

POLIO NETWORK NEWS

International Polio Network

Spring 1990 ■ Vol. 6, No. 2

Polio Eradication & Rehabilitation in India

By Sunny Roller, M.A.

A team of health care professionals visited India from January 25-February 14, 1990. Frederick M. Maynard, M.D., an Associate Professor of Physical Medicine and Rehabilitation at the University of Michigan Medical School, led the group sponsored by Michigan's Rotary District 638 and Rotary International's Special Projects Program. Team members included: Celest Van Wert, PT; Hans Schaepper, CO; and Sunny Roller, Coordinator of the Post-Polio Research and Training Program. An orthopedic surgeon originally from India and past president of Rotary District 638, Mav Sanghvi, M.D., was instrumental in organizing the trip.

An estimated 12 million polio survivors are living in India today with 80,000-100,000 new cases per year. The team evaluated over 50 children with polio paralysis, lectured at the Trivandrum Medical College, visited several homes for children with polio and participated in India's Polio Eradication and Rehabilitation conference.

The national conference, sponsored by the Home for Handicapped (Polio) Children in Trivandrum, Kerala, was attended by 100 professionals who participate in polio eradication and rehabilitation programs in India.

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"Prescription for Fatigue" from Fifth International Polio & Independent Living Conference in St. Louis

Polio survivor, Jane Dummer, Baltimore, MD, introduced the topic of fatigue as it relates to the late effects of polio. Her remarks are followed by comments and suggestions from William Waring, M.D., University Hospital, Ann Arbor, MI, Richard Owen, M.D., Sister Kenny Institute, Minneapolis, MN, and Martin Wice, M.D., St. John's Mercy Medical Center, St. Louis, MO.

JANE DUMMER: I am qualified to introduce the panel on fatigue because I fade right after lunch. When I agreed to speak, I realized very quickly I was going to discuss something which is global, yet something I really can't define for you.

So what am I going to say? Fatigue is a normal part of living. Perhaps I can say something about what I've experienced that would help people who don't yet know they have polio-related fatigue to see how it may be different from the fatigue that anyone who is alive has.

I had polio many years ago and did fine with a brace and cane while pursuing normal activities for about 30 years. I knew my baseline. I've always been limited in what I could do, but within the parameters of my limitation, I was able to carry on a fairly normal existence. About ten years ago, I started to develop weakness and pain. Much of the weakness was in my better leg, which started giving way on occasion. I was very concerned.

But I was not aware that I had overall fatigue until the day I was coming back from a meeting in an enormous federal complex in Baltimore. About halfway back, my better leg started to shake. I stopped

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After two days of professional presentations and discussions, a third day of deliberations resulted in a series of recommendations for action to promote polio rehabilitation and eradication.

The Indian subcontinent may account for 40% of current worldwide new cases of polio. Approximately half of the new cases occur in children less than one year of age and 95% in children under age five. Dr. Maynard comments, "The problems of polio rehabilitation are those of providing continuing rehabilitation services to children who are growing and developing with significant paralytic involvement of leg muscles." This problem is most evident in poor, rural areas and is compounded by inadequate transportation and limited rehabilitation services.

Rehabilitation professionals need additional training. Programs could be set up in the U.S. to train individuals from India in advanced techniques, and professionals from Western countries could visit and teach local health care workers about proper exercise programs, orthotics, etc. Programs for families with children with polio could be established to provide information, resources, and emotional support.

In Indian communities, adults with a disability are not visible as productive members of society. Independent use of a wheelchair is a problem throughout India because of poor accessibility. Maynard concludes, "Clearly, there is a need for

greater awareness concerning the potential of people with disabilities."

Polio eradication was the second topic of concern. Discussions at the conference and a later review of the medical literature revealed that eradication of polio in developing tropical countries may not be successful by using the same vaccination techniques that have proved to be successful in developed temperate nations. Dr. Maynard reports, "There are significant differences in the epidemiology of new cases of poliomyelitis in tropical developing countries. Many of the problems relate to the type of vaccine, vaccination procedures, and to the practical issues of administering vaccine to large rural populations of poor people." The conference concluded that there are 10 major problems preventing effective polio eradication in India. These have been outlined in a report to the leaders of Rotary International's PolioPlus Program. *

"It is possible to consolidate worldwide knowledge and expertise," says Maynard. "However, if solutions are to be found within the next few years, a meeting of experts is urgently needed." An International Symposium on Worldwide Polio Eradication could be co-sponsored by interested organizations. A proposal to sponsor this symposium has recently been submitted to Rotary International.

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dead in my tracks. I had to sit down; I could not move. After I rested, I limped back to my desk. I sat in a state of "zombie-ism" for about two hours, thinking, "This is it! You know you have to go to meetings in other buildings. You need a wheelchair."

I bought a wheelchair that afternoon. (I didn't buy the right kind, but that's another lecture!) The next day I rode over to the same place and back in my wheelchair, and I was absolutely amazed! I came back as rested as when I had left for the meeting. I was able to work for the rest of the afternoon. At that particular moment, I realized that over a period of three or four years, I had gradually been curtailing my activities to deal with chronic overall, unaccustomed fatigue (about which we hear so much), and I didn't even know I was doing it!

I'm a very pragmatic person. As a general rule I deal with things in a straightforward manner, but it really shocked me to think how much I had altered my life-style and didn't even know it!

In the last couple of years, it's been obvious that fatigue is my main problem. I couldn't ignore it forever. It's had an impact on my job, on my social life. I had a nap before lunch today, and that's why I'm here. I'm good for six hours. I have an eight-hour-a-day job.

What helps me the most is rest. I asked if I could take a rest period on my lunch hour at work. I was nervous because I knew they were going to think I was not doing a competent job if I couldn't stay awake for eight hours. It was hard to go and ask, but I did it. They agreed.

