and someone gushes over us as if it were something extraordinary. This tells us the person really thinks our disabilities are awful and our capabilities low. Yes, we do have to try harder. Yes, we do deserve credit for the extra efforts we have to make, but we would much rather have you pitch in and help us reach the rest of our goals than just applaud what we have already achieved.

PLEASE DON'T TELL US WE ARE ALREADY DOING ENOUGH OR TO STOP TRYING SO HARD.

It makes some people uncomfortable to see us struggling with our wheelchairs or assistive devices or they want us to accept our disabled lot quietly, graciously submitting

(continued on next page)

What People Hope For

(continued from page 15)

to the status of being served instead of trying to serve. Perhaps some of us have reached the limits of our capabilities or are content to maintain our present positions, but the decision when to stop should be ours, not yours. Many of us still have abilities and inner resources we want to develop and use, even if it is going to be difficult. Disability does not take away our right to pursue the full development of our potentials. Instead of preparing us a comfortable place to rest at the bottom of the stairs, we would rather you help us find a way to get up the stairs to where the action is.

Rev. Robert J. Ronald, S.J. wrote this article when reflecting on his thirty years of living with a disability for the 30th Anniversary edition of the Rehabilitation Gazette. Father Ronald, a polio survivor, will attend the Fifth International Polio and Independent Living Conference in St. Louis. His address is Operation De-Handicap, P.O. Box 7-553, Taipei, Taiwan 10098 R.O.C.

Rehabilitation Gazette

Members of Gazette International Networking Institute (G.I.N.I.) and subscribers of the Rehabilitation Gazette were sent renewal notices in early September. Vol. 29, No. 1 & 2 of the Rehabilitation Gazette, a special 30th anniversary double issue, will feature the reflections and motivations of individuals with a disability that have lived fully and productively in their communities for more than 30 years. This Gazette will be published at the end of the year.

Abilities Expo-Midwest

(continued from page 2)

hibitors and show visitors. "With more than six months to go, exhibitors have already purchased approximately half of the booth space and for a first show, that is a fantastic start."

The Los Angeles Abilities Expo will be held May 19-21, 1989 at the Los Angeles Convention Center. Over half of the booths are sold for this fifth annual show.

Both the Los Angeles and St. Louis shows will have a series of one-hour workshops presented by exhibitors who have expertise in their particular area.

For further information about either show, write to RCW Productions, Inc., 1106 2nd Street, Suite 118, Encinitas, CA 92024 or call 619/944-1122.

New Post-Polio Clinics

San Jose, CA: Michael Berlly, M.D., Valley Health Center, Department of Physical Medicine and Rehabilitation, 750 South Bascom Avenue, San Jose, CA 95128 (408/299-8082).

Nashville, TN: James Little, M.D., Tennessee Christian Medical Center, 500 Hospital Drive, Madison, TN 37115 (615/865-9105).

POTPOURRI

Dr. Maynard Receives Grant

Frederick Maynard, MD and his team at the University of Michigan Medical, Ann Arbor, MI has received \$200,000 for the first year of a two-year project. The purpose of the grant, awarded by the Centers for Disease Control, Atlanta, GA, is to develop a practical questionnaire that can be used by public health personnel to identify potentially preventable secondary disabilities among polio survivors. Starting in the spring of 1989, 125 Michigan residents with the late effects of polio will receive a 4-hour physical exam to confirm the self-perceptions of the participants about their physical condition.

Polio Outbreak in Israel

From July 31 to September 28, 1988, 16 persons in Israel (population 4.6 million) were reported with confirmed or suspected paralytic poliomyelitis. Because of the outbreak, vaccination of all persons up to 40 years was carried out.

In developed countries such as Japan, Australia, New Zealand, Canada, and the countries of industrialized Europe, the risk of acquiring poliomyelitis is usually no greater than in the United States. In contrast, all developing countries generally should be considered endemic for polio. Proof of polio immunization is not required for international travel. However, the Immunization Practices Advisory Committee (ACIP) recommends that travelers to countries where polio is occurring, which now temporarily includes Israel, be immunized. Consult your personal physician before traveling abroad.

The booklet "International Travel & Your Health" may be obtained by contacting the UCLA Travel and Tropical Medicine Program, UCLA

Medical Center, 10833 Le Conte Avenue, Los Angeles, CA 90024.

