

# POLIO NETWORK NEWS

FALL 1996 ♦ VOL. 12, NO. 4



## Sixth International Post-Polio and Independent Living Conference

### Managing Your Need in Relationships

*Margaret E. Backman, PhD, Clinical Psychologist, New York, New York*

As a psychologist, I tend to hear the problem-side of relationships. And what I often hear when I speak with groups like this are comments such as "What do I do? My husband won't listen to me. He's tired of hearing about my problems."

I am not thinking just about husbands and wives: I am thinking about lovers, friends, children, siblings, and parents. I am also thinking about how the effects of post-polio syndrome can upset the balance in these relationships, and everyone has to get in balance again, often creating a new type of relationship.

In fact, one of the issues that we talk about in therapy is how to handle your dependency needs: how to have them and manage them in relationships; how to avoid letting them become a burden to you or to others; and how to avoid predicaments where anyone who says "I'm going to take care of you" gets into your life.

Another kind of relationship in which dependency plays a role that can cause conflict may occur when you are living with or caring for an elderly parent. In one such case, the person who had had polio started developing symptoms of post-polio syndrome as he aged. At the same time, his elderly mother was getting older and becoming more dependent. She began making more demands and did not understand that her child (now an adult) also needed some care. There may be people in similar situations here in this audience. We are all getting to that age where we are becoming caregivers of parents or older relatives. What do you do when all of a sudden your own functioning is being compromised, and yet you are expected to care for someone who does not understand or does not want to understand your new problems? There is no easy solution.

Relationships with children, of course, can be another source of stress. The direction that the stress takes depends in part upon the age of the child; but regardless of age, children — even if they are twenty or thirty

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### Expanding Our Energy Spheres and Sources

*Linda Bieniek, CEAP, Chicago, Illinois*

Are there days when you want to trade in your body? When I see children running around, I often comment, "I would pay for their energy," and think, "If only I had the energy, I would ..."

I struggle with fatigue, one of the most common characteristics of post-polio syndrome. It has interfered with my physical functioning, relationships, and career — the quality of my life. Although I have an energetic mind, feeling physically exhausted has forced me to make many adjustments in my lifestyle and aspirations.

Dealing with my body's limits has been depressing. When I feel discouraged or like a "victim of my body," I transform these self-defeating attitudes into productive strategies by focusing on what I 'want.' In this case, I want ENERGY — this intangible force allows me to do what I want and live my life in satisfying and fulfilling ways. Yet, unlike gasoline that fuels a car, unfortunately, I cannot purchase it directly.

This dilemma has provoked me to apply my professional skills to my own search for energy. As an employee assistance professional, I use a variety of approaches in coaching others with personal and career concerns. A combination of the following techniques has enhanced my resourcefulness and success in improving my health: Neuro-Linguistic Programming "Well-Formed Outcome" model's logical decision-making framework; Self-Acceptance Training's (SAT) emotional principles; and strategies employed by Masters and Johnson treatment program. They have transformed limiting aspects of myself into productive behaviors and desirable feelings.

These techniques recognize the value of looking at the big picture of life — of taking a holistic view — and searching for energy with the curiosity and imagination of a private detective. When I am distressed because of lacking energy, I assess the various parts of my life

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years old — do not like to see parents becoming weak, becoming less than the strong people they once were. Children are often slow to realize that parents need help and are unable to do what they once did. So there may be a lot of denial in the family that puts a lot of pressure on the relationship between parent and child.

When you experience a slowly progressive disability like the late effects of polio, it has an effect on the way you relate to others and they to you, particularly those with whom you live. As your condition changes, roles also begin to change. One difficulty is that your symptoms and needs may not always be obvious. You may dislike having to keep reminding others that you need assistance. Your family and friends may encourage you to continue to do things that are now difficult for you. They may be partly in a state of denial, having their own problems and anxieties in accepting your changing condition. Tempers can flair and resentments can build. What can you do?

- ◆ Keep the lines of communication open.
- ◆ Share literature about your condition.
- ◆ Talk with others about your situation and the changing roles.
- ◆ Look for ways to change behaviors. Find new ways of talking with and helping each other. Be an active participant in managing your needs.
- ◆ Set limits. Learn how and when to ask for help.
- ◆ Remind people if they need prompting. Do not expect others to always remember or anticipate your needs.
- ◆ Find people outside of your family and primary relationships for additional support. Be aware of your own feelings and those of others.
- ◆ Recognize others' contributions and show appreciation. Refrain from manipulation by laying guilt or referring to yourself as a "burden." Remind yourself that others close to you also have days when they may feel afraid, anxious, angry, and tired.

We are talking about empathy. A relationship is a unit in which feelings converge and diverge. It is a give and take. Keep reminding others of what you want and how you feel. You may become irritated when you have

already told people over the weeks or years that sometimes you get very tired. Do not take their forgetfulness as a personal insult. Just quietly learn gentle ways of reminding them again that you are feeling tired. Seek individual counseling or family therapy if problems continue.

Naturally I have a bias in this direction, being a therapist myself. I am concerned when I see the lists of treatment teams set up by some of the medical centers and I realize that no psychologist or other mental health professional is on them. The OT is on there; the PT is on there. Occasionally they include a social worker, which usually means someone to handle the practical matters related to benefits or placement. I ask all of you to urge your medical professionals to think more about your mental health — to have them not be afraid of emotions. A physician once said to me (in another context, as I work with people with various illnesses and conditions besides polio), "God bless them! Somehow they cope!" And I thought, "Would you say that of patents who had a pain in their leg or their back? No, you'd treat them or send them to a professional with experience in that area to help stop the pain."

