

## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** “There is some question about what all is expected and not expected of the leaders of our group. We have a couple of new members who have come in and seem to think that we don't ask for or take suggestions from anyone and that we are a three run group which we are not. We ask for help but none is really offered and I have tried as well as the two others to get people to be more forthcoming.”

**ANSWER:** Effective leadership is a great challenge these days with many support groups facing the changes our aging members require. Generally speaking, leaders are chosen for such traits as their innovative vision, their ability to speak to the emotional needs of the group, and the atmosphere of fairness and inclusiveness they create.

Many groups operate well through committees developed to carry out special tasks. A key here is for each committee to fully understand its function. If a steering committee or board has already established parameters, these should be stated clearly, but once a committee has been given a job, it must also be given complete authority to carry out that job.

Another tip some leaders use when they haven't gotten the hoped-for response to a general request for participation is to approach individuals one-on-one. Often it's not enough to say to a group, “We really need some help with the newsletter. If you'd like to participate, please sign up on your way out.”

It may take a call to Sue to ask if she'd use her writing talent for a column about anesthesia, a chat with Frank and Betty and Chris to see if they could stamp and label before next Friday, and a talk with Kelly about drawing a handicap parking cartoon. Getting specific usually yields results—and this might be just the job for a “casting” committee. Being singled out says something about our value to the group. The trick is to be sure everyone gets singled out.

Here's something we all know: Laughter is infectious—members love having fun with a project. Keeping things light relieves stress and often turns a chore into enticing play.

Today many support groups are shifting focus. Now we not only help those newly-diagnosed with post-polio syndrome, but we also have begun to explore what our groups can do for those who are aging with the late effects of polio. This brings with it the freshness and excitement of a new beginning.

\* Nancy Baldwin Carter and Joan L. Headley are co-authors of the chapter "Support Groups: Keeping Them Active and Useful" in Lauro Halstead, MD's new book *Managing Post-Polio: A Guide to Living and Aging Well With Post-Polio Syndrome*. Watch [www.nrhrehab.org](http://www.nrhrehab.org).

### **Why call the column LEADERSHIP?**

The symbol for infinity represents the boundless creative energy and limitless resourcefulness displayed by post- polio group leaders everywhere.

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**QUESTION:** “Our group is down to about half a dozen members who rotate meeting at each other’s homes for lunch once a month. I’ve heard of other groups that are losing members as well. What can we do to keep our post-polio data bases from eroding to the point where we lose all contacts and are then unable to help anyone?”

**ANSWER:** It’s true that some post-polio groups have lost members recently. It would be easy to attribute this to a lower energy level as we age and meet new health challenges. However, that wouldn’t paint the entire picture. There are many other reasons why a group’s membership falls off over time. A lack of rotation in leadership can lead to burnout. A group can quickly get stale when everyone doesn’t get involved, leading members to tire of it. Groups where all members aren’t included in decision-making can find it hard to stay alive.

Members who fit in the slowing-down category bring great strength to a meeting. They have the advantage of experience and knowledge that newcomers seek. Many groups create jobs for these valued members that others might find difficult to fill—jobs that can be done from home. For instance, taking newcomer calls most effectively requires the voice of one who has been there and knows what to pass on. Various computer tasks, such as writing certain types of articles for the newsletter or making personal cards of thanks, “missing you” or “loved your brownies” for the group to send are easily done in a leisurely way as we pace ourselves throughout the day. There are many such low-energy pursuits.

### GETTING THE JUICES FLOWING

More physically ambitious assignments are tackled by those on the second tier. That’s why it’s essential to have a second tier. Every day polio survivors discover they have post-polio syndrome—these are the potential newcomers who prove that the work of our groups is necessary. Developing effective outreach is essential. We need these people every bit as much as they need us. Perfect symbiosis. This represents the new blood that keeps our meetings active. Effective leaders are good at making room for new members and welcoming their fresh ideas and healthy enthusiasm.

Brainstorming is the key to revitalization. Start by bringing everyone to the table, including as many as possible of those who have left the group. Agree in the beginning to keep personalities out of the discussion. This has to be an open, friendly group, objective and supremely honest. Check egos at the door. Then get down to business. Listen to every voice. Examine every detail. Be specific:

- What made this group worthwhile in the beginning?
- What have we done that we’d like the group to repeat?
- What is stopping us from doing these things?
- What elements make up the vision of our ideal post-polio support group?
- How can we put these into play?
- What can we do to take the excitement of today’s discussion into the future of our group?

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We must be aware that though this difficult soul searching will likely generate change—many things will not be done the way we did them before—looking at our groups through a new pair of glasses can provide the buzz of excitement we hope for.

### **MAXIMIZING TIME**

Socializing can be a part of every meeting, but more ambitious goals often attract busy members who want to be certain the way they spend their time will pack a punch. They want to play an important role in meeting the needs of those still searching for the support most of our groups are designed to offer. Talented leaders learn to point the way and then step back and watch their committees go to it. Wonderful things happen when members know that their time and effort carry impact, that what they do truly matters.

In the end, there may be groups that decide their work is done. They may ask for guidance from other groups, attend workshops for inspiration, do everything they know of to breathe life back into their once-thriving organization, and still conclude this group cannot continue. Such a thoughtful outcome is always best. But for those who are anxious to keep going, the possibilities abound.

\* Nancy Baldwin Carter and Joan L. Headley are co-authors of the Chapter "Support Groups: Keeping Them Active and Useful" in Lauro Halstead, MD's new book *Managing Post-Polio: A Guide to Living and Aging Well With Post-Polio Syndrome*. The book sells for \$13.95 per copy with \$4.25 postage for one book; \$7.50 postage for two or more books. For more details, contact NRH Press, National Rehabilitation Hospital, Publication Office, 102 Irving St. NW, Washington, DC 20010-2949; 202-877-1776; 202-829-5161 fax. Watch <http://www.nrhrehab.org/>.

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**QUESTION:** "I read with enthusiasm that PHI awarded \$25,000 to the University of Arkansas for Medical Sciences to do a pilot study to determine if there is a unique biomarker (Tregs) in the immune system of individuals with post-polio syndrome. One member was less-enthusiastic because it was feared that if he/she did not have the biomarker the physicians would not treat them for PPS. This fear was fueled by the fact that it was so difficult to get the diagnosis of post-polio syndrome in the first place. Can you help resolve this fear?"

**ANSWER:** We've come a long way, baby! And what a switch! Isn't it refreshing to hear concerns from people who are worried that having a PPS diagnosis available will get in the way of appropriate medical treatment—when for years some of us were certain that NOT having a PPS diagnosis would end our chances to be properly cared for!

Indeed, there was a time when some of us seemed more concerned with having the initials "PPS" tacked onto our condition than we were with having an accurate diagnosis. Years ago some fought for those initials even when such a designation made it difficult to get disability, and perhaps impossible to get treatment. Were we truly looking for a solution?

Remember how it was in the beginning? For a while we didn't even have a name for the condition that needed a diagnosis. Should it be "Post - Polio Sequelae"? Or "Late Onset Polio Sequelae"? Or "Late Effects of Polio"? Or, well, any number of others that indicated that something was happening beyond polio that needed attention. In the end, the powers that be settled on post-polio syndrome, and for all these years we've received various degrees of help for PPS, even without a definitive method of diagnosis. We still rely pretty much on a diagnosis of exclusion.