Canadian Conference

A national conference on the late effects of polio convened November 3-5, 1988 in Toronto. Under the auspices of the Ontario March of Dimes with assistance from the National Department of Health and Welfare, the conference attracted over 240 polio survivors and health professionals from all across Canada.

The conference, chaired by Jeanette Shannon and coordinated by Shirley Teolis, addressed the many issues relating to the late effects of polio, increased Canada's awareness of the problem, and expanded the network of polio survivors.

Among the physicians participating were Vera Brill, FRCP(C), Neil Cashman, MD, Peter Cameron, FRCP(C), Marinos Dalakas, MD, Rubin M. Feldman, FRCP(C), William M. Franks, FRCP(C), Joseph Kaufert, PhD, Marek J. Gawel, FRCP(C), Roger S. Goldstein, FRCP(C), Cecil Hershler, FRCP(C), William J. Litchy, MD, and Karen E. Pape, FRCP(C).

IPN was represented by Gini Laurie and Joan Headley. Gini Laurie was the luncheon speaker on Saturday and explained the worldwide perspective on the post-polio support group network.

World Health Day

World Health Day is an international observance of global health issues that takes place in 166 countries and the United States each year on April 7. The 1989 theme is "Health For All: Pass It Along." For more information and a complete planning kit, write: American Association for World Health, 2001 "S" Street, N.W., Suite 530, Washington, D.C. 20009 or call 202/265-0286.

POTPOURRI

Americans With Disabilities Act
A hearing on the Americans with Disabilities Act (ADA) before the Senate Subcommittee on the Handicapped and the House Subcommittee on Select Education was held September 27. This very successful and well-attended hearing provided momentum for the ADA for 1989.

Continue to urge your Senators and Congressmen to sponsor this important act which will be re-introduced in the 101st Congress after the first of the year.

Ventilator Resources

Many long-time ventilator users have found that their equipment company has been "bought out." Jerry Daniels, Vancouver, WA has compiled a listing of ventilator manufacturers and distributors along with the equipment they sell and service. Send a self-addressed stamped envelop to IPN, 4502 Maryland Avenue, St. Louis, MO 63108 for a copy.

Resources for Foot Problems

For a directory of certified pedorthists in the United States, Send \$1 to ASI, 718 Arch Street, Philadelphia, PA 19106.

For the name of a pedorthist in your area call the Prescription Footwear Association, 9861 Brokenland Parkway, Columbia, MD 21046 (301/381-7278).

For referral to the nearest health professional to cast a mold for custom-made shoes contact Jerry Miller I.D. Shoes, Marble Street, Whitman, MA 02382 (617/447-6671).

For the location of the nearest BIO-PED foot care centres in Ontario, Canada, call 416/896-4825.

Sharon Redmond, La Jolla, CA writes that she can purchase her two sizes of shoes for the price of one at Nordstroms Department Stores in California, Oregon, and Washington.

Polio Information

The Post Polio Program of the Polio Network of Illinois has a new toll-free number for use in the state: 1-800-24-POLIO.

The Polio Network, Inc. serving Michigan has opened their library for post-polio information. June Shelly, whose husband Leon is a polio survivor, is the Director of the Brandon Township Library in Ortonville, MI. Visit the library, located between Pontiac and Flint, at 476 Mill Street, P.O. Box 489, Ortonville, MI 48462 or call 313/627-6449.

Publications

ACCENT Buyer's Guide

The 1988-89 Edition of ACCENT Buyer's Guide is available from Accent Special Publications, Box 700, Bloomington, IL 61702. A payment of \$10 (Canada, Mexico, and other foreign countries add \$.50) must accompany the order for this 145-page updated guide of hundreds of products and sources for persons with a disability.

Building a Ramp

A 57-page consumer manual on planning and constructing a ramp may be purchased for \$10 from Independent Living Resource Center, Inc., Box 55127, Little Rock, AR 72225.

Cookbook

Nebraska Polio Survivors Association has published a personalized

cookbook with full color cover, tabbed dividers, and 550 prized recipes. Write NPSA, P.O. Box 37139, Omaha, NE 68137. Books are \$7 each, plus mailing fee in USA of \$2.50 for 1 to 5 books, \$3.75 for 6-10 books.