Emotional pain can be dealt with as well. Problems in relationships can cause pain, too, and that pain can be dealt with by those with professional training. I hope that you will feel it a strength, not a weakness, on your part to seek help for any problems that arise in your relationships. □

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which provide me focus to take steps to increase my energy.

In this context, I envision the various parts of my life as “energy spheres.” Like circles of influence, each part of life offers some potential to provide energy and improve my overall sense of well-being. In other words, each “energy sphere” or circle offers sources of energy.

In the columns below, “Energy Spheres” represents a crucial component of life that contributes to my overall health — where I can find energy. The center column identifies “Desired Outcomes” — what can increase my energy in each area of life. The column of “Energy Sources” cites examples of specific ways I have increased my energy in that part of life.

Each time I choose resources that satisfy my individual needs, I contribute to my overall wellness. For example, I have experienced the benefits of energizing relationships, spiritual connections, and creative expressions. While these experiences may not enable me to fulfill some of my physical desires, like walking a mile — they can give me the mental and emotional energy to express my talents and strengths in non-physical ways.

## HOW CAN WE EXPAND OUR ENERGY?

**We need to assess** the various parts of our lives and identify what we want and need within each area.

A Harvard study that traced graduates for 25 years found that those who wrote down their goals actually achieved and experienced much more than their counterparts who did not use this technique.

I believe we can increase our energy by identifying what we want in each part of our lives, and then by exploring resources that match our needs and approach to wellness. The “Well-Formed Outcome” model outlined below offers a decision-making process that can help us clarify what we want and find realistic ways of getting that.

### **Decide What You Want: Develop a Well-Formed Outcome**

- ◆ *Desired Outcome:* What do you want? Make sure it is within your control and something you can initiate.
- ◆ *Specifics:* Where, when and with whom do you want this outcome?

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<b>Energy Spheres</b>	<b>Desired Outcomes</b>	<b>Energy Sources</b>
<b>Physical Body</b>	energy, vitality, comfort, pleasure	ventilators, bodywork, acupuncture, aquatic exercising
<b>Emotions</b>	awareness, acceptance, compassion healthy forms of expression	psychotherapy, journaling, dreamwork, bodywork
<b>Intellect/Cognitive Mind</b>	clear, rational and congruent thinking; ability to analyze and problem solve	ventilators, Neuro-Linguistic Programming, cognitive therapy, Self-Acceptance Training
<b>Relationships</b>	genuine, nurturing, respectful, loving interactions with others	psychodrama, assertiveness training, psychotherapy, Neuro-Linguistic Programming
<b>Creativity: Self Expression</b>	consistency between our values and the way we express ourselves: our behaviors, communications, choices, decisions, interests, and occupations	movement therapy, guided imagery, music therapy, art therapy
<b>Personal Experiences</b>	finding meaning in our life experiences; intimate connections with others; harmony between our rational and intuitive minds	Self-Acceptance Training, Life Planning Workshop, journaling, psychotherapy
<b>Spirituality/Intuition</b>	serenity; feeling connected with the universe, a spiritual force/being, a higher power, and purpose	meditation, prayer, yoga, aquatic exercising, music therapy

- ◆ *Evidence:* How will you know when you have your outcome? How will things look, sound, feel to you?
- ◆ *Benefits:* How will getting what you want benefit you? What will it do for you?
- ◆ *Ecology:* How will experiencing what you want affect other parts of your life? Are there any parts of your life or people that may be adversely affected? Will there be any losses, negative consequences? Is what you want consistent with what you value in life? Is there any part of you that does not favor what you want? What is the positive intent of this resistance? How can you fulfill this need (i.e., the positive intent of your resistance) in a healthier way that is aligned with your desired outcome? Or, is your resistance a message from your intuition that for some reason your desired outcome is not good for you at this time?
- ◆ *Obstacles:* What stops you from experiencing what you want already?
- ◆ *What resources do you already have* to get what you want? What additional resources do you need?
- ◆ *Action Steps:* What is the first concrete step you will take? When? Where? Is this achievable? What are other options?

(Neuro-Linguistic Programming is a series of models, skills, and techniques that uses the senses and language to enhance a person's abilities to think, communicate, and achieve results. NLP Comprehensive, 1990. All Rights Reserved. Used by permission. For more information on this material, please contact 800/233-1657.)

The chart on the previous page suggests Energy Sources. In looking at your life, from which spheres do you derive the most energy? Which parts are most stressful, draining, or disappointing? These areas may need your attention and benefit from your investing in "energy sources." Which are you interested in exploring?

**We need to face** ourselves with awareness, acceptance, and compassion for our strengths and limitations rather than with judgment, self-criticism, and resentment.

I continue to learn how my emotions and state of mind affect my physical health and energy. Previously, I resented my body and acted as though it was "not good enough." I pushed it to perform beyond its capacity until I could no longer force my body to do what I wanted. Instead, it compelled and humbled me to look at how I was hurting myself when I did not respect its needs for rest, assistance, and nurturance.

I learned I needed to express the feelings — the sadness, anger, and fear that accompanies loss — in constructive ways. This grieving process freed mental and emotional energy, which in turn, has had a ripple effect on my physical energy and relationships. In addition,

when I respect my body's needs, I make healthy choices and conserve my valuable energy.