In case anyone thinks we're at the end of the line here, and there's no longer a need to develop easy diagnosis, take a look at these estimated figures: Of 640,000 \* polio survivors in the United States, 300,000 of them may already have PPS. Population-based studies show that anywhere from 20-78% of polio survivors complain of new neuromuscular symptoms often attributed to PPS. Worldwide, as many as twenty million polio survivors live with, or are at risk for acquiring, PPS. And acute poliomyelitis continues to this day in certain parts of the world. It's going to be a long time before there won't be any more polio survivors seeking a diagnosis for PPS.

Small preliminary studies already indicate that excessive numbers of regulatory T cells (Tregs) show up in people with PPS, but not in healthy individuals who were vaccinated with oral (live) polio vaccine, and that Tregs from some of those with PPS do not function normally. If this situation occurs in a larger study (this time including those with PPS, those with polio but no PPS, and those who are healthy), then this could mean these Tregs are a biomarker pointing to PPS. That could be cause for a PPS diagnosis.

Would this mean that polio survivors without those extra Tregs will not receive treatment for PPS? Possibly. This is all speculative, of course, but I can't imagine why people without PPS would be treated for PPS—or why they would want to be. At the same time, I'm not exactly sure what that

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means. We all had polio, and surely we would be treated for our polio problems, commensurate with their severity. Certainly no doctor would insist on seeing further deterioration through PPS before treating an imminent difficulty.

Leaders of polio groups can find a wonderful opportunity for discussion in this topic. What do your members have to say about some of these questions?

- Can certain polio survivors who may never develop PPS still have significant physical difficulties? What if these problems require careful attention or even necessitate procedures such as major surgery, for example? Would any doctor refuse to address these situations adequately?
- Isn't "the late effects of polio" a term that defines all of us, while "post-polio syndrome" indicates that some of us have late effects that go further than our initial polio? Do we all fall at a slightly different place in this continuum? What does this have to do with diagnosing PPS?
- How do we explain the importance of this research? If this hypothesis regarding regulatory T cells in PPS immune systems proves significant, is it possible that this could lead to even greater discoveries, perhaps in the area of PPS treatment?

Years ago we had a quadriplegic member on our board of directors at Nebraska Polio Survivors Association who used to joke he wasn't worried about getting PPS since he had nothing more to lose. Whether he was right or wrong was irrelevant. It didn't matter where he landed on the "late effects" progression. We were glad he was there, lending his considerable expertise, helping our organization bring valid information to as many as possible in the polio and medical communities, and demonstrating the importance of reaching out. It was a good mission.

\* Joan L. Headley tells me that PHI is investigating this number as well as the age distribution of polio survivors. We await the analysis and the numbers.

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**QUESTION:** “How do we help our members find good online information and use this in communicating with those in the medical community and others?”

**ANSWER:** Finding reliable and relevant polio information online can sometimes be a challenge. The difficulty is not a paucity of information but rather the overwhelming number of possibilities to sort through in the search. Sources indicate there are approximately 400 million websites on the Internet. This means the first thing to know is what to look for.

Polio information seems to be offered everywhere, and quality ranges from hard scientific facts described on legitimate websites to opinions and guesses offered on others. It matters that conclusions are backed by properly-conducted studies or recognized authorities in the field. The credentials of the experts we cite also matter. Do we know the difference between an M.D. and a Ph.D.? A psychiatrist and a psychologist? A physiatrist and a podiatrist?

Anecdotal stories related on polio listservs or in chat rooms may be interesting, but they are not a dependable source of polio information. Passing on chat room twaddle in our support groups can actually be dangerous. Of course there is considerable value in discussing personal experiences—this is a main function of support groups. However, it's one thing to inform someone where I bought my comfy shoes. It's quite another to advise that person not to take a certain medication because I, or a polio survivor I know, had a reaction to it. We can all learn to identify and to become reliable resources.

Questions to ask to determine if online information is trustworthy:

- **Has the website been updated frequently?**  
*Websites often state at the top or bottom of their homepage the last time they updated (and how often they do this). Specific pages or articles that have been updated may also give that revision date.*
- **Is the report we're using recent?**  
*Current material usually tells us more of what we need to know. It might be important to find out if there is a follow up to older reports and if not, why not.*
- **If we use a medical article, does it come from a well-known medical research institution, a government medical institution, or a professional medical journal?**  
*Learning to know the difference may be an ongoing education project for groups. Each source must be evaluated on its merits. An excellent source for one topic may not meet the requirements for another.*
- **Are our chosen medical journal articles peer reviewed?**  
*Journals indicate if they are peer reviewed. It's reassuring to know that professionals in the same field have read and evaluated articles for their scientific and technical quality.*

- **Do medical articles represent scientific investigation rather than stories gathered from non-credentialed sources?**

Organized research by skilled professionals yields much more reliable information than reports of individual experiences do.

- **Have all articles been written by individuals qualified by training and expertise to speak on the subject?**

*The best person to talk about a subject is an expert in that field. It rarely works to go to a shoe store to buy bread.*

- **Are the name and credentials of the author clearly stated?**

It's much easier to judge the worth of an article if we know that the author is a recognized expert on the topic. Anonymous pieces belong at the bottom of the list.

- **Have we been careful to avoid “sponsored” links, which may simply try to sell something rather than offer reliable facts?**

*Reviewing pages carefully makes this simple—there is discussion of products being sold on sponsored pages. If a product is linked with a “medical finding,” this may be reason for suspicion.*

- **Are product and treatment claims backed up with clinical studies and scientific proof?**

*Various types of legitimate research exist. If studies weren't done, a claim may not be as genuine as it purports to be.*

Group leaders are always interested in good ways to pass on what's new to members. At the top of the list is being sure that everyone leaves a meeting with dependable facts. This requires leaders to find ways to stay on top of the situation so that factual discussions don't turn into prattle.

Individuals unaware of the difference between an anecdotal tale and significant medical information may not understand the importance of knowing we have the facts right. It might be a good idea to devote a meeting to the art of evaluating material so everyone is on the same page. In the hands of a clever member, such a meeting can be a lot of fun—even exciting!

Mainly we want to avoid those awkward moments when members verbally attack another member or even an invited speaker because the assailants may not be as informed (or as tactful) as they should be. Leaders can help!

One idea is to direct members to appropriate information when the next meeting's topic is announced. The topic committee could hand out a list of excellent websites so members can take a look and be well-informed when the time comes. The committee might also copy the text of a special article (being sure they have permission if it is copyrighted) to give members so they can become familiar with it before the meeting.

It's a good idea to provide this material to invited speakers, as well, if they have been asked to talk on a subject of the group's choosing. If speakers select the topic, perhaps they would be willing to offer the group the same kind information, especially if they are told that the group likes to have a Q&A session with speakers when they finish their talks.

A few tips on asking questions can bring out amazing skills in members interested in the give and take of interactive meetings. How can we get what we're after? Let's say a doctor has described various types of anesthesia used in differing procedures. Does it work best for me to say, "That's just dumb. Everybody knows polio survivors shouldn't be given some of those anesthetics!" Or "Doctor, let me show you this article that says polio survivors are usually better off if they aren't given that particular anesthetic. Would you explain why that's the case?"