About three weeks later my supervisor said, "Jane, I'm just not sure this rest period is working out." I said, "What do you mean?" She said, "Before you started to take that nap you were so docile and quiet all afternoon, I didn't have to worry about supervising you. Now I don't know what you're going to stir up!"

One of the biggest things about fatigue as a polio survivor is its assault on your self-esteem. You suddenly cannot do what

you've always done. You may start an activity and can't continue it. You may have to work part-time. You may have to forego the promotion because the job might be too taxing. If you let it, these circumstances hurt your self-esteem. I think the trick is to take as much control as you can. Make your own choices and be aware that you can change them! You have to alter your life-style and see what works for you. That's what I'm doing. I'm trying things, and if they don't work, I drop them and I try something else. I'm going to look at part-time work, think about disability retirement, and look at getting some hobbies that aren't so taxing. I'm trying to focus on quality of life, retain my sense of humor, and learn. I'm trying to listen to my body, not deny what's going on, and live within it. I came here to share with people like you, to learn from you, and hopefully to help you.

DR. WARING: I'm very happy to be here because it's a chance for me to thank some of you for being my patients. You have taught me about my profession, and you are a pleasure to work with because you're so involved. You care about what's going on and want to learn more.

It is evident that from a medical and scientific standpoint, fatigue is confusing. From a clinical standpoint, the biggest challenge I face is to understand the symptom or complaint and to correlate that with what I understand in terms of the physiology.

One definition of the post-polio syndrome is based on five points.

The first point is a history of polio. The second is a period of recovery, which is followed by the third step--stability. The next step is the onset of problems, such as fatigue, weakness, shortness of breath, and pain. The last point is the exclusion of any other medical diagnosis to explain these symptoms.

One of the changes I've seen in the last few years is that there has been a change in the flexibility of thinking about these post-polio problems. We not only continue to study what might be a potential nerve

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problem, but we also now look at things that are obvious. There are symptoms that can be identified and symptoms that can be treated. That's our challenge as clinicians--find things we can treat.

From a physiological standpoint, fatigue is best studied and best understood at the muscle-nerve level where fatigue can be defined as the normal loss of maximal or sustained tension over time. In this context, all muscle will fatigue if it's asked to work hard enough. It is also true for a muscle that is already weak.

Scientists have developed a curve on a graph that compares strength and fatigue by the amount of work the muscle does. When muscles are asked to do very little work, they don't get fatigued, or it takes a very long time for that to happen. As we approach the maximal strength of the muscle, it fatigues very quickly. In fact, it can fatigue at maximal strength in seconds.

Now, with a weakened muscle, whatever the cause, the curve has the same shape, but it's in a slightly different location on the graph. The muscle fatigues earlier at lower loads and it's maximal point is also less. So a muscle that's weakened from polio might do pretty well and not fatigue, as long as it's not at the maximal end of its function. If you ask the muscle to work harder, it fatigues very quickly. If there's an absolute loss of strength, the curve will move down.

Fatigue as a symptom is not as well studied or understood, because we could look at it as a perception of how you feel. It tends to be more clinical than basic science, and we have a number of conditions that have fatigue as a symptom--multiple sclerosis, strokes, pain disorders, anxiety, stress, sleep disorders, and chronic pain.

In our clinic at the University of Michigan, we have a number of patients who do not have any evidence of polio. This is determined by clinical examination, electromyography, and by screening with single-fiber electromyography. When we compare the symptoms these individuals report to those of the survivors who have

obvious weakness from polio, we find that their complaints about fatigue are about the same. I think this points out that fatigue can be a sign of a disease but is not a specific sign of anything. Because of that, we need to have an open mind and work on developing a list of possible causes.

I approach this problem in terms of what could be causing this person's fatigue. I start with a clear history. Some survivors will talk about fatigue in a very specific manner ("If I walk a lot, my foot drags") while others speak more of a perception ("I just feel wiped out"). Fatigue changes from individual to individual.

Some possible causes of fatigue include deconditioning of muscle, severe sleep disorders, and pain. Pain, the major complaint of survivors who see us, can cause fatigue because one reaction to pain is inactivity. Severe pain can also affect your sense of how you feel.

Fatigue results when muscles work harder as a result of weight gain. Fatigue can also be the presenting symptom of depression. As a whole, the post-polio population is probably less depressed than the normal population. Anxiety and stress can cause fatigue, and these two factors are very common in the post-polio population.

A cause of fatigue is the development of any progressive deformity. For those of you who have knees that are becoming unstable or giving out, the leg in effect is made shorter. It's like stepping in a hole and you use extra energy picking that leg up to walk. Any pain that might cause a limp will tend to be translated into more energy cost. (Remember the curve. If you're on the end of the curve, a little change might make a big difference, and the muscle is now fatiguing.)

I want to discuss walking and relate some of the results of a study done last summer with polio survivors and non-disabled people who were in the same age group. The people wore a pedometer, which measures how many steps you take, and if you know your stride length, you can figure distances walked.

What we found, not surprisingly, is that polio survivors walked about an average of two kilometers a day, while the controls walked about four kilometers a day or almost twice as far.

The polio survivors walked fewer steps but proportionately more in terms of distance. People with polio tend to walk slower--the average speed for polio survivors was 50 meters per minute compared to 75 meters per minute. Their stride length was also shorter--56 centimeters versus 70 centimeters. These changes in terms of walking slower with shorter strides can be very useful in terms of pain management and safety, but the price is paid with more work for the distance. Many survivors have experienced a major decrease in walking ability.