**We need to explore** our options with open minds. When we increase our awareness of the obstacles, we can discover possible resources and strategies that work.

When I am lacking energy, I find the Well-Formed Outcome Model useful in helping me discover obstacles. Sometimes, I get stuck because of unresolved feelings; other times, because of some ambivalence about the changes I need to make. Often, when I am not respecting my limits, some part of myself expresses that need by interfering with my experiencing what I want.

Using my resourcefulness to work through such obstacles has enabled me to discover strategies and resources that affect other parts of my life.

**We need to commit** to our well-being and make conscious choices that match our values and abilities.

I recognize that I choose how I expend my valuable energy. The reality is that life involves limits and I cannot change aspects of my body. I want to respond to this reality in a resourceful, realistic way rather than allowing feelings of helplessness and hopelessness to deplete my energy level. Life Planning Workshops and other resources have enhanced my ability to make daily choices that preserve the energy I value.

**We need to support** ourselves internally and get appropriate support from others whom we trust, to make this process work.

Learning to accept myself and the effects of having post-polio syndrome has freed me to focus on my strengths, respect my limits, and recapture my resourcefulness and commitment to live life fully.

Seeking support from others confronts my ability to practice the self-acceptance I promote. I value working with competent and ethical professionals who respect my involvement in my healthcare decisions and recognize the connections among my mind, body, and emotions.

Professionals in this panel have offered "What Works" for them. By listening and learning from others, we broaden our perspectives and options. Since 1981, others who attend these international post-polio conferences have continued to display resourcefulness in adding value to the quality of their lives and contributing to our community — living as well as they are able. Their energy strengthens my own efforts to live life fully. I am challenged by the saying, "Living well is the best revenge." □



## Sixth International Post-Polio and Independent Living Conference

# Strengthening Our Spirituality

*Robert Ronald, SJ, Taiwan*

As you start to meet the declines that come with post-polio complications, I want to give you some of the ideas that have helped me along the way, particularly from a spiritual dimension. I have five steps — five steps for helping to keep you up while you're going down.

The first step is to just look at reality. Look the world square in the eye. What you see may be frightening and upset you, but remember that the truth will make you free. The first thing you're going to see is a post-polio thingamajig out there, whatever they call it, that's causing you trouble now, that's going to cause you trouble later. This knowledge can free you from the illusion that you can still go on and do everything. It can free you from having to try to prove that you can still do everything. Knowing that you have to slow down when the road starts to wind and go uphill may be a limitation you don't want to face, but it's a life-saving one — if you slow down.

Another truth that will make you free is the realization that the most important part of you is not your physical function at all: it's the spiritual part of you. The outcome of what you do, often beyond your control, is far less important than the intention with which you do it and the extent to which you put the best of yourself into it, regardless of the outcome.

Another truth that sustains me is that I'm not alone. I have a God that goes with me. This God is not an aspirin that I can take every time I get a headache or a muscle ache. And this God isn't a magic genie that runs ahead of me and removes all the barriers and all the troubles. Instead, it's a God who gives me the courage to go on. Some people say that we're all looking for a light at the end of the tunnel. Well, frankly, that's not what I'm looking for at all. I want the tunnel I'm going through to be brightly illuminated so that every day has its consolations and its accomplishments, and God is the light that guides me through the tunnel.

One of the mysteries of life is that almost anything worthwhile has to be done through effort and pain. And I wonder which is the greater miracle — to go through life without any pain, or to go through pain and turn it to gain?

As you see, the first step is rather gentle: accept; look at what's out there. The second one, I think, is that you must give yourself permission to punch reality in the eye — to give it a good kick in the shins. We see things out there that are injuring us. We learn about pain. We find troubles, and we sometimes feel resentment. We feel angry; we feel upset. God is unjust. Why did this

happen to me? I don't deserve it. Okay, we must give ourselves permission to express these feelings, to get this anger off our chest, even if doing so means shaking our fist at God. That's not anything new. Look in the Old Testament, look in the Psalms, and you'll find all sorts of expressions: "My God, why have you forgotten me?" "Why have you forsaken me?" "I ask you for help and where is it? I can't find it!" If we let this anger and this resentment build up inside us without letting out, we're just causing ourselves all sorts of trouble. We have to let it out: to express our grief; to express our anger in a way that doesn't harm others. Take your anger out on your pillow, not on your mother or your wife or your friend. You'll find that if you do express your anger, even to God, you'll wake up the next morning with its weight off your shoulders. And you'll find out that God was there all the time. You were so angry and upset that you didn't see Him waiting to help you along to the next step.

What is the next step? To open your eyes and look out the window. We tend to look in a mirror, seeing only ourselves and our problems and the difference between what we are now from what we used to be; but the more we look in a mirror at ourselves, the more depressed we get. We have to look away from ourselves. Look out that window: there's still a world out there; there are still people out there. There are still horizons that we can reach out for, even if they're different from the horizons that, at another time, we thought we'd be reaching out for.

Here's a verse I like — I don't know who wrote it or where it came from, but it goes like this: "Two men looked through prison bars. One saw mud, the other stars." The person looking only down misses a lot of the blessings of life. The person looking only up is in danger of getting muddy feet from the puddles. So we have to look both up and down. We have to see what's there and its possibilities.