Consider Jane, who mentions at a meeting that the pain in her shoulder has been diagnosed as a torn rotator cuff and that she and the doctor are figuring out whether therapy or surgery is the way to go. What happens if another member, Fred, rather than wishing her the best, chimes in with "You'd better have the surgery--my cousin Jack had the same problem, and he couldn't raise a fork to his face today if he hadn't had surgery"? Does Fred understand the implications of surgery for Jane, a paraplegic? Does he know anything about her general condition? Maybe it's better if members don't give advice and, instead, try to stick with their own lives, rather than getting into situations they truly know little about.

Open-minded discussion can be healthy and exhilarating. Everyone learns through energetic participation, which leads to invigorating meetings that members are anxious to return to. Can't beat that!

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**QUESTION:** “We continue to hear about post-polio clinics and what they can offer, but many are miles from our community. Members of our group want to know what help is available closer to home.”

**ANSWER:** I smell OPPORTUNITY ! Talk about serendipity—this is a polio group leader’s dream. Out of nowhere comes the perfect project for a group committee to tackle!

Leaders are always searching for undertakings that energize members, add spark to their lives. We can sit around talking about the problem only so long before we begin to lose people. Leaders are charged with rocketing our groups out of the doldrums. Studies show that an antidote to such maladies as depression and low self-esteem is getting active. Good leadership can offer groups a bit of much-needed pizzazz for individuals to grab hold of.

Committees have a special function in polio groups. They work well because members get to use their unique talents, and yet everyone can participate on some level. It can be stimulating—and a real hoot—to work together toward a worthy goal, and at the same time lend necessary purpose to meetings. As many of us have discovered, without a worthwhile reason for being, groups simply die.

Projects can be revitalizing. All of a sudden it’s the “Oh boy! Let’s put on a play in the barn!” sort of thing. Something meaningful the gang can do. Something exhilarating. And this would make a doozy of a project:

Members want to know what help is available closer to home? Well, why not find out? Form a committee—maybe even one with subcommittees! Let them define the parameters. For instance:

- **What territory will the search cover?**
- **What categories will it encompass?**  
Will it be medical care, equipment, equipment repairs, advocacy, personal services, housing, entertainment, vacations—or what?
- **How detailed should each category be? Will the list be all-inclusive, or merely name those known by members for excellent quality?**

*Health care*—PTs? OTs? RTs? Orthotists? Home care? Visiting nurses? Accessible/warm pools? Doctors in certain specialties? What should go on the list?

*Equipment*—chairs, scooters, braces, crutches/canes, chair glides, chair lifts, cushions, bumper lifts, vans? What? Rent or buy?

*Equipment repairs*—Who can fit the brace into shoes well? Who can handle the electronics on a power chair? Who does van conversions? What else?

*Advocacy*—Need help interpreting the ADA ? Need a lawyer? What?

*Personal services*—Does a grocery store deliver? A pharmacy? Need someone to prepare meals for your freezer? Household help? What?

*Housing*—Accessible apartments, condos, houses, motels, hotels? What?

*Entertainment*—What's fun to do and still accessible? Which restaurants? Zoos? Theaters? Parks? Museums? Sports events?

*Vacations*—What companies offer accessible cruises, tours?

● **How will the committee get needed information?**

Ask all members of the group to submit their recommendations within listed categories to the committee? Divide into subcommittees to investigate possibilities for each category?

Visit sites? Get info by telephone?

● **Should the committee devise a system for reporting findings? A format with uniform questions? A checklist?**

What items should be covered? Name of company? Address? Phone number? Hours?

Name of manager? Type of Service? Specialty? Accessibility details? Price ranges?

The committee decides what to do and how to do it. They may need a little boost now and then, a time frame, cheers from an admiring leader, pizza. But THEY make the decisions. They might want to publish a pamphlet or a fold-out chart or a "Polio Survivors' Guide to Easier Living" on their website. It doesn't matter. Whatever they come up with will be terrific—because everyone needs it, and they did it, and they had a rousing good time working on it.

Everybody wins!

P.S. Next Project? A Manual of Guidelines: What to Look For When Choosing a ...

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**QUESTION:** “Members in our group have been commenting on certain changes that affect our lives in many ways. Seems as if various government agencies aren't as willing to help as before, for instance, and sometimes we're left with a financial burden we can't handle. Are we in danger of losing some of the rights so many of us fought for?”

**ANSWER:** Sure. We are forever in danger of losing some of the rights so many of us fought for. The reason this was such a tough struggle in the first place is that there are always those with an agenda they're more interested in than ours.

We have to remind those people that we deserve our hard-earned rights, and we intend to keep them. We don't dare let up.

Taking our civil rights protections for granted has crippled our cause, left us scrambling to re-gain promises lost by our inattention. There have been setbacks in the courts, attempts to dismantle the planks of the Americans with Disabilities Act (ADA), which atrophy the muscle of the main legislation that defends our rights. Now we get to be a part of the faction that is doing its best to put that Humpty Dumpty together again.

Years ago I talked with a Target store manager about making some of his checkout lanes wide enough for chairs, with low enough counters for the people in those chairs to use. He wouldn't hear of it—until one day when I went back to make my final pitch, he suddenly understood. His wife had broken her leg and was forced to use a chair! The guy had to take her everywhere and was telling me with great passion what a huge hassle this was! "Can you imagine," he shouted, "we have to leave thirty minutes early just to get her into the building on time!" You should see that store now--we got everything we asked for and more! There's nothing like a little experience to wake people up. Is there any way we can simulate this kind of exposure in the minds of the decision-makers of the world?

Of course I'm proud of what our polio groups have accomplished. Surely each one of us can drive around in our home towns and see a zoo's "rain forest" that's no longer restricted to the ambulatory; ramps into public buildings, countless curb cuts, accessible parking stalls, smooth, wide pathways. We know there are accessible restrooms and regulation doors and uncluttered aisles and wheelchair theater seats that didn't exist before—all the result of our undying insistence on pulling the ADA together and putting it in action. Others now recognize our right to be here and accommodate our independence. We can't afford to lose any of this to those who seem to have no idea of the necessity for our goals.

For example, when I read that a governing body is attempting to strip us of our self-sufficiency by insisting that only agency workers can provide in-home services, I know it's time to start demanding those legislators get a more enlightened idea of who's in control of my choices here—and it had better be ME, not the agencies.

And what's up with "the scooter issue"? We can only get help paying for equipment used inside the home? Never mind that I can't walk half a block and am imprisoned in my house without money for wheels to get me into the market or down the street. We have to learn to stop these roadblocks to our quest to live independently.

Let's be sure our voices are heard when Medicare or Medicaid guidelines are put in place or changes are made. Let's be listened to when health insurance and medication costs are legislated. How can we get our message across?

Unfortunately, occasionally the problem of not expressing our might is compounded by some of us in the disability community who fail to see ourselves as playing a role in our own destiny. Perhaps we remember a time when folks with disabilities were regarded as children, not allowed to think for themselves and make their own decisions. We may recall a past when others attempted to make us feel less-than, unworthy of wielding the power that is ours. Guess what--those days are gone.