We recently had a paper published in the Archives of Physical Medicine concerning gait management with polio. The survivors who got an appropriate brace for their legs and used it daily (which was about 60%) reported not only increased walking distances, less pain, increased safety, but also less fatigue.

Another potential cause for fatigue is in terms of deconditioning of heart and lungs. The polio population shares with the normal population the fact that most of you do walk; over 90% of you learned to walk after polio. I think 90% of you are still ambulating, and that accounts for the majority of the energy you expend daily. It also is the main way people can stress their heart and lungs to get the beneficial effects of exercise. As there is a major drop in the ability to walk distances, there is a gradual loss of heart and lung conditioning.

I can't tell clinically by looking at you whether your fatigue is from heart and lung deconditioning. But certainly by taking a good history, I can get an idea whether I think you are at risk for this problem. I think that we're beginning to believe (and to practice) that we need to treat each of you separately and develop your own individualized program recommendations. It's not a case now of "use it or lose it" or "preserve it" but rather understanding which one of these is appropriate for you and which might be

appropriate at different times for the same person.

DR. OWEN: I think the more I listen to other experts, the more I'm convinced that the concept of post-polio syndrome is the process of aging in conjunction with a pre-existing disease. Yet, there are parts of us that can age more gracefully than other parts of us. Thinking about taking advantage of the difference is what led to Sister Kenny's heart and lung conditioning program.

There are some issues that I'd like to mention about our program. I feel it is very critical to establish whether or not there's any under-oxygenation in the involved musculature. There are factors about the oxygen available to muscles that have to be assessed prior to participating in our cardio-pulmonary conditioning program. (Many times labs schedule studies first thing in the morning, and they turn out normal pulmonary function. It would be very helpful to measure oxygen saturation at night time and during the day on people who experience severe fatigue. If the tests were done late in the afternoon, the result might be entirely different.)

A common error is that people talk about their "incidental exercise" as though it was good for their health. In Jane's case, she found that walking great distances was so fatiguing that it was not good exercise. Dr. Waring points out that people with polio walk so slowly that they fatigue their muscles, are worn out, and have done nothing for their health.

Two years ago in St. Louis, Northwest Orient's plane landed at a gate on the furthest concourse. Because the plane was threatening to take off, I walked very fast carrying my suitcase, and all of a sudden I lost my anterior tibia and my long toe extensor on my "better leg!" Every crack was leaping up to grab my toe and toss me to the ground. That experience is so vivid to me now and was very embarrassing then because I had just been talking about staying healthy and being wise. I had some odd pride in thinking that I should walk that distance. I came back this year and brought my wheelchair and my baggage carrier. I zip

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on and off the plane, and I pass all people who are trying to be brave!

My point is that intentional structured exercise can be beneficial to you, and that's one of the nice pieces of news from our first of three studies at Sister Kenny, Minneapolis, MN.

The question of "global fatigue" as opposed to "specific fatigue" is really a tough one. Your vulnerability to local fatigue depends on what you're doing, like the long distance walk that suddenly made Jane's "better leg" start to feel weak or my long toe extensor and anterior tibia drop out. These experiences are memorable, but they are not the "hit-the-wall" fatigue. I feel the basic mechanism is somewhat the same and that the person is experiencing degrees of under-oxygenation in involved musculature. Some of the involved musculature may well be the muscles of ventilation. Those muscles might fatigue in much the same way as my anterior tibia or Jane's quadriceps.

There's a similar experience of under-oxygenation that takes place in the bulbar innervated muscles of swallowing and speaking. People with bulbar involvement are more fatigued in the afternoon, their swallowing and speech are often weak in the afternoon. People who used to sing in the choir have had to quit, particularly after extended periods of speaking and talking.

I feel we should address the adequacy of oxygenation, and whether that comes from something you can do yourself or whether it comes from a need for supplementary oxygenation and whether that depends on your individualized status.

The one problem we've had in fatigue measurement is that we don't have good statistics. I can remember when I used to "play football" as a post-polio youngster. (I actually stood with one crutch and passed left handed or blocked with my right crutch.) And yet, if I told a physician that I used to play football, he would think that I am really wasting away. We have to have some measurements that are self-inflicted so you can establish both subjective and objective changes. Start

recording information, not in a neurotic diary system but by a once-a-month or once-a-year look at what you're able to do.

How long do you have to rest after you fatigue? I think this is very critical. I used to find that I could drop out a muscle, stop for two or three minutes, and get back up and go again. It takes longer now, and I think that would be a nice measurement for a clinician.

One of the points about muscle strengthening in general is that a lot of people think they are strengthening muscle, but often are stronger by retraining their brain to use what they have more effectively.

DR. WICE: I'd like to discuss how I approach individuals who complain of fatigue in our post-polio program. I see things both as an internist and a physiatrist. For this presentation, I'm defining fatigue as excessive tiredness after exertion which is inadequate to cause the fatigue.

I'd like to make a statement that I don't think has been made before at this conference--a dog is not a cat. People come to our clinic as a polio survivor and think that they are a polio survivor and in a state of excessive fatigue. An individual with post-polio syndrome is also in a state of excessive fatigue. Therefore, a polio survivor is an individual with the post-polio syndrome. I can use the same rationale and say, "A dog is brown. A cat is brown. Therefore, a dog is a cat." I'd just like to reiterate, a dog is not a cat!

So what is the cause for fatigue? I reviewed the different diagnoses for fatigue in a book (French's Index of Differential Diagnoses) that lists various problems and possible causes. It made it very simple, "any medical problem can cause fatigue."

From a practical point of view, how do I approach fatigue? I think the most important thing is to do a good history and physical. I also get a complete blood count, check the serum electrolytes, check blood chemistry for liver and kidney

function, and do a thyroid screen because hypothyroidism can present only with fatigue. I also check vital capacity to make sure that ventilation is adequate.