And then we're at the fourth step, which is to close our eyes and reflect or meditate or pray, whatever we want to call it. Now that we see the realities of our own position, the realities of post-polio complications, we have choices to make, priorities to set. Perhaps we have to choose a new lifestyle or change some of the ways we do things. We need to reflect very quietly, to discern within ourselves what we really want. In a way, we are like heavy smokers — at some point they'll realize that either they've got to quit smoking or they may face terrible consequences for their health. Some smokers decide not to stop smoking. It's their choice. We, too,

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# dogs can do what?

Marie Davis, Support Dogs, Inc. ♦ Saint Louis, Missouri

One way to enter the world of canines as human partners is to look at how the canine can help. Just like us, canines have many career choices: some are policemen in the K-9 corps; others are athletes, entertainers, watchmen, hunters, janitors, etc. Canines that choose to work in the human services field are known as assistance dogs.

Assistance dogs are trained to work in partnership with a person who has a disability. They function as guide dogs, hearing dogs, service dogs, and therapy dogs.

A guide dog is trained to help someone who is blind or has a vision impairment. It assists its partner to independently and safely negotiate the environment by guiding around obstacles and across streets.

A hearing dog is trained to help someone who is deaf or has a hearing impairment. It alerts its partner to such sounds as the doorbell, the oven buzzer, a siren, or an approaching vehicle. It also leads its partner to safety when a smoke alarm sounds.

A service dog is trained to help a person with a physical disability. It may be partnered with someone who uses either a manual or a



power chair or with someone who is ambulatory but needs balancing assistance. This dog does such tasks as retrieve objects, open doors, carry trash, move furniture to clear a pathway, set alarms, and make beds.

A therapy dog is trained to provide additional companionship and to follow specific directions of a therapist to help humans during recovery or rehabilitation.

When you see an assistance dog "on duty" with a partner who does not "look disabled," you can be sure that the partner has been diagnosed with a "hidden disability." For example, it may be cancer, chronic back pain, pain from injuries, a neuro-seizure disorder, or deafness.

What should you expect from an assistance dog when the dog is at work? Because it has many months and, sometimes, years of training before starting its career, it should have "house manners," be able to maintain a down-stay command unless asked to do a specific task, and be quiet, non-threatening, and at ease with its surroundings. The dog must not solicit affection from humans, approach other dogs, or bark or run around the room, sniffing or looking for food. (Assistance dogs are taught not to want "people food" and are fed on a daily schedule. When they go into restaurants, they are expected not to beg for food, scarf crumbs from the floor, or beg for treats.)

What should an assistance dog expect from you? You are to respect the dog's duties. You are not to call or whistle for the dog to leave its post. You are not to touch or pet the dog while it is on the job. (Many partners of assistance dogs use a cape on their dogs that says "Please do not pet.")

Do assistance dogs ever have fun, or are they just workaholics? When its partner puts on its harness, its uniform, the dog knows that its business day has started. After work and out of harness, the assistance dog lets down its hair: it romps and plays, stretching and exercising, before settling down for a nap or a spot of TV.

More and more people are finding an assistance dog helpful in the office, at home, or outside. Federal, state, and local laws permit these dogs in all public places. They are busy on the college campus, at the church-hall reunion, by the copy machine, or next to the dryer as they wait to help fold the towels.

For answers to questions regarding the legal rights of assistance dogs, contact Assistance Dogs International, Inc. (ADI), P.O. Box 150217, Lakewood, Colorado 80215-0217, 303/234-9512. Incorporated in 1987 by a coalition of individuals representing training centers and assistance dog partners, ADI promotes standards and ethics, facilitates communication among centers, and educates the public about the benefits of assistance dogs. It publishes a pocket guide explaining the laws of each state.

Partners of assistance dogs may want to join the International Association of Assistance Dog Partners (IAADP), 810/826-3938. This organization enables partners to share information, voice their concerns, and take the lead in solving any problems.

There are assistance dog training centers across the United States, England, Australia, and South Africa.

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# polio survivor + service dog = success

Sara Castelli, Canine Companions for Independence ♦ Palm Bay, Florida

Getting dressed, you drop your shoe. You reach for it, lean forward a little, lean a little more ... and there you are, on the floor beside your shoe! Your wheelchair just sits there, a silent witness. We polio survivors see this scenario played out daily in hundreds of different ways.

Although we who “conquered” polio in the early years thought we had come to terms with adaptive equipment, even going from braces and crutches to the wheelchair, we now find that the floor seems farther away than ever. The chair creates a barrier around us that prevents us from reaching things.

But after having had polio for almost 50 years, I now have the luxury of a new type of assistive device: it picks up everything I drop — from coins, credit cards on tile floors, earring clutch backs, soap, shoes, magazines, books — and reaches things I can't reach. It kisses me frequently during the day. What is it? My service dog, Bennie (Bennette), a golden retriever from Canine Companions for Independence.

For us with mobility impairments, wheelchair or not, a service dog is one awesome device. In fact, after Bennie's five years with me, I don't know what I did before she came to help. The most cooperative of assistants, she is never too busy to get what I cannot. She is eager to go shopping, to eat out, to attend the theater and conventions, to travel. In short, she has made my life much better and my physical losses less frustrating.

A service dog can enhance your life in ways you never imagined. For example, before I acquired a power wheelchair, Bennie pulled my manual chair. I went from “the person in the wheelchair” to “the person with the dog.” Few remember my name, but they always remember the dog! People see me in a new way, as a functioning person. Moreover, a service dog can go to work with you. Can't reach out to the elevator buttons? Say “switch,” and the elevator is on the way! Your pencil rolled back under your desk? Say “get it.” You need to send a paper to the next office ... “get it, hold, go to Susie.” What a deal!