The squeeze is on. As luck would have it, we're moving swiftly into next year's elections. This summer could be the perfect time to help our groups dive in. Dispelling the notion that we don't count should be at the top of the list.

Leaders can:

- Bring the issues to meetings for lively discussions.
- Hand out a list of candidates, naming where they stand on the issues, spelling out their disability records, and discussing the consequences of our votes.
- Provide candidate addresses and phone numbers for members who want to let them know in person how they feel about issues.
- Explore ways the state handles registering to vote in order to make it as simple as possible for everyone to participate.
- List accessible polling places (for members who don't want to give officials the chance to say they don't need accessible polls because people who are disabled never come there) and arrange car pooling if necessary.
- Familiarize members with the voting options available.
- Discuss why it's so important for polio survivors to retain our rights.

Since most decision-makers are either elected or appointed by those who are elected, voting becomes paramount. The message: Want to keep those hard-gained rights? Then REGISTER and VOTE!

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**QUESTION:** “My physician seems to have little knowledge of potential polio problems. Should I be worried? What are my options?”

**ANSWER:** The good news is that we are way beyond the days when polio survivors took their complaints to a puzzled doctor who felt his only recourse was to refer us to shrinks for what he thought were our imaginary ailments. Today’s medical community is aware of post-polio syndrome. Most doctors now see PPS as a legitimate medical problem. That’s one hurdle behind us.

Are all physicians prepared to treat the many manifestations and nuances of this condition? Of course not—no more so than they were when polio came our way in the first place. There’s nothing new about the fact that medical science seems woefully inadequate to individuals who pose perplexing challenges beyond a doctor’s knowledge. I’ll bet it seems that way to doctors, as well. There’s plenty of frustration to go around.

Polio support groups can help.

Why not start by working together to figure out sensible ways to think about the situation? We have all known survivors who, amazingly, seem devoted to whining about yesterday, rather than considering today’s possibilities. Dynamic groups discuss healthy ways to bring issues into focus. Seeking solutions is always better than dwelling endlessly on the problem.

Groups can explore creating better partnerships with doctors. For our part, we must give up expecting the quick fix of a pill for every malady. We must learn to work together with our doctors. If physicians and patients, together, approach this alliance with open minds and the willingness to listen, we will both learn new things. It’s not a matter of magic—if we expect answers beyond what we now receive, then we must participate in the search for our wellness.

Herein lies the opportunity for a most productive meeting. Members might talk their way to truly helpful revelations. They could also devise an “office visit list”—some DOs and DON’Ts to propel individuals way beyond the usual. Perceptive groups will come up with lists much keener than the short one below—let these few simple samples serve as inspiration:

- DO write a list of personal concerns and take it to discuss with the doc.
- DO present issues succinctly and clearly.
- DO ask pertinent questions.
- DON’T be shrill and demanding—or a wilted petunia, either.
- DON’T waste the doctor’s time.
- DON’T assume patients know nothing (or everything)—and doctors know everything (or nothing).

- Another good activity—Groups can answer these questions, as well:
  - How can we successfully vie for the attention of a physician who is overscheduled and underinformed?
  - How can we improve our own behavior as patient-physician partners?
  - How should we judge our expectations—is what we expect reasonable?
  - How do we ready ourselves factually to carry the post-polio message?
  - How do members respond to the statement “If we want better doctors, we must become better patients”?
  - How accurate is it to believe that younger doctors know little about polio, whereas older ones are well-informed?
  - How do we encourage members to tell doctors they had polio and to be persistent in asking if their difficulties could be connected to PPS?

Interactive meetings provide a further step in the right direction. Our groups can be outstanding liaisons between doctors and survivors. We help educate physicians and members alike when we invite doctors to speak at our meetings on specific polio issues. Be sure to provide everyone with reliable material pertaining to the subject at hand ahead of time. Thus we spare the doctor hours of research, and members are more able to ask relevant questions during the after-speech Q&A session.\*

What all of this leads to is exactly what support groups do best: working together to produce beneficial results. Let us hear more voices, breathe new ideas into our discussions. Active groups are always on the lookout for new members, and we'll find them, since many individuals are only now experiencing the signs of PPS. Voila! There is much yet to do in our mission to make life easier for polio survivors, and infusing our groups with “fresh blood” is sure to build enthusiasm for the task. Why not go for it!

\*A few excellent sources for material:

1. Jubelt, Burk, M.D. and James C. Agre, M.D., “Characteristics and Management of Postpolio Syndrome,” July 26, 2000, JAMA copyright 2000, American Medical Association.
2. Halstead, Lauro S., M.D., Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome, NRH Press, copyright 1998 by Lauro S. Halstead, M.D.
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4. Maynard, Frederick M, M.D. and Joan.Headley, M.S, Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors, copyright 1999 by Gazette International Networking Institute.
5. Post-Polio Health International website: [www.post-polio.org](http://www.post-polio.org)

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**QUESTION:** “We have published a support group newsletter for more than ten years and feel it is time to re-evaluate its content. What should go into a good polio newsletter?”

**ANSWER:** I love this old *Encyclopaedia Britannica* definition: a newsletter is an “informal publication, often simple in format and crisp in style that provides special information for a defined audience....” Simplicity and crispness—terrific bywords!

Luckily, we needn’t spend time trying to determine who our audience is. Our readers are polio survivors, family members, medical professionals, and maybe even vendors. First clue: Every item in a polio newsletter should relate in some way to polio.

Surely a goal of any worthwhile polio newsletter would be to create a publication that tugs at readers. One that generates the feeling that we’re not alone, we’re in this together—and our organization is here for you. Polio survivors should come away from the experience of reading the newsletter feeling somehow better for having read it. AND waiting excitedly for the next issue.

What does it take to do this?

Variety is one answer. News articles dancing with relevant information. Columns doling out dazzlingly penetrating opinion. Feature stories brimming with heartfelt human interest. Photos. Cartoons. Reader letters. Q&A’s. Interactive bits. Member spotlights. Imaginative fillers. An occasional splash of color. Wide-ranging, inventive stuff that’s fresh, often delivered with humor, and always presented with style.

The best newsletters are innovative. They look to their state legislature, for instance, to report what’s happening with a local disability issue. Or they check out the rehab center’s new handicap pool. Or they feature a chat with an old shoe repair guy who specialized in fitting leg braces onto shoes. Or interview the childhood pal of a member who can describe what it was like when her friend was whisked off to a hospital, and how they managed to bond in recovery. Such newsletters are original. Prime plums.

Certainly few of us yearn for newsletters made up of endlessly patched-together recycled articles. There’s great value in seeing the creative self-expression of our fellow members. It doesn’t take someone else to write a good news story.

If done at all, copying should be done with caution.

First, we must always give credit—each “borrowed” article must be accompanied by a “used with express written permission of...” acknowledgement. This means we must contact the author or publisher for written consent to use the piece. In addition, we need to be careful not to pass on bad information—just because another newsletter publishes something, that doesn’t automatically mean it’s factual.