Direct Link

A quarterly publication of the Center for Computer Assistance to the Disabled is free and may be obtained by writing C-CAD, 2501 Avenue J, Suite 100, Arlington, Texas 76006-6191.

Guide to Federal Help

A free copy of the 26-page booklet, "Pocket Guide to Federal Help for Individuals with Disabilities," is available from Clearinghouse on the Handicapped, U.S. Department of Education, 330 C Street S.W., Room 3132, Washington DC 20202.

Handbook on the Late Effects

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors edited by Gini Laurie, Frederick Maynard, MD, D. Armin Fischer, MD, and Judith Raymond utilizes a practical dictionary format to relate information on such topics as aging and weakness, diet, exercise, frog breathing, hospitalization, misdiagnosis, oxygen misuse, sleep apnea, vaccines and ventilators. Send \$6.75 to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. (Discount prices for bulk orders.)

History of IL Movement

To order a 37-page monograph of A People's History of the Independent Living Movement by Chava Willig Levy contact RTC/IL Training Department, University of Kansas, BCK/348 Haworth, Lawrence, Kansas 66045-2930 (913/864-4095).

IVUN NEWS

Membership in the International Ventilators Users Network is available to all ventilator users, their families, and health professionals interested in home mechanical ventilation. Members will receive the IVUN NEWS, a biannual newsletter, featuring individual experiences, family adjustment, equipment and techniques, community support systems, travel, and resources. The fall issue features underventilation and is an excellent resource for anyone having breathing problems. Send \$5 for ventilator users or \$15 for health professionals (\$3 extra for postage outside the U.S. and Canada) to IVUN, 4502 Maryland Avenue, St. Louis, MO 63108.

Pain - Learning to Live Without It

David Corey, PhD, director of the Behavioral Health Clinic in Toronto, Canada, works from the premise that all pain is real and is "not in your head." In his book, he explains how the body's pain system works and then offers strategies to reduce pain. To order mail \$14 Canadian or \$12 U.S. to Canada Publishing Corporation, Attn: Mary Henderson, 164 Commander Blvd., Agincourt, Ontario, M1S 3C7.

The Self-Help Sourcebook

The new updated edition of a comprehensive national guide to finding mutual aid and self-help groups is available from Self-Help Clearinghouse, St. Clares-Riverside Medical Center, Pocono Road, Denville, NJ 07834. Send \$8 for book-rate postage or \$9 for first class postage to receive this valuable resource.

International Polio Network

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St. Louis, MO 63108 U.S.A.

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Calendar

December 4-7, 1988. Rehabilitation and Geriatric Education: Perspectives and Potential. Hyatt Regency Crystal City, Arlington, VA. Contact: Registration Coordinator, The Circle, Inc., 8201 Greensboro Drive, Suite 600, McLean VA 22102. 703/821-8955.

January 26-27, 1989. International Conference on Home Mechanical Ventilation. J.I.V.D. Service de Reanimation - Assistance Respiratoire Hopital de la Croix-Rousse, 93, Grande-Rue de la Croix-Rousse, 69317 LYON Cedex 04 - France Tel. 78.39.54.06.

March 30-April, 1989. Symposium on Life Threatening Conditions: Self-Help Groups and Health Care Providers in Partnersip. McCormick Center Hotel, Chicago, IL. Contact: Hannah L. Hedrick, Ph.D., American Medical Association, 535 N. Dearborn, Chicago, IL 60610. 312/645-4697.

April 5-8, 1989. Respiratory Care from Prevention to Disease Care - The Full Spectrum. Webb-Waring Institute, Denver, CO. Contact: Louise Nett, R.N., R.P.T., Box C-321, 4200 East 9th Avenue, Denver, CO 80262.

April 29-30, 1989. Texas-Oklahoma Post-Polio Symposium. Wichita Falls Hilton, 401 Broad, Wichita Falls, TX 76301. Contact: Barbara Miller, 4503 Allison, Wichita Falls, TX 76308. 817/691-3497.

April 29, 1989. Post-Polio Conference. Oakbrook Marriott, Oakbrook, IL. Contact: Roberta Simon, R.N., 7835 Pine Parkway, Darien, IL 60559. 319/969-0287.

May 31-June 4, 1989. International Polio Network's Fifth International Polio and Independent Living Conference. Sheraton St. Louis Hotel, St. Louis, MO. Contact: Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108. 314/361-0475.