The growing population with post-polio syndrome is clearly reflected in the increase in the number of applicants for service dogs. We, as polio survivors, are finding a way to face new challenges, to handle new loss of strength, to deal with new loss of energy: we are finding these wonderful service dogs!

If you are thinking about applying for one of these “wonder dogs,” think about Canine Companions for Independence, a national non-profit organization whose mission is to provide trained dogs to assist people with

disabilities other than blindness. It has five regional facilities scattered throughout the U.S., where dogs are trained to pull wheelchairs, open doors, turn on and off light switches, call elevators, and retrieve dropped items. Its “graduates” usually develop many other commands for their dogs to assist them, such as bringing shoes, socks, phones, pulling off socks, getting help, etc.

Bennie was bred by Canine Companions for Independence for this special work, and a volunteer foster family raised her for about 14 months, teaching her basic obedience commands, and socializing her. She then went to a regional training facility for 6-8 months of specialized training before



being placed with me.

I trained with her for two weeks. Once back home, I asked the center and its trainers for help and advice as I needed it. We have attended periodic events where puppy raisers and we graduates get together for socializing. The regional offices sponsor these, and they provide a unique opportunity for us graduates to see how puppies start out and for puppy raisers to see what their efforts produce. To obtain additional information and to locate the facility nearest you, contact Canine Companions for Independence, P.O. Box 446, 2965 Dutton Ave., Santa Rosa, California 95402-0446; voice 707/577-1700; TDD 707/577-1756. See the web site at <http://www.caninecompanions.org/>. □

A retired program manager and a volunteer for Canine Companions, Sara Castelli had polio in 1948. She received her dog in 1992 and serves on the National Board of Directors. Sara travels extensively speaking about Canine Companions for Independence and disability issues.

## Strengthening Our Spirituality

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have to make decisions. Every day we should close our eyes, as it were, figuratively, and reflect upon where we are, where we want to go, and what we have to do — or not to do — to get there. God, if He's going to talk to us, isn't going to give us a telephone call or send us a fax or tap us on the shoulder. Generally, God speaks to us through the circumstances of our lives. But unless we quietly close our eyes and listen, we will miss the direction and the help He might have given us.

The last step is to just get out there and do it. Whatever it is you've decided to do, just do it. And do it not looking back and regretting that you're not doing something else, or comparing what you're doing with what other people are doing. Just do it. And even if your decision is that because of your polio condition, your age, or whatever, it's time to retire, then retire fully. Put your whole energy into resting and enjoying life. And if at the end of the day, you can say, "Well, today I had an enjoyable day. I had fun with my leisure and my rest," then you've had a full day, a day to be proud of.

Here are some lines from a poem that I read once and liked. They're probably not the exact lines, but what influenced me is what I remember, not what the poet actually said. They go something like this: "The woods are lovely, dark and deep, But I have promises to keep, And miles to go before I sleep." So do all of us have miles to go before we sleep. But the woods don't have to be lonely if we reach out to other people. And the woods don't have to be dark if we have a God or other support going with us. But the woods are deep. Well, that's what makes life interesting. Our lives are full of mystery, full of hidden treasures, full of we-know-not-whats ... that's what gives life spice.

I used to say, "Have wheelchair, will travel." Maybe the day will come when I must say, "Have wheelchair, will sit." Or maybe to go on to another step, I'll say, "Have bed, will lie." But whatever my situation, I have life, and to the best of my ability, I will go on living it as fully as I can, so help me God. □

### **G.I.N.I.'s Seventh International**

SEVENTH INTERNATIONAL  
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AND  
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**Post-Polio and  
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## Dogs Can Do What?

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One of these centers is Support Dogs, Inc., 3958 Union Road, St. Louis, Missouri 63125, 314/892-2554, which breeds and trains service and therapy dogs.

From age 49 days to around 18 months, Support Dogs' trainees are socialized in foster-care homes, which provide love, environmental stimuli, activities, and obedience training. The foster-care providers attend class with the puppy-in-training to help it prepare for the next step — college. From age 18 months to 24-32 months, the puppy is officially in finishing school, where professional trainers evaluate its attitude, aptitude, and work ethic.

If a dog loves to pull, is strong, and has no health problems, it may train to do "para" work, helping someone who uses a manual chair. If the dog is a "couch potato" that just wants to be a well behaved companion who plays fetch for fun, it may train to become a home companion for a child with a severe disability or an elderly person.

The list of applicants for service dogs (which are placed nationally at no cost) is long, so no dog has a long wait for its new job. In fact, after its professional training, it is matched with a partner of like interests, attitude, and aptitude and trained for an additional 30-day period with its new partner. During this time, they both learn to problem-solve, custom-train, and, of course, fulfill the bond between canine and human.

Support Dogs also trains dogs for therapy careers, toward which are two paths: one is facility-based, for the dog that wants to serve more than one person. Austin, for example, is a dog trained to work with a speech therapist who works with children with autism or behavioral problems; another example is a retired service dog now working with a psychologist who teaches elementary-school children responsibility.