A few words about length: With so many newsletters now presented online, the temptation may be to use infinity as a yardstick. Longer isn't necessarily better. Most excellent publications set length limits. It's said that the average adult newsletter reader has an attention span of 30 seconds. It pays to be succinct.

**TIPS:**

- Design a practical, eye-catching format (consider attractive nameplate, width of columns, font type and size, paragraph style, uncluttered appearance) and stick with it.
- Have a plan—and use it without fail. How many pages? How much space devoted to various sections? How many articles on a page? How to break a story that must continue to a second page? Who will write what? Deadline for contributions? Reliable date of publication?
- Be consistent and uniform. Designate certain pages for regular features that readers look forward to in each issue. Is the main news article always top right on the front page? Is the editorial column always at the top of the last page? Whatever works.
- Follow accepted rules of writing. If unsure, take a quick look at Strunk and White's *The Elements of Style* or even the more sophisticated *The Chicago Manual of Style*.
- Entice readers with intriguing headlines. Short. Catchy. On target.
- Look around; take notes; keep a file. Ideas for articles can come from anywhere.
- Be fearless—and have fun.

In the end, newsletters often turn out to be pretty much a matter of personal taste. Jack's may not be June's. With some productive brainstorming, though, a newsletter staff (or committee) can come up with a superior product for any group. It's bound to be worth the effort.

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** “I was shocked, but I have come to learn that people in our group who can walk expressed at a recent meeting their opinion that the people in wheelchairs and less mobile have limited the activities of the group. They want to go downtown, for instance. Also, they say they are sick of hearing about polio. Has this ever been a problem in other groups? How was the issue resolved? What recommendation would you give to other groups, so it doesn’t happen to them?”

**ANSWER:** Whoooooa! What on earth...! We’d all be screaming bloody murder and calling in the ADA police if we heard this kind of discrimination coming out of the mouths of “outsiders,” wouldn’t we? A polio support group with a prejudice against polio survivors who find it difficult to get around? Think about it.

Here’s the deal: You have a polio support group, you’re going to offer support to polio survivors—ALL of them. And you’re going to talk about the polio condition and solutions. You want a group for ambulatory members who only go shopping or out to lunch? Start The Walking-Mall-Lovers Club or Lunchin’ Ladies Afoot—but don’t call it a polio support group.

Most groups have operating charters that spell out the mission of the organization. Goals usually include objectives like support, information, advocacy. The idea is to bring polio individuals and their loved ones together with others who have questions, concerns, even fears, about what’s happening now that PPS and aging have entered the picture—and then deal with these issues.

Membership often creates bonding. Words like camaraderie, friendship, fellowship, compassion, empathy, tolerance, understanding come quickly to mind. If members aren’t there for each other as well as for themselves, that group’s in trouble. It’s an almost magical thing: A certain amount of healing comes from one person’s helping others get through the same experiences he has been through. We share our stories, our knowledge, our regard for our fellow survivors. The process itself makes us feel better.

A successful polio support group is not simply a social gathering. There’s room for socializing, of course, and an occasional social outing can be a lot of fun. Many members might relish the opportunity to prove they have no intention of tempting the fates with an ungenerous attitude toward the less mobile, lest they themselves be next in line. Groups could ponder the advantages of checking out accessible venues ahead of time and learning from those in chairs the “ins and outs” of negotiating the streets with that limitation. Not a bad project, actually.

But polio support groups exist primarily so that survivors can examine serious polio concerns. We see newcomers seeking this kind of relief every day. Many people are just beginning this search. They are not looking for lunch. It’s essential to live up to our “polio support group” billing and address their needs. Oldtimers face new uncertainties as their conditions progress into unfamiliar territory. They, too, deserve the relevance of polio support.

What to do:

- Rotate leadership before meetings begin to smell like rotting fish.
- Bring in a breath of fresh air by actively encouraging new membership.
- Wake members up with variety and exciting ways of presenting information—listen to their ideas, allow them to participate, put their solutions into action.
- Look to reliable sources for new information—and there IS new information. Let a committee's curiosity and expertise get to work on it.
- Nip divisiveness in the bud with shared decision-making and an open mike at business meetings. Talk about problems out loud and up front.
- Discuss reasons for the group's existence, goals, how everyone can help. Discuss attitudes, the big picture. Get out your crystal ball.

There's an abundance of diversity among polio support group members. Some folks use chairs, others walkers or crutches. Still others walk freely. Sally's shoulder doesn't work; Phil has trouble breathing. This one is a size 42; that one wears a hearing aid. Doesn't matter. What unites us is that we're a group of polio survivors reaching out for support. It doesn't take much. A friendly smile. A hopeful word. A little information to keep us afloat as we try to figure out how to bring balance back into our lives. We do this for each other.

What we don't do is forget about why we're here.

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** “Our group is excited about PHI’s WE’RE STILL HERE initiative. We have our letter ready to send to the newspaper, but would like to do more. Do you have other ideas for ways we can get this important campaign before the public eye?”

**ANSWER:** Hurrah! Hats off to your group for moving quickly to organize your involvement in the WE’RE STILL HERE campaign. It’s exciting to see groups chomping at the bit to MAKE THIS WORK! Coming this far, this soon, creates the valuable time you’ll need to be most effective.

What’s great about WE’RE STILL HERE is that this is a campaign that means something. In the past here in Nebraska, anyway, we have been satisfied with getting a proclamation from our governor or Unicameral Legislature setting aside a special time to honor polio survivors. Nobody ever noticed. WE’RE STILL HERE is different. NOW we get the chance to point out that we’re not simply has-beens sitting idly by, needing to be honored--we’re here, living an integrated life, actively participating.

You have your initial letter—now the next step is to get the word out to as many people, and through as many avenues, as possible, which is what it appears your group is prepared to do.

WE’RE STILL HERE can be our rallying cry—the voice of polio survivors everywhere rising up as one to remind the world that not only do we still exist, we’re a vital force in our communities: Leaders, workers, volunteers, significant family members. And then as a footnote we add that not only are we still here, so are some of the problems that accompany disability. And so also, in much of the world, is the scourge of polio itself.

Just imagine—suddenly on October 14 the words “WE’RE STILL HERE!” explode into the consciousness of citizens of the world from a million different angles all at once. POW! KAZAAM! HOME RUN!

How can we make this happen? What can EACH OF US do?

First, every group and individual writing a letter to the editor can send it on to many papers—the idea is to get letters into every newspaper in the state—indeed, in the world. Once the letter is written, it’s fairly easy to send duplicates. The National Newspaper Association website ([www.nna.org](http://www.nna.org)) lists state press associations under “Partners,” and some of these give names and addresses of member newspapers. Also, most libraries have Gale’s Directory of Print and Broadcast Media, which lists names, addresses, phone numbers, and even e-mail addresses for newspapers in every state.

Most papers also publish op-ed articles, which offer the opportunity to illuminate the message behind WE’RE STILL HERE. Why not follow your paper’s op-ed guidelines and give it a shot?

Call the media, talk with whoever it is who does feature pieces for local radio and TV stations and try to arrange for an interview in that week of October 14-20. Got a good talker in your group?

Send her on! (OK—or him.) Or how about a panel discussion? Get the media interested, and they'll give you time.

And then there are Internet interviews and blogs—there may be no end to the possibilities.