Raymond Adams, a well-known neurologist at Harvard, is one of the principle authors of a major internal medicine text (Harrison's Principles of Internal Medicine). He wrote a section on lassitude and fatigue. With hospitalized patients, it is clear that of most of the commonly overlooked diagnoses, psychoneurosis and depression, should be considered. This statement jumped out at me because many people who come to my clinic talk about fatigue and other symptoms of post-polio syndrome. They're convinced that it's in their head! Their spouses and their family members may also be convinced that it's in their head. Their co-workers or their bosses may think they're lazy. It could even be that their own physician is not so certain that they are not a little anxious or a little depressed. Whatever the cause for fatigue, the medical cause should be treated.

As a physician, I think it's important that if someone has post-polio syndrome and fatigue from it, that it be legitimized. Dr. Adams says that if there is true weakness, it's almost never due to psychological factors alone. So it's important to validate the post-polio syndrome and the fatigue from it. Polio survivors should also tell their spouses and family members, and if necessary, tell their co-workers and their bosses, and if they have to, tell social security disability and also if they have to, tell the referring physician.

The non-disabled population talks about exercise being a good way to build up endurance, strength, and energy level. That is a good way for many people even with post-polio syndrome to build up their energy level. But polio survivors have a dilemma in that if they push themselves too hard, they pay the price. The body just cannot seem to take additional stress, which is quite difficult to tell individuals who have had polio and recovered by working very hard, by pushing themselves to the point of pain and seeing positive results. The secret is to be

active enough to prevent deconditioning but not so active that they pay the price of exacerbating the post-polio syndrome.

Polio survivors should listen to their bodies. Everybody is different, and I cannot give a prescription for a whole group. As a general comment, if you do something where you feel worse for several hours or a day or two later, you are doing too much. But if you feel better afterwards, it probably is going to be OK.

The other thing to remember is that there are other causes for fatigue, and if they can be treated, treat them. If taking certain medication causes the fatigue, you may be able to stop the medication. Also, we have heard repeatedly from polio survivors with the post-polio syndrome that rest is the best treatment. Make sure you get a good nights sleep. Also be aware of the problem of hypoventilation. Another problem is excess weight because it takes more energy to move.

Braces really do work. If they are recommended for you to improve your energy reserve, your gait technique, and for safety and decreasing pain, seriously consider it.

Also consider work simplification. Think efficiently on how you plan your day so that you can do as much as possible with as little energy expenditure as possible. It's not a matter of being lazy, it's a matter of being smart. Don't do activities that will exhaust you. If you can hire out work or have other family members do work for you, do it. Also, organize work areas. Try to have everything close at hand and use energy saving devices like a mixer, a food processor. Slide objects on a countertop versus picking them up.

Don't stand if you can help it. If you have trouble going up and down steps, don't live in a three-story home! If you need a brace for walking, use a brace. If a wheelchair or electric scooter will allow you to go from point A to point B, by all means, use it! Don't be afraid to ask for a handicapped parking sticker. Everyone else seems to be using them. Why shouldn't you?

Post-Polio Bibliography

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Post-Polio Syndrome, edited by Theodore L. Munsat, M.D. Butterworths, 80 Montvale Avenue, Stoneham, MA 02180. Publication date: October 19, 1990.

Congratulations!

Dr. Stanley Yarnell

1990 Health Care Professional of the Year

Stanley K. Yarnell, M.D., Director of Spinal Cord Injury Services at St. Mary's Hospital and Medical Center, San Francisco, CA, has been selected by the President's Committee on Employment of People with Disabilities as the 1990 Health Care Professional of the Year.

Yarnell chose to enter the field of physical medicine-rehabilitation after completing medical school in 1973. "This specialty is viewed as unglamorous, but it appeals to me because the emphasis is on function." Legally blind since 1978, Yarnell will do anything within his power to inspire and motivate his patients to discover their own abilities.

"Rehab is really about choices," says Yarnell. "We stress function and give them options to do what they want to do so they don't feel trapped by an imperfect body." He feels that when people have options, it helps diffuse their anger and helps them feel less victimized. When people have choices, they are empowered to control their lives.

Yarnell has pursued this philosophy since 1977 when he worked with his first post-polio patient, Renah Shnaider. She had been very mobile in a manual wheelchair, but one day while crossing an

intersection, she could not push herself any longer. She thought she was not working hard enough. Yarnell discovered Shnaider was developing arthritis in addition to the post-polio symptoms. Under his guidance, she made successful life-style changes. She also began to send her post-polio friends to Dr. Yarnell.

After a while, he identified common factors and began to keep statistics. He founded a post-polio clinic at St. Mary's in 1981, one of the first in the country.

Successful treatment, he believes, comes from listening. This is particularly true, he feels, with individuals with a disability who are keenly interested in participating in their care. "They have a peculiar situation of having a body that is different and they know their bodies better than anyone else -- including doctors."

Shnaider reports that the Second Post-Polio Western Conference, "Perspectives for the 90's," will be held at the beginning of 1991.

Leaders Write ... Readers Write ...

Thoughts About Fund Raising

By Richard Daggett, Polio Survivors Association (PSA), Downey, CA

Before a group undertakes any fund raising activities, they should first decide what their goals and ultimate objectives are to be. This is important because it determines the amounts needed, and the proper organizational structure required to handle these funds.

If all that is desired is enough money to print and distribute a monthly flyer or a one-page newsletter, then little organization is required. Designating a person, or persons, to type, print, and mail the flyer will do. A voluntary collection at meetings should cover costs. Some groups get mailing assistance from the March of Dimes or Easter Seal Society.