The second career path in therapy work for a dog is volunteering to help people in hospitals, rehabilitation centers, or long-term care centers. This dog's vocation is being a pet; his avocation is being a therapist. If a pet and his owner want to be volunteers in this program, the dog must pass an entrance examination, and both owner and dog must attend a 14-week training program for two hours each week. After graduation, they may help children get over the trauma of hospitalization or help people in elder care enjoy the pleasures of walking a dog. They can even help people forget the pain of stretching sore muscles as they all participate in an active game of toss-and-fetch. These dogs are always pets and do their work as volunteers. □



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

**Self-help group(s) ...**

- ... share a common health concern
- ... **govern themselves and their agenda with success dependent on each member's feelings of ownership.**
- ... **may use professionals as resource persons but not as leaders.**
- ... provide non-judgmental emotional support.
- ... gather and share accurate and specialized information.
- ... membership is fluid; newcomers are helped by veterans and become veterans who may outgrow the need for the group.
- ... have a cause and actively promote that cause.
- ... increase public awareness and knowledge by sharing their unique and relevant information.
- ... charge small or no dues for involvement and typically struggle to survive.

\*International Polio Network, 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915

## Effective Support Group Facilitators ...

- \* Are knowledgeable of group behaviors/leadership. Facilitators tend to have some familiarity with or past experience as a group leader; understand how people behave in groups; understand the helpful things one can do in group settings; and acquire skills through books or classes on group leadership.
- \* Possess a basic commitment to the self-help process. Effective leaders are committed to three basic assumptions: each member can make a contribution to the group; each is the ultimate authority on his/her needs and what will work for him/her; communications will be open and honest to promote positive group experiences.
- \* Are capable of distinguishing/controlling personal views. Effective facilitators are able to separate their personal needs from those of the group or member needs. Those having their own agenda or "axe to grind" can end up promoting their views and opinions over those of the group. At times, the facilitator may need to step out of his/her role for the purpose of expressing personal needs and opinions.
- \* Are willing to work toward the group's goals. Effective facilitators are enthusiastic about the goals of the group and are willing to work for their accomplishment; see themselves as a part of a team and are emotionally and physically committed to the team's success; and actively and creatively look for ways to give members the opportunity to participate in the process of setting and carrying out the goals.
- \* Have the ability to initiate activity. Every facilitator seeks to develop shared responsibility and leadership for the group. There will, however, be occasions when no one else is capable, ready, or willing to do what needs to be done. The facilitator must be prepared to

get the ball rolling, always balancing the need to generate member participation against the need to protect from burnout.

- \* Are comfortable with the expression of emotion, tension, and conflict. Emotion, tension, and conflict are likely to arise in a support group. Leaders should be comfortable with this, not only as it occurs in others but in themselves. Leaders should expect that conflicts within the group will appear and that criticism will be directed toward the leader; learn to look at criticism objectively and avoid taking it personally; and learn some basic communication skills to better deal with the emotions that may surface.
- \* Are committed to the welfare of the group and all of its members. Commitment of an effective facilitator lies with the group — how to make it succeed, how to meet needs — requiring a willingness to look for the forest and not be distracted by the trees. A good facilitator will focus on building a sense of community, group cohesiveness, and consensus decision-making within the group.
- \* Value and respect each member as an individual. Although the facilitators' focus is on the group, they do not lose sight of the individual. Each member is unique. Members are seen as equals, deserving mutual respect and consideration for the values they hold as individuals. All members are potential teachers, having a reservoir of knowledge and experience from which others may benefit.

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Excerpted from *You Can Do It! Building and Strengthening Your Self-Help Group*, available from the Self-Help Network of Kansas for a suggested donation of \$15. Contact Self-Help Network of Kansas, Wichita State University, Box 34, 1845 Fairmount, Wichita, Kansas 67260-0034 (800/445-0116; 316/978-3593 FAX).

## Post-Polio Bibliography, Projects, Literature, etc.

Perry, J., Fontaine, J. & Mulroy, S. (1995). Findings in post-poliomyelitis syndrome. *J. Bone and Joint Surg.*, 77-A(8), 1148-1153.

Westbrook, M., & McIlwain, D. (1996). Living with the late effects of disability: A five year follow-up survey of coping among post-polio survivors. *Australian Occupational Therapy Journal*, 43, 60-71.

Regular readers of *Polio Network News* will recall the article "Disability as a Life Course: Implications of Early Experiences for Later Coping" in the last issue. Dr. Westbrook, a polio survivor, reported on a survey of 176 individuals from Australia with post-polio syndrome.

The article cited above discusses the implications of a follow-up survey. In general, polio survivors experienced a significant decline in their health over the five-year period. The study revealed that survivors who focused on their symptoms while maintaining previous activity levels felt the most helpless, depressed, and angry.

On a positive note, the survey rated how helpful certain treatments and lifestyle changes were when tried. The top five most helpful treatments were massage, hot baths, special shoes, swimming, and hydrotherapy. The top five most frequently tried treatments were drugs for pain relief, swimming, exercise program, vitamins, and massage. The top five most helpful lifestyle changes were employed household help, bought special furniture/equipment, modified home, paced self, and planned life more efficiently. The most tried lifestyle changes were rested more, reduced physical activity, paced self, and planned life more efficiently.



**"Wellness for Women with Polio: A Holistic Program Model,"** a new post-polio research study, was awarded to the University of Michigan. Funded by the National Institutes of Health, the three-year study is being conducted by a 14-member study team led by Denise G. Tate, PhD, and James Leonard, MD. Sunny Roller, MA and polio survivor, serves as the project's manager.