We can be as innovative as our talents take us. This is the time to put imagination to work. Be creative! For starters, do any of these ideas interest your group? Maybe there's something here you can build on:

- Some ad agencies do freebies in certain non-profit situations. Rather than let a small billboard sit empty, they might light up its side with the words WE'RE STILL HERE! Or maybe your group has an angel who will help you rent the space! Start now--plans need to be initiated TODAY.
- Think of the effect of WE'RE STILL HERE! shouting out at the riders of your city's public transportation. Can your group find a way to finance some of these ad spaces?
- How about a WE'RE STILL HERE! T-shirt?
- Libraries are always happy to give away bookmarks at their check-out counters. It's easy to make bookmarks on a computer and have them laminated at a copy center. Who in your group can make WE'RE STILL HERE! bookmarks?
- Plaster the town! Make up a zillion 8 ½" x 11" WE'RE STILL HERE! signs and place them in every mall, every store window in every shopping center. Hang them on all public bulletin boards (often in grocery stores, laundromats, libraries, banks, senior centers, universities, health clubs). This one's easy: Run them off on your computer or make a dash to Kinko's with one to be copied. If you need help taking them around, call in the family or a scout troop looking for a project. Be sure whoever is taking the signs around asks the proprietor or manager for permission before hanging signs.
- Remember to hit places where people work with those who are disabled, such as clinics, rehab and therapy centers, waiting rooms.
- Take out a small ad in a local or state-wide professional journal meant for architects or realtors—those who see firsthand our need for building access.
- Put a WE'RE STILL HERE notice in members' church bulletins. A simple message of thanks and hope may go farther than one might expect.

PHI is interested in what you and your group come up with. Send your best ideas to [info@post-polio.org](mailto:info@post-polio.org). Check the WE'RE STILL HERE logo on the site often yourself, as well. Much will be added as plans proceed.

Everyone can play a role in the success of this initiative. Are you networking? Why not talk up WE'RE STILL HERE! Help other groups and survivors understand the importance of getting people's attention, arousing curiosity about this campaign. We can give each other a hand and turn this initiative into dynamite!

Together we can wake up the world and make sure they know WE'RE STILL HERE!

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** "Who's in charge? In our group, some of the spouses have taken over the leadership roles and they are not as understanding of our situation. Has this happened to other groups? How was it rectified?"

**ANSWER:** Who do you want to be in charge?

I have this theory that I read about years ago and have seen many times since, and it is this: WE ALL DO WHAT WE WANT TO DO. I know right off, some folks are beginning to argue—coming up with their first excuses to invalidate this hypothesis. Give it some time.

When I was a kid—I don't know, maybe five years old—my dad took my older brothers and me to Mandy's Café in our home town for ice cream one afternoon. As we sat in our booth waiting for the waitress, he asked each of us what flavor we wanted. Joe wanted chocolate. Bill chose strawberry. When it came my turn, I said, "I don't care."

"Well then," my dad replied, "If you don't care, you don't get any ice cream."

Yes, yes, I can almost hear it now—a few readers saying, "What a mean ol' guy he was!" Keep reading.

Truth is, my dad taught me something extremely valuable that day. I learned to care—about me, about what is important to me—and he taught me to speak up, to express myself, and to be sure what I'm saying is what I mean.

So we all do what we want to do. Thing is, we're likely to trick ourselves if we aren't honest about what we want. At the moment my dad asked me that question, I wasn't thinking through the consequences. I was aiming at the wrong target. Surely when I said what I said, it hadn't occurred to me that my desire to act coy or humble actually didn't begin to approach my desire for a big bowl of chocolate ice cream.

Or maybe I had in my subconscious that I could pull off both—was there a way to parlay being a demure sweetie into getting that chocolate ice cream? Somehow grab a frozen goodie without actually appearing to want it? Or maybe toss a little sympathy into the mix—convince my dad I believed "poor, pitiful me" was so unworthy that just any flavor would do, and shoot for a compensating two scoops? Or win the bonus prize of being begged to choose a flavor? Clearly I didn't want to eat ice cream nearly as much as I wanted to play games.

Knowing what we want is important. And how to stand up for ourselves, how to take charge of our lives. This is especially true for polio survivors—it's too easy for people to see those of us with disabilities as individuals whose choices others should make.

Of course polio support groups should be run by the polio survivors who come for support. Otherwise they're not polio support groups. We members should be talking about our own problems and finding our own solutions—running our own meetings and doing our own thing.

Spouses have a need, as well. Most spouses are interested in how best to understand what PPS means to a loved one immersed in this new polio dilemma and how best to help. Because of this, it seems a healthy thing for spouses to sit in on polio meetings, if they like, to find out what's going on. Additionally, certain spouses find themselves requiring their own support group, figuring out how to tackle these changes in their lives, talking about what's happening to them.

There can't be much benefit to allowing spouses to control the direction of the discussions and activities of a polio support group. It may feel easier at first to "let George do it." But much as he wants to assist the one he loves, George can't do it—he's not a polio survivor and will never have the heart and mind of a polio survivor. Maybe the best help George can provide is to encourage the independence polio survivors strive for. (Oh yes—and carry a few boxes.)

Now, if it's true that we all do what we want to do (and I'm sticking with this), then groups have to decide what they want. If they want to be in charge and, instead, spouses have taken over, members will step forward, thank the spouses for their kindness and dedication to the group, and assert they are ready to do the job themselves now. They will then do exactly that.

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** “I have been a support group leader for years and I was surprised how difficult it was to decide what to write in my letter to the editor. Can you help me understand why it was so difficult?”



**ANSWER:** Remember that line in Shakespeare’s *Two Gentlemen of Verona*? The guy is supposed to write a letter for the woman he works for, and he makes such a production of it in his own mind.... Finally she says, “Perchance you think too much of so much pains.” I’ll bet we all do this to ourselves sometimes—think so much about doing something, that we drive ourselves batty.

Maybe the task takes on too much importance. If we’re not used to the job, perhaps it seems to be something out of our league. Could be, a touch of self-doubt creeps in—the “I’m not good enough” feeling that we are sure proves our lack of worth.

Then we start projecting: “Oh man, I’m going to say something that sounds really dumb; I’ll embarrass myself in print; everyone in town is going to see it—what am I doing! I’ll have to change my identity and move to Bhutan!”

Truth is, it’s merely 200 words in the Public Pulse. Editors love letters like this. WE’RE STILL HERE! is something important and real—they get to pass on relevant information. If our letters don’t fit in a space or seem to need a word change, editors will fix them.

We’ll never get all that needs to be said into such a short letter. It’s important to pick only an issue or two—will it be the fact that many polio survivors contribute immensely to their communities? Or a short explanation of the universal need for barrier-free surroundings? Or the significance of everyone’s having access to opportunity, to jobs, to good health care, and to health insurance? Whatever. We can take a look at the suggested issues listed on the PHI website if we’d like help. Focus narrowly. Then go for it.

We must remember to mention the name: the WE’RE STILL HERE! campaign. And the dates: October 14-20. And a brief explanation about why the campaign exists: How about to let the public know who we are? Or to locate additional polio survivors, young and old? Or to educate others about post-polio syndrome? Or to publicize our serious need for health professionals? We’ll find even more great ideas under “A Few Possible Talking Points” on the PHI website.