A more comprehensive newsletter requires planning and a stable income source. This is usually maintained by establishing yearly dues or membership fee. We have

found that \$10.00 a year will just about cover printing and mailing at bulk rates.

Now, what if your objectives are more extensive? How do you proceed when your organization decides to provide financial assistance to those with unique needs, or to underwrite research projects, etc.? This is when a realistic approach to goals and objectives is critical. A small group should be formed to work on this process, with a written statement outlining goals submitted to your membership, or governing body.

With your statement of goals completed, you need to establish an organizational structure. Most groups form a non-profit corporation. This is not difficult. There are reference books in most public libraries that cover this topic. You might already have someone within your membership that is experienced in this area, or you may be able to enlist the help of a local attorney. Many groups have articles of incorporation to satisfy state corporation requirements, and by-laws that provide guidance for day to day operation.

One area that needs to be made clear is financial accountability. You need to specify who will be authorized to write checks, how expenditures are approved, and audit procedures. A general safe guard is to have two signatures required when writing checks. If you intend to provide assistance to individuals it is probably wise to specify the limits of your service area. This will allow you to identify needs and provide adequate oversight.

After you file as a non-profit corporation you should contact the Internal Revenue Service to obtain the appropriate tax status. Most non-profit organizations are classified as 501(c)3. This is especially important if you are going to approach the public for contributions.

The Polio Survivors Association (PSA) is the oldest support group formed by polio survivors, themselves. We were incorporated in February 1975. Our objective was to promote the well-being and improve the quality of life for severely disabled polio survivors. A high percentage of our early membership had

some degree of respiratory impairment. Little was known about polio's late effects, and we concentrated our efforts toward making it possible for our members to live safely in their own homes.

Our efforts were directed in two areas: advocacy and financial assistance. As the PSA's advocacy role expanded, a decision was made to create a separate organization to handle financial assistance. This is the Polio Survivors Foundation (PSF). PSA expanded to national status and continued to provide limited financial assistance in special cases, but the bulk of fund raising activities were taken over by PSF. Two individuals serve on both boards but the day-to-day operations are entirely separate.

The PSF has tried various types of fund raising activities. Some have been successful, while others have not. Successful fund raisers have been an annual bowl-a-thon, book sales, bake sales, luncheons, and yard sales. Not as successful have been special shows or plays that required ticket sales. It is always important to have enough volunteer help available. Relying on one or two individuals to handle the work involved is not fair to these individuals and, in the long run, will result in diminished efforts.

Community outreach has been an important avenue for education and support. PSF seeks invitations from civic and service organizations to speak to their membership. PSF President, Lee Seitz, usually makes this presentation. She describes polio and its late effects, and shows slides of polio survivors who have been helped by the Foundation. When possible, one of these individuals will accompany her. A printed pamphlet is available, but Lee feels this direct approach is much more effective. In addition, letters to possible donors are sent regularly.

The local chapters of Rotary International have been especially receptive. Rotary has taken on the formidable task of eliminating polio world-wide, and their members have shown a gratifying interest in the "old" polios as well.

Group Purchases Polio Network News Subscriptions

Betty Cassady of the Central Florida Post-Polio Group reports that subscriptions to the Polio Network News have been bought for its membership so "all of the members can be aware of your high-quality publication and what it has to offer the post-polio community. This purchase was made possible by the generosity of the Rotary Club of Casselberry, Florida."

Participants Needed

Dorothy Woods Smith, R.N., polio survivor and doctoral candidate in the New York University Division of Nursing, is seeking potential participants for an upcoming research study comparing beliefs and attitudes of polio survivors with those of people who have not had polio. Participants will be asked to answer questionnaires which can be completed in an hour or less. Return postage will be provided. Confidentiality is assured, and volunteers are free to change their minds if they decide not to answer the questions. When the study is completed, a summary of the findings will be mailed to participants who request it.

Letters of explanation will be mailed with the printed questions within the next few months. If you are a polio survivor and would like to be considered for this project, please send your name and address to Dorothy Woods Smith, 188 Pride Street, Westbrook, ME 04092 between now and September 15.

New Polio Video

The Post Polio Awareness and Support Society (PPASS) of British Columbia has produced a video. "Post Polio Syndrome" is available for \$29.95 (Canadian) per tape. Segments were taped at the November 1989 polio conference held in British Columbia. The video was aired March 21, 1990 on the Knowledge Network. Contact: PPASS, 813 Darwin Avenue, Victoria, BC V8X 2X7 Canada.

Cofflators

Cofflators are no longer made and are wanted by several pulmonologists. Please contact IPN, 4502 Maryland Avenue, St. Louis, MO 63108 if you have one available.

New Organization to Assist Vaccine-associated Polio Cases

For the last two years, Kathryn A. Todd, R.N., and Nanette S. Plumley, M.A., have been involved in the health care of a three-year-old child who has vaccine-caused polio. As a result they have started an organization to assist individuals with vaccine-associated polio.

Polio Survivors Standing Strong Today (p.s.s.s.t.) has identified several needs including: physicians to recognize and diagnose polio, physical therapists and other health professionals who are knowledgeable and experienced in treating polio, and agencies to assist with finances.

IPN requests its readers to help. If you (or know people who) are knowledgeable and experienced in treating active polio and would be willing to offer treatment or advice, please notify p.s.s.s.t.

p.s.s.s.t. is also collecting literature and information about polio immunization and immunization practices. Again, if you have any information, please forward it or your name to p.s.s.s.t., P.O. Box 148, Midland, PA 15059 (421/643-6702).