The study will test the effectiveness of an eight-week wellness program for women 41 years of age or older. Two hundred women who have various levels of disability from polio and who live in southern Michigan and northern Ohio will be invited to participate. Of these 200, 100 will be asked to attend a three-pronged wellness program covering exercise, nutrition, and stress management customized to their needs. To assess the program's impact on health and quality of life, medical and psychological information will be collected before, right after, and six months following the wellness workshop. This study's results will be used as a basis for designing future holistic wellness programs for women with physical disabilities.

**Albert Einstein Health Network** is still seeking individuals who had paralytic polio for a research study that will examine muscle overuse. The study will take place at Moss Rehabilitation Research Institute, 1200 West Tabor Road, Philadelphia, Pennsylvania. Each participant will be seen four times over a 15-month period to have his or her strength measured and to evaluate any joint or muscle-related complaints and symptoms.

Interested participants should contact the Post-Polio Project, Moss Rehabilitation Research Institute, Korman Building, Suite 213, 1200 West Tabor Road, Philadelphia, PA 19141. Call 215/456-4993 or FAX 215/456-9514.



A new **Fact Sheet — Post-Polio Syndrome** prepared by the National Institute of Neurological Disorders and Stroke of the National Institutes of Health, Bethesda, Maryland, summarizes the status of drug treatment research for post-polio syndrome.

— Treatment with alpha 2 recombinant interferon proved ineffective.

— Treatment with high doses of prednisone is not recommended because of the side effects and the fact that the mild improvement demonstrated lacked statistical significance.

— Treatment with low doses of pyridostigmine did reduce fatigue in some patients. Research continues.

— Treatment with amantadine, in a controlled study, was not helpful in reducing fatigue.

— Research is being done on selegiline.

— A preliminary study to test whether insulin-like growth factor (IGF-1) "can enhance the ability of motor neurons to sprout new branches, maintain existing branches, and rejuvenate synapses (the space between nerve cells where signals pass from one cell to another)" is underway. Plans are also underway for a multi-centered controlled trial.

*Extracted from Fact Sheet — Post-Polio Syndrome (NIH publication No. 96-4030), Office of Scientific and Health Reports, NIH Neurological Institute, P.O. Box 5801, Bethesda, MD 20824, 800/352-9424.*

*Reminder about prescription and over the counter medication:* Many medications have side effects, some of which are weakness and fatigue, non-specific symptoms of post-polio syndrome. Polio survivors are encouraged to discuss with their physician the side effects of any medications they take. Anecdotal evidence suggests that survivors' symptoms of muscle pain and weakness subsided when certain medications for lowering cholesterol were no longer taken. The benefits of taking a medication and its possible magnification of post-polio symptoms should be balanced against the risk of not taking the medication.

In addition to side effects, polio survivors and physicians should discuss dosage. Many polio survivors particularly those with a lesser muscle mass tolerate only lower dosages, as is also suggested for the aging population.



*Current Trends in Post-Poliomyelitis Syndrome* by Daria A. Trojan, MD, MSc, and Neil R. Cashman, MD, Montreal Neurological Institute and Hospital, is a newly-published monograph written for health professionals. International Polio Network will send it to the primary care physician, with an acknowledgment card, of current subscribers of *Polio Network News* upon request and while the supply lasts. Additional single copies are available to subscribers and non-subscribers for pre-paid shipping and handling charges of \$3.00. Single copies are available with invoice for \$4.00. Contact International Polio Network for shipping and handling fees for multiple copies.

Matthew N. Bartels, MD, MPH (Columbia Presbyterian Medical Center, New York, NY presented a poster, "Unique Physiatriac Managment Issues in Pregnancy in a Patient with Post-Polio Syndrome," at the 58th Annual Assembly of the American Academy of Physical Medicine and Rehabilitation. The case presented was that of a 27-year-old women who had polio at age 1, with residual weakness in both lower extremities. The case illustrated that a post-polio patient may have a successful pregnancy and delivery if a team approach is used. The management of her progressive weakness, special bracing needs, and peripartum care were discussed and a model for the care of the pregnant PPS patient was presented. For more information, contact Matthew N. Bartels, MD, 622 West 168th Street, VC 3, Rm. 363, New York, NY 10032, 212/305-8592.

*Post-Polio Syndrome: Rehabilitation and Conservation* (96 pages) consists of chapters by physicians and therapists with a chapter on the psychological aspects written by polio survivor Father Robert Ronald, SJ. The manual, published by the Republic of China Ministry of Health, is in Chinese.



### **Change in Polio Vaccination Policy in the United States**

The Centers for Disease Control and Prevention (CDC) accepted the recommendations of its Advisory Committee on Immunization Practices (ACIP) to change the routine childhood polio vaccination schedule, beginning in early 1997. CDC recommends that children in the United States receive two doses (shots) of inactivated polio vaccine (IPV) followed by two doses of oral polio vaccine (OPV). The recommended sequential series consists of two doses of IPV (at 2 and 4 months of age), and two doses of OPV (at 12-18 months and 4-6 years). This new schedule is aimed at preventing the eight to nine cases of paralytic polio caused by OPV which are reported in the United States each year.

### **Global Polio Eradication**

The CDC statement emphasizes that the vaccination change is possible because progress in global polio eradication has substantially reduced, though not eliminated, the risk of importation of polio into the United States. "This new recommendation for a greater role of IPV applies only to the United States because it has sustained interruption of polio for more than 16 years. CDC remains firmly committed to global polio eradication by the year 2000, which relies on the exclusive use of OPV in countries that have or have recently had circulating wild poliovirus. Aggressive immunization efforts and surveillance programs must continue until polio is eliminated worldwide," the CDC statement says.