When I was a kid, I really wanted a decoder ring. Didn’t everyone? As I recall, all I had to do was write twenty-five words about WHY I wanted that ring, send it in to the listed address (could be some box tops were involved as well), and the ring was mine. I labored over that letter for hours. I wanted to say just the right words to convince them I deserved the ring. I didn’t know there’s no such thing as “perfect,” that what really mattered was simply that I wrote the letter. The prize was in the doing—they were going to send me the ring.

Whatever we write to these editors about WE'RE STILL HERE! is going to be fine. We're all bright polio survivors who have dedicated years to post-polio efforts. What we have to say will be terrific. Most of our letters will be published and read—and we'll all be the better for it.

One polio leader I heard from the other day said, "I don't know. What I'm writing about sounds an awful lot like we're tooting our own horn."

Hurrah! Toot away! If we don't take our ideas to the world, who will? This is our big opportunity to let everyone know that we're not those plucky little poster kids any more—we're all grown up, doing our share, and delivering a message that will surely help our communities prosper. Good for us. WE'RE STILL HERE!

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** “Some people in my group seem to have very definite, strong and unwavering opinions. Their voices are always heard, because they speak up. Now, I am hesitant to open up any discussion because they dominate and others clam up. What can I do to create a better atmosphere during the meetings, so others can be heard (and want to come back to the meetings)?”

**ANSWER:** Item number one: Sit down with the group and talk about what everyone wants—what would their ideal group look like? Discuss it. Do they want a non-threatening atmosphere where members feel free to say what they think? A safe place where people are not judged or criticized? A friendly place where they know members will keep each other’s confidences and will not gossip about each other behind their backs? Talk about it. What kind of leadership do they hope for? What bothers them about the meetings now? What would it take for their group to be the way they want it to be? Keep talking until consensus is reached.

OK, OK, I know—everyone’s already tried this one. It was a horror. Things got out of hand. Members refused to stick with the issues. People got personal. And loud. This can be frightening—a real turn off. OR nobody would talk. Members were gazing out the window, filing their nails, yawning, rolling their eyes. It’s not easy to get a group to be this honest, this introspective, this engaged.

But this step is so important it’s worth another try. Do something different this time. Set ground rules and insist they’re followed. Bring a timer with a musical sound to cut off long-winded speakers—or maybe a cute little rubber ducky to quack when their time is up. Present the agenda in a different way. Start with an easy question. Maybe draw questions out of a hat. Entice everyone to speak. (“On a five-point scale, where do you stand on the notion that we should have fewer medical speakers this year?”) Have fun. Provide something devastatingly yummy to snack on. Remind members you’re all there to help make this a better group because of their input. Who knows? It could work the second time around (or third, or fourth!)

### LEADERS

Here’s a thought: leaders lead. They guide. They facilitate. They encourage. They inspire groups to set the standard, and then they help them stay on track. They set the tone, exhibiting enthusiasm and positive, happy expectations. They are models of agreement, trying to get everyone in on the act. They allow, indeed even expect, members to have their say. They trot out a hearty sense of humor. They keep their mouths shut a lot and try to remain neutral. They listen carefully. They set a positive example for those in their groups.

And when it’s time for them to step in, they do. Groups want leaders. Good leadership creates an aura of fairness, so that even the least likely member to speak up feels protected enough to participate. Leaders help engender the courage it takes for members to talk about the tough stuff. They learn how to keep discussions moving without seeming to intrude.

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What leaders don't do is insist their way is always right. They don't give personal advice or tell others what they have to think or do. They don't express their own strong opinions or try to humiliate those who don't agree with them. They don't get their noses bent out of shape by taking things personally. They don't throw cold water on other people's ideas, dash creativity, or squelch passion. They don't impose their own rigid standards upon the groups.

Upshot: Leaders don't own the groups they lead.

## DYNAMICS

Now, about those pesky members with opinions: Hurrah! Blessed be the groups whose members are thinking! But they're dominating the conversation, you say? Well, that's where leaders step in. Members can't be allowed to speak endlessly or to be attack dogs, so forceful that others become intimidated. Leaders must confidently express the power they've been given to enforce time limits and keep order so everyone feels free to participate. The answer isn't to muzzle those who attempt to drown out others; the answer is to make them feel more a part of the group.

At the same time, open-minded leaders are not frightened by new thoughts. They understand it's all right for members to express a minority view. This isn't *controversy*—it's merely someone airing an opposing opinion. They rejoice when members think outside the box—they're not threatened by ideas that are different from their own.

## MEMBERS

Members can do their best by assisting with meeting activities. They can get on committees that choose topics for discussion, mindful of the difference between having discussions that stimulate thinking rather than those that are merely fact based or chatter.

They can respect each other's right to speak, realizing that others are there to participate, not to have someone tell them what to do. They can listen well and talk about their own experiences, rather than only making comments about what others say. Will small groups work better? Then divide up and sit in small circles. Want ways to bring everyone into the picture? Let all members decide the structure for this path.

No meeting will please everyone. But groups that are working on producing the kinds of meetings members want to come back to will have the most success. Good enough reason to try, isn't it? In fact, the most beneficial help would probably come from others of us who have been through this situation—there's power in numbers! *How about letting PHI hear from you? What was your solution? What worked? What didn't? We can learn a lot from each other, don't you think?*

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** "We have a number of new members as a result of the publicity our group got through the WE'RE STILL HERE! campaign. Several of the people who called expressed their fears, which I think we all have. How can we help members address their fears in a meaningful way?"

**ANSWER:** Fear. So many people have fears of so many kinds. Unfortunately, some of us imagine we're the only ones who do. We might look around, thinking everyone in sight appears to be strong and happy. We don't want them to see us looking wimpy and scared, so we keep a lid on our secret fears, put on our best brave smile, and set out to fool those around us. What if everybody's doing that? What if everybody's running around smiling, thinking theirs must be the only fear in all the world?

That scenario could happen in support groups, without the right leadership. On the other hand, a support group can be the perfect place for individuals to express their fears and begin to deal with them. Take a look at a few examples from the wide ranging fears members at polio support group meetings might be harboring:

Some of us simply feel uneasy around new people. The thought of thrusting ourselves into a room of polio survivors we don't know terrifies us. Will a friendly greeting and another's effort to include us in the proceedings quickly put us at ease?

It's different for each of us. Perhaps as polio children we learned to tuck away our fears in the darkest corner of our souls. The traumatizing experience of working our way through a mysterious and foreign polio maze may have left us too apprehensive to whisper our fears even to ourselves. Will the group hear us, permit us to say the words we've needed to say for so long?

Many of us were blind-sided by post-polio. We felt betrayed by the very bodies we had spent years befriending. We felt humiliated and angry that we could no longer do what we used to do, be who we used to be. And suddenly we were afraid. Can we talk about this with the group?

Fear of the unknown is huge. What lies in our futures? What if we get worse? What if we can't find the medical help we need? What if we run out of money or our insurance coverage turns sour? What if we're left alone, our loved ones and beloved caretakers gone before us? How will the group find ways to support our need for hope and compassion? How can we understand the worth of staying in today instead of projecting ourselves into a fearsome future?