A West German Experience

Juliana Sawyer Stolle, Kaninchenbergweg 63, 2400 Lubeck, West Germany

I had polio in 1955 and am left with a paralyzed braced right leg and a very weak left leg. After years of trying to prove I could do things as well as everyone else, I was forced to radically cut back my style of life as all we post-polios have. I stopped physical therapy, mainly because I was just sick of it after all these years and tired of the hassle of getting there. Unfortunately swimming stopped too because of construction of the local pool. I started sleeping longer in the morning and napping in the afternoon. And to make matters worse I gained weight.

After a trip back from the United States I felt terrible. I went to the orthopaedic surgeon who has treated me since I had an artificial hip put in my better leg. He suggested I take the "cure." This is the European way of treating chronic illness. Most Germans have health insurance that

covers this and can apply every three years.

From January 9 to February 20 I lived in a rehabilitation clinic in Bad Sooden, a town near Gottingen and Kassel in middle Germany. Run by the German State Insurance, the clinic had 185 patients (all work-related illness). Fifty percent were treated for lung problems and 50% for orthopaedic problems so I didn't exactly fit in. No one had ever heard of the post-polio syndrome but the experience turned out to be a very positive one.

From 7:30 a.m. to 4:00 p.m. every day, I was occupied with some kind of physical therapy--bicycle riding, massage (regular and underwater), hot tub baths, regular physical therapy, and swimming. Most of the patients, including me, were on a 1000 calorie diet and I had a room with special bath facilities.

My back pain went away, my headaches went away, and my ankles stopped swelling. I felt and feel wonderful. Of course, a lot of rest and no responsibilities of family and household helped. The main catch to this is expense. I have private insurance that does not cover the so-called "cure." I found the six weeks very worth while, considering meals and board, the treatment, and attention of the doctors. I am going back to physical therapy, swimming, and being more active.

Post-Polio Support Group of SA

We received a grant of A\$25,700 from the Australian Commonwealth Department of Health to fund the researching, writing, and printing of a handbook for professionals treating post-polios. Contact: Heather Trenorden, P.P.S.G. of SA, Inc., Neurological Resource Centre, 37 Woodville Rd., Woodville, SA 5011.

Thank you

Thank you for printing my letter regarding involuntary eye movement in your fall edition of Polio Network News. "I was very surprised and pleased at the response I have received, too numerous to thank each person individually. However, I would like to convey the message I have received from each letter: 'rest helps.'" Gertrude Steiman.

Swallowing Problems

"My swallowing problem is becoming more and more of a problem. I would like to collect experiences and suggestions of other polio survivors for publication." Contact: Roberta Simon, 7835 Pine Parkway, Darien, IL 60559.

Post Asthmatic Pseudo Polio

"My son has post asthmatic pseudo polio. Do you know of any other individuals with the same problem?" Contact: IPN, 4502 Maryland Avenue, St. Louis, MO 63108.

Insurance Request

"My company that has covered me to date recently raised my rates from an outrageous \$700 per month to a scandalous \$1,100 per month. Other companies I have contacted have refused to cover me. Can you suggest anything?" Please send similar experiences and/or suggestions to IPN, 4502 Maryland Avenue, St. Louis, MO 63108.

RV and Porta-Lung for Sale

"Since I changed to a positive pressure ventilator, I'm selling my Porta-lung. I'd like to offer a package deal to someone because we have a unique travel rig. The Porta-lung fits comfortably into an RV (1980 American Clipper). Contact: Marsha Ballard, Route 5, Box 450, Tyler, Texas 75706.

Americans with Disabilities Act (ADA)

In late May, the House of Representatives voted overwhelmingly (403-20) in favor of the Americans with Disabilities Act (ADA).

When enacted, the civil rights legislation will open new doors of opportunity to people with disabilities for equal employment, public accommodations, transportation, and communications.

Minor differences with the Senate version are expected to be worked out easily. Senate and House sponsors hope to present the bill to President Bush in late June.

Through the Storm

by Robert F. Hall

Polio survivor, Robert F. Hall submitted "The Eye of the Storm" (Part II) from his recently published book, Through the Storm: A Polio Story. "The Storm" (Part I) is the account of his time in County Hospital in Omaha, Nebraska. "Stormy and Clearing" (Part III) describes the rehabilitation experiences of seven polio survivors in the V.A. Hospital in Lincoln, Nebraska. The descriptions of polio and polio rehabilitation were written in the late 40s while the impressions were very fresh in his mind.

To order, send \$9.95 to North Star Press, P.O. Box 451, Saint Cloud, MN 56302-0441.

"The Eye of the Storm" Part II

The ten days I spent at the Colonial Hotel in Omaha were pivotal in my life. Going to and from the hospital for the out-patient therapy each day took a long two hours. The rest of the time I was at the hotel, and I was incredibly bored. I came into a bad attitude. Depressed over not making progress, I didn't know what to do with myself in that drab hotel room. Maybe I had already become institutionalized in the six weeks I had been in the hospital. Maybe that's why I couldn't get a positive attitude going. I probably didn't know I was dependent on the system, and now it wasn't there. Whatever it was, I was hard to get along with.

"Leave me alone! I can do it myself." I don't know how many times I snapped this at Mother as I tried to get around in the hotel room. If it was going to be done, I was going to do it. I tried pulling on my pants one time, got my feet twisted in them and fell heavily against the radiator. I didn't say to myself, "You were lucky," but I was able to scream at Mother often in my anger. She was hearing a very big "I" and an equally strong will expressed in my anger.

I can never ever recall praying during this entire experience with polio. Never once did I ask God to help me. Never once did I thank Him. I was going this one all by myself, and there was more loneliness

and agony going along inside of me than I cared to realize. The pain of my polio experience had laid bare feelings that were ready for healing, but I didn't know how to ask for healing. I didn't know I needed healing of "feeling" feelings. I only knew I was trying to get back feelings in my legs and wanted to walk again.