This year marks the fifth anniversary of the last wild poliovirus case in the Americas. Since then, there have been four importations of wild poliovirus into the Western Hemisphere, two from India and two from the Netherlands. Importations remain the greatest threat to the polio free status in the Americas.

*Extracted from Expanded Program on Immunization in the Americas Newsletter, Vol. 18, No. 5, October 1996.*

### **Poliomyelitis Outbreak — Albania, 1996**

During April 17 — September 16, 1996, an ongoing outbreak of paralytic poliomyelitis in Albania resulted in 66 cases of acute flaccid paralysis, including seven (11%) deaths. Wild poliovirus type 1 was isolated from seven cases.

*Source: Morbidity and Mortality Weekly Report, Vol. 45, No. 38, September 27, 1996.*

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### **Effective Support Group Facilitators**

continued from page 8

\* Emphasize the positive aspects of the support group. It is all too easy to focus on the negatives generated at having to deal with the demands and consequences of the problem. Effective facilitators attempt to put a greater emphasis upon the positive aspects — education, learning successful coping strategies, the support of others who really understand, etc. Negatives are not avoided, but they do not become the group's primary focus.

\* Encourage members to identify/evaluate alternatives for themselves. They do not decide what is right for the members. All members are encouraged to examine problem-solving strategies and potential solutions for themselves. Facilitators provide a process by which members explore options and alternatives and offer their support as the members carry out this process and their respective choices. □

## Readers Write

Please send your responses to International Polio Network.

"Aljan Company, 2008 Fish Hatchery Rd., Madison, Wisconsin 53713, 608/257-4256, is great in coming up with inventive solutions ... a wonderful place to recommend for all kinds of pedorthic/orthotic work on shoes."  
CAROL, WISCONSIN

"I have had success in receiving payment from my insurance company for special extra-depth shoes to accommodate an orthotic insert in my non-polio foot shoe. I requested a prescription from a podiatrist and took it to a certified pedorthist. He made the orthotic, ordered the extra-depth shoes from P.W. Minor (800/PW MINOR), and made the necessary modifications to correct walking problems. The prescription noted that extra-depth shoes were required to accommodate a custom-made orthotic insert."  
JOHN, ARIZONA

"I sell Birkenstock sandals and shoes through the mail. For years we have worked with our local customers who have difficulty finding shoes due to the effects of polio. Birkenstock USA, the importer, has a program for purchasing split-sized pairs of sandals in two styles (the Arizona and the Milano) for a slightly higher charge. Most fittings can be done through the mail from foot tracings.

"My business can do "footbed swaps" in most styles of Birkenstocks. The footbed in one sandal is replaced with the correct size for that foot. We add lifts and can custom taper them to allow for a natural, balanced gait. We also make custom footbeds."  
PETER WENDEL, BIRKENSTOCK EXPRESS, 301 SW MADISON AVE., CORVALLIS, OR 97333 USA, 800/451-1459 (USA AND CANADA), 541/758-7631 (OTHER COUNTRIES), [HTTP://WWW.FOOTWISE.COM](http://www.footwise.com)

"I have found hand-crafted leather sandals that are wonderful. For a flyer, contact Lee W. Risler at KIWIS, P.O. Box 763, Lucerne Valley, CA 92356, 619/248-7195."  
SHARON, CALIFORNIA

"I've been getting lumbrosacral corsets for several decades from a company here in the Twin Cities called Trautmans (aka Minneapolis Artificial Limb Co.), which recently changed its name and main office address to:

ACTRA Rehabilitation Associates, 4500 Park Glen Road, Suite 390, St. Louis Park, MN 55416, 612/922-1055. The procedure in the past was for the company corset person to take or confirm my measurements. The corset was custom made to fit my frame at the factory, and any adjustments necessary after the initial fitting were done locally."  
LEROY, MINNESOTA

"I require a leather customized corset type back brace. There are not many orthotists capable enough or willing to make this time-consuming and labor-intensive support. High-tech methods and materials are preferred. Unfortunately, high-tech doesn't work for me; I need a customized brace that I buy from Scheck and Sires, Robert Wahlen, 1141 Madison Street, Oak Park, IL 60302, 708/383-2257, 708/383-0739 FAX."  
DAVID, ILLINOIS

"A new post-polio support group called Boca Area Post-Polio Group meets the second Wednesday of the month at the Spanish River Presbyterian Church. For more information, contact Carolyn C. DeMasi, 21577 Guadelajara Avenue, Boca Raton, FL 33433-7502."

"Researchers investigating ALS and other neurological disorders have been helped by the willingness of individuals to donate tissue specimens upon their deaths. I've been told by one experienced researcher that it is rare for polio survivors to make such donations, and that this lack of tissue has been a significant hindrance in efforts to investigate the late effects of polio. Your mention of the National Neurological Research Specimen Bank (The Brain Bank) in the spring *Polio Network News* was good and I urge you to repeat it.\*

"It is not hard to make arrangements to donate, doing so will not interfere with any family plans for funeral or burial procedures, and should not entail any extra expense to the donor. I urge polio survivors to make plans now to donate tissue specimens."  
ROBERT, NEW YORK

\*For information on how to enroll yourself and your brothers and sisters to serve as controls, in the Gift-of-Hope tissue donor program, contact Iris Rosario, RN, MA, National Neurological Research Specimen Bank, W. Los Angeles, CA 90073 (310/268-3536 or 310/268-4768 FAX).