Fear isn't easy without someone to discuss it with. It's like a kid alone in his room at night. It's dark. He hears the monster in the closet. The longer he lies there, filled with the dread of the hideous beast about to jump out and devour him, the more frightened he becomes. Soon he is nearly paralyzed with fear. Then, if he's lucky, his mom cracks open the door and switches on the light. She moves to his bed, wipes his tears, and comforts him as she listens to his terrifying tale. Soon he has no problem closing his eyes, falling to sleep.

We need to be able to shed light on our fears—and we need to be heard as we talk about them in meetings. Leaders can work with the group to set up guidelines. These should create a safe, non-threatening meeting environment where members can express themselves freely, comfortable in the feeling of support and encouragement from other members. A few tips:

- Learn to listen. Let the member speaking speak without interruption. Know that when your turn comes, you will be treated with the same courtesy.
- Avoid giving advice. Let members say whatever they want to say without being told what they should or should not do about their situation. Understand that what is right for one person may not be right for someone else.
- Refrain from asking personal questions. Simply wanting to know is not a good enough reason for individuals to poke their noses into a person's life. If members want others to know details, they will talk about them without being prompted.
- Stick with your own story. Suzie can describe her fears and how they make her feel. Jack can get into his fears and what that means to him. But Suzie must stay out of Jack's business and vice versa.
- Empathize in a healthy way. Most members are made uncomfortable by overly solicitous expressions of concern. Watching people fawn all over members who are discussing difficult experiences in their private lives may cause other individuals to choose not to share their thoughts with the group at all.
- Give people space. Remember that expressing our fears and emotions after years of not acknowledging them to others may be frightening in itself. Let members do this entirely in their own way, without our causing unpleasant consequences.

Leaders should make this process as easy as possible for members. Have the room set up so that individuals can sit in small, intimate circles—the entire group doesn't need to hear everyone speak. Maintain rather flexible time limits if possible, so that various members will have the opportunity to express themselves, rather than allowing one person to dominate the entire meeting.

We all know this is a polio support group, not a therapy session. There may be many issues without answers here, but often positive feelings emerge when we begin to let go of our fears. We may learn that getting rid of fears doesn't mean we're losing a part of US, but rather it brings us the gift of freedom to move forward with our lives.

Let's talk about it!

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## LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**QUESTION:** “Our support group periodically asks the attendees for a donation, which I am glad to do. Are they obligated to send me a receipt for my taxes? Are registered non-profit group requirements different from others? Our group recently received its 501(c)(3) status.”

**ANSWER:** Donors should have documented evidence of their donations to 501(c)(3) organizations, showing the date a donation is made, to whom, in what amount, and donor details. Certainly a cancelled check is a receipt that gives all the required information for cash gifts. So does a credit card statement. Without these, a receipt from the group is necessary. Non-profits acknowledge non-cash donations in writing if they are worth \$250 or more.

Here’s a question—why wouldn’t every polio support group WANT to send receipts to all donors in the form of short thank-you notes? Why not express the gratitude we all feel for those who offer our groups financial assistance? Individuals ought to hear that their gifts are appreciated.

Many polio support groups are not registered, and they operate just fine. But for those that are 501(c)(3) charitable organizations, there’s much to know. The rules are not to be taken casually. It’s always prudent to check with a tax advisor or lawyer. Also, take a look at the Internal Revenue Service (United States Department of the Treasury) website (<http://www.irs.gov/charities/charitable/index.html>). Study all the specifics. Perhaps this column can point out some directions to travel, as well:

The IRS 501(c)(3) pages are fascinating. For instance, did you know:

- Non-profit groups operate under strict guidelines. They choose specific charitable purposes when they organize, which they must always follow. Most of our polio support groups fit the bill by stating ways we intend to help polio survivors and their families, the medical community, and the general public. The goal is usually to understand and deal with post-polio issues through such venues as:
  - providing support group meetings
  - supplying polio information
  - developing educational outlets
  - advocating in a variety of directions
  - cooperating with research efforts.
- The assets of 501(c)(3) groups are meant to be dedicated to the charitable purposes listed (such as described above) in their organizing documents. It’s a good idea to check these periodically to be sure your group is still on target. The corporation can pay reasonable amounts to keep the organization running, but the rest of the funds need to go to the official purposes stated.

continued

- If a 501(c)(3) group dissolves, whatever money is left in the pot must be given for one of the specific purposes named in the charitable tax information section of the code.

Interestingly enough, these policies serve equally well as guidelines for unincorporated support groups—actually, most may already follow a similar path. Our groups have a history of choosing worthy goals that are remarkably alike, regardless of whether or not they are registered organizations.

Becoming a 501(c)(3) nonprofit corporation means something special to a group—and to its donors. That designation should assure people their gifts will be spent for the charitable activities named as **purposes** of the group. Knowing groups are trustworthy is one reason people prefer to donate to such charities. That's a valuable incentive.

It doesn't pay to violate this trust. Initially, treating our members to special events and dinners at upscale restaurants, paid for by donations to the group, might sound like fun. We might even harbor momentary fantasies of getting away with such a spree by calling it "support." But it doesn't take the IRS to tell most of us that squandering the group's cash in that way is just plain wrong.

Polio survivors are better than that. We understand we have ethical responsibilities to uphold, whether our groups are non-profit or not. All of us should expect group funds to go to honorable purposes. We should also expect to hear regular financial reports, full disclosure, so that everyone knows the status of the treasury—how much comes in from where, how much goes out to where, and the balance of all funds. It's a good idea to have the books reviewed annually by an independent CPA.

Polio support groups have much left to do to meet our goals. Think of it—we've been making an impact all these years (with or without 501(c)(3) status). There are many reasons to continue. Here are only a few:

Recently PHI printed a sad letter from a grieving woman whose brother died from respiratory difficulties left untreated by uninformed medical personnel. Merely knowing that treating underventilation with the right breathing machine rather than with oxygen most certainly would have saved the man's life. Surely we can get vital polio information like this into the right hands. Why not use our group money to save lives?

PHI's "TAKE CHARGE, NOT CHANCES" is the perfect portfolio guide for everyone connected with home mechanical ventilation. Shouldn't groups buy these and distribute them wisely to help survivors avoid respiratory crises?

Polio survivors have benefited immensely from understanding how various kinds of anesthesia can affect their polio bodies. Likewise, consider how being aware of how certain medications affect polio survivors—and how prescribing lower doses often prevents problems. Why not put our treasuries to vigorous use passing on this kind of important information?

Providing continuing education opportunities for survivors and those in the medical community is one of the best uses of group funds. Workshops, conferences, speakers—a myriad of ways exist. Groups with money can perform miracles! (Well, almost...)

WE'RE STILL HERE taught us that there are still many polio survivors newly experiencing polio problems, looking for information and support. Through this campaign we saw members devise ingenious publicity angles to draw newcomers to our meetings. What better use for our finances!

So, as 501(c)(3) organizations or not, groups can use their cash in healthy, productive, and highly beneficial ways. Regardless of how our lives have changed over the years, there is still much our groups can accomplish—and a lot of that may be achieved by simple judicious spending.

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