I knew I was a survivor, and I knew I had a very strong will. What I didn't know was that I was an Adult Child of an Alcoholic and that I had adopted a role in life as a rescuer. The drunken behavior of my father, whom I dearly loved, had led me to shut off my feelings completely. I found that having them was too expensive, so I turned to rescuing to cover up dealing with them.

As a boy, I had done very well at rescuing both my father and then my mother, but right now I couldn't seem to rescue me. Since I didn't know God, and I had to rely solely on my own plan, my plan was badly bent in the shape of two weak and fumbling legs. I couldn't have articulated all of this then, but at least I was aware that anger was running the show. Eventually, my polio experience was going to show me how to deal with the "feelings" disease of family alcoholism.

At the moment, my pride was shutting down my practice of patience the way Dennis had taught me how to do it. And my self-pity bag was stifling me from relying on courage the way Bobby had. Right then, I simply didn't have any peace or serenity to draw on. I was truly out of sorts, and the frustration and anger were the reality of my life. Some life. I just couldn't see how anything was going to fit and make sense.

When Mother came back from California to take her position as nurse's aide at the hospital, she was able to come back to Omaha because she was offered the use of an apartment by an old friend who was away for the summer. That helped her make ends meet financially so she could take the job at the hospital and be near me.

While living in this apartment, she became acquainted with a woman living in an apartment on the floor below, Mrs. Melinda

Lockwood. She heard that I was bored and was looking for something to do. Her response was to give Mother her typewriter for me to have. Just like that, out of the kindness of her heart, she gave me her typewriter, and she didn't even know me.

I had a hard time believing the story about Mrs. Lockwood and her typewriter, but once it sank in, I felt overwhelmed by her kindness. I sat down to write her a "thank you" note on her green typewriter. In the process, I told her some things about Dennis. Then I heard that she had shown my letter to a friend. The friend was moved by my account of Dennis to give \$150 to the National Foundation for Infantile Paralysis.

That was a lot of money! It sparked an idea in my head.

"Holy smokes," I thought, "I wonder if I could write more about my polio experience. It might do some good. I've never written anything to speak of, except term papers and my thesis. This is a whole new area. I'll see what I can do."

Suddenly, I had some purpose to my life, and my anger found some positive expression. I was revving up inside. I could feel it. So I set out to write my story about polio in the County Hospital at Omaha. The story, as it is written up to this point, is what I wrote on the green typewriter during those ten days in that hotel room.

Mrs. Carpenter, the woman who gave the money, also gave me a present. It was a beautiful leather bound Bible with her name printed on the cover in gold, "Mrs. I. W. Carpenter." I didn't use that Bible for a long time. It had no meaning to me then. But then, neither the Bible nor God had any place in my life.

Writing the polio account kept me busy and away from dealing with my deeper feelings which were trying to get out. For instance, I was totally incapable of saying, "I am getting more and more anxious about what is going to happen to me as my out-patient therapy deteriorates. What kind of a plan will work? What will I do for money? I am totally broke, and

the National Foundation has paid over \$300.00 of my hospital bill."

There was absolutely no peace working in me during those ten days at the hotel. I really did not have any place to go other than the V.A. hospital at Lincoln. I felt battered. I wanted to be cheerful over my move to Lincoln, but I was close to being desperate. I didn't know what was left in the polio storm for me, but I did know that the peace in the eye of the storm was a false peace.

Rehabilitation Gazette

Polio Network News is a "spin-off" of the Rehabilitation Gazette, an international journal published since 1961. Edited by the late Gini Laurie, the journal is written by individuals with a disability for individuals with a disability. To receive 23 back issues (1962-1987) of the Rehabilitation Gazette, send \$30 to G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. We will ship them UPS.

Information on ...

Fibromyalgia

Contact: Fibromyalgia Network, 7001 School House Lane, Bakersfield, CA 93309.

Chronic Pain

National Chronic Pain Outreach Association, Inc., 4922 Hampden Lane, Bethesda, MD 20814 or Chronic Pain Newsletter, Box 1303, Old Chelsea Station, New York, NY 10011.

Environmental Illness

Human Ecology Action League (H.E.A.L.), P.O. Box 49126, Atlanta, GA 30359. (404/248-1898) or National Foundation for the Chemically Hypersensitive P.O. Box 9, Wrightsville Beach, NC 28480. (919/270-9441).

"Role of the Primary Care Physician in Occupational and Environmental Medicine" is available from National Academy Press, 2101 Constitution Avenue N.W., Washington, D.C. 20418 for \$3.

Post-Polio Directory

Once again we must ask all individuals to screen carefully all materials they receive as a result of being listed in the Directory.

The Chicago suburbs now have a 708 area code not a 312.

Please ADD the following:

SUPPORT GROUPS

Nevada County Post-Polio SG (FREED)
154 Hughes Rd., Suite 1
Grass Valley, CA 95945
916/272-1732
Eva Strach 916/265-4585

Post Polio Support Group of Delaware
Daniese McMullin-Powell
24 South Old Baltimore Pike
Newark, DE 19702

Post-Polio SG, Easter Seal
Joel M. Gaylord
1115 E. 65th Street
Kansas City, MO 64131
816/333-3233

Gary Reinhard
1422 Robin Lane
Bozeman, MT 59715
406/587-8935

William Smithers
203 Lakeshore Drive
Kalispell, MT 59901
406/755-3136

Ira Holland
540 Main Street
Roosevelt Island
New York, NY 10044
212/826-6270

Betty L. Sugarman, Ohio Easter Seal
2204 South Hamilton Road
Columbus, Ohio 43232-0462
614/868-9126

Southeastern PA Post-Polio SG
Lisa Haines
R.D. 5, Box 180
Coatesville, PA 19320
215/383-5249

Leslie Heywood, Easter Seal
331 South Rio Grande St., Suite 206
Salt Lake City, UT 84101
801/531-0522

Manitowoc Post-Polio SG
Stephen P. Mickey
224 W. Main St., Box 172
St. Nanzianz, WI 54232

HEALTH PROFESSIONAL

Peter Katona, MD, FACP
16100 Ventura Blvd.
Encino, CA 91436
818/788-7500

Please make the following CHANGES:

SUPPORT GROUPS

UCLA Polio Survivors SG
Carol Mutchnik
2215 Crescent Ave.
Montrose, CA 91020
818/957-4160

Eva Hoffman
702 Vista Place
Lady Lake, FL 32159

Webster Cash, Ph.D.
1501 Clairmont Dr.
Decatur, GA 30033
404/636-1490

Kelley McCall, Idaho Easter Seal
1350 Vista Avenue
Boise, ID 83705
208/384-1910

Colleen Nadould, Idaho Easter Seal
2110 Rollandet
Route 3, Box 301
Idaho Falls, ID 83401
208/529-5979

Sheila Lemmon
1827 Hurley Drive
Pocatello, ID 83201
208/237-8317

United Post-Polio Survivors, Inc.
Phyllis Doering
2702 West Ainslie
Chicago, IL 60625
312/784-6332

Rockford Post-Polio SG
Tim McSweeney c/o RAMP
1040 North 2nd St.
Rockford, IL 61107
815/968-7467

Polio SG of East Central IL
Patricia Minogue c/o The March of Dimes
717 Philo Road
Urbana, IL 61801
217/337-0966

Post-Polio SG of SW Michigan
Connie Ketcham
409 Naomi, Apt. 1
Plainwell, MI 49080
616/685-5642

Jan Haider, Easter Seal
1130 16th Ave. W., Suite 6A
Billings, MT 59102
406/252-9600

Jackie Knutson
The Growing Place
518 South Avenue West
Missoula, MT 59801
406/728-1243

S.N.A.P.S.
Sara Tritch-Hoyt
P.O. Box 81585
Las Vegas, NV 89180

Delaware Valley Polio SG
Arnold Snyder
P.O. Box 102
Flourtown, PA 19031
215/576-5500

Independence Resource Center
Shirley H. Paul
201 West Main Street
Charlottesville, VA 22901
804/971-9629 (Voice)
804/971-9634 (tdd)

CLINICS

Good Shepherd Rehab Hospital
Deborah Kimmel, MD
5th and St. John Streets
Allentown, PA 18103
215/776-3278

University of WA Hospital, Clinic 7
Larry Robinson
Seattle, WA 98195
206/548-4294

G.I.N.I. Subscription Information

The Spring issue of Polio Network News is late. Thanks to several people, we now have a functioning computer program to record subscriptions and to run mailing labels.

A new combined brochure, order form, and renewal notice is used for all Gazette International Networking Institute (G.I.N.I.) publications (Polio Network News, I.V.U.N. News, and Rehabilitation Gazette). The Polio Network News notices are sent quarterly. (If you do not renew in the quarter you receive the notice, you will miss an issue.) We will be glad to coordinate all your subscriptions so they are due at the same time each year. Please notify the office if you have any questions about your subscription.

An unfortunate delay in matters of the estate of Gini Laurie also contributed to the postponement of this publication.

In spite of our financial problems, we believe networking to be vital to the post-polio movement in the world. G.I.N.I. was instrumental in organizing the 1981 conference, "What Ever Happened to the Polio Patient?," which focused attention on the new problems facing polio survivors. During the last ten years, G.I.N.I. has collected and shared information with thousands of polio survivors, health professionals, organizations, and institutions.

All individuals and organizations who benefit from the network can assist by sharing their expertise and by financially supporting our efforts.

Gazette International Networking Institute (G.I.N.I.), the umbrella organization for IPN, is a 501(c)3 and any donation is tax-deductible. Please mail your contributions to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. Thank you.

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Calendar

September 8, 1990. Polio & Post-Polio Sequelae: The Lived Experience.
Pine Tree Camp, Bath, ME Contact: Rick Meade, Post-Polio Support Group
of Maine, Box 518, Bath, ME 04530. 207/443-3341.

September 15-16, 1990. Post-Polio Conference. Holiday Inn, Billings,
MT. Contact: Shirley Tankink, Easter Seal Society of Idaho, Montana,
and Wyoming, 4400 Central Avenue, Great Falls, MT 59405-1695. 406/761-
3680.

September 28, 1990. The Late Effects of Polio. Allis Plaza Hotel,
Kansas City, MO. Contact: Sheryl Max, R.N., M.N., Research College of
Nursing, 2316 East Meyer Boulevard, Kansas City, MO 64132. 816/276-
9340.

October 13, 1990. N.J. Conference on the Late Effects of Polio.
Somerset Marriott Hotel, Somerset, NJ. Contact: Post-Polio Conference
of New Jersey, Box 537, Martinsville, NJ 08836. Attention: Jean
Brogdon.

November 13-16, 1990. The First Czechoslovak Medical Conference on
Post-Polio Syndrome. Hodonin near Kunstat. Contact: Mrs. M.
Fidlerova, UV SI v CSR - OSR I, Karlinske nam. 12, 186 03 Prague 8,
Czechoslovakia, Europe.

MOVING?

PLEASE SEND BOTH YOUR OLD AND NEW ADDRESSES TO INTERNATIONAL
POLIO NETWORK, 4502 MARYLAND AVENUE, ST. LOUIS, MO 63108
WHEN YOU MOVE. POLIO NETWORK NEWS WILL NO LONGER BE
FORWARDED BY YOUR POST OFFICE.