

# POLIO NETWORK NEWS

International Polio Network

Winter 1993 ♦ Vol. 9, No. 1

## Becoming an Intelligent Consumer of Physical Therapy Services

Marianne T. Weiss, P.T.

In the nearly ten years that I have been treating polio survivors, I have found that the people who come to my door for assistance usually fall into one of two categories. Some of these people have not had contact with a physical therapist (P.T.) since their acute phase of polio. Others have become frustrated and often seriously depressed after seeing several P.T.'s and several physicians prior to coming to see me. They could not find someone knowledgeable about the late effects of polio and how physical therapy can adequately assist survivors in coping with these late effects.

It is my hope in this document to provide a two-fold service:

♦ I wish to describe the evaluation and treatment that a knowledgeable, skilled P.T. should be able to provide a polio survivor. By so doing, I hope to significantly reduce the frequency with which polio survivors are turned away from physical therapy clinics with the statement, "There's nothing we can do for you."

♦ I would also like to give encouragement to survivors who have not yet found a P.T. who has been knowledgeable about meeting their needs. Hopefully you can go armed with the data in this article to request that certain services be performed.

Certainly many health professionals other than P.T.'s can help to lessen the impact of the late effects of polio. In some cases, the services of other professionals overlap those of the P.T. However, in this paper I will confine my comments primarily to P.T. services.

This paper is based on principles in the resources listed on the accompanying bibliography.\* Some of the following concepts listed under "STRENGTHS" are derived from my own experience in treating polio survivors.

\*The bibliography will be made available in the next *Polio Network News*.

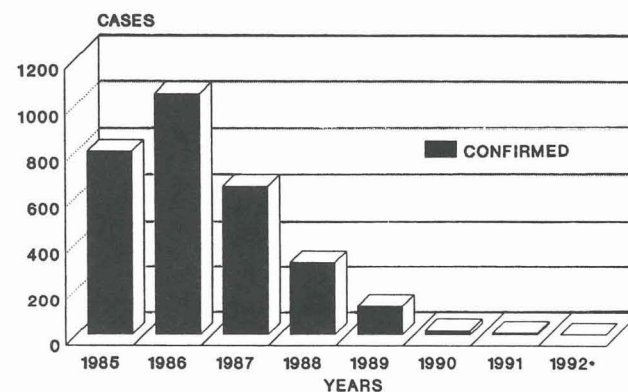
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## One Year without Polio in the Region of the Americas

August 23, 1992 marked the first year that the Region of the Americas has been free of wild poliovirus. The last detected case occurred in Junin, Peru on August 23, 1991.

This achievement has been possible thanks to the eradication campaign launched by the Director of the Pan American Health Organization (PAHO), Dr. Carlyle Guerra de Macedo, in May of 1985. The principal strategies used were the National Vaccination Days with applications of poliomyelitis oral vaccine and the intensified surveillance of reported cases of flaccid paralysis. These efforts succeeded in reducing the number of polio cases caused by wild virus from approximately 1,000 reported cases in 1986 to nine in 1991 (eight in Colombia and one in Peru). Since the virus was isolated from the Peruvian case, no other wild virus has been isolated in the Region (Figure 1).

Figure 1. Confirmed cases of polio in the Region of the Americas, 1986-1992



\* Information for 1992 through week 34

\*\* Source: PESS/PAHO

At the inception of the Expanded Program on Immunization in 1978, less than 25% of the children in the Region of the Americas were vaccinated against the principal childhood diseases (polio, measles, diphtheria, tetanus, pertussis, and tuberculosis). By 1991, the overall coverage extended to over 75% of the population under one year of age.

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### Why should you consider seeing a P.T.?

- ◆ One excellent reason for seeing a P.T. in the absence of declining physical function is to undergo a well-rounded baseline evaluation against which future problems might be measured.
- ◆ Individuals who have not experienced recent functional decline may seek the services of a P.T., so that they may be educated in ways to minimize the effects of their polio problems on their bodies. For example, a P.T. can set up a muscle-specific exercise program that can be used to normalize (to the extent that is possible) the biomechanic forces acting on the body. A P.T. can also serve to educate a person in lifestyle modifications that may make it easier for a person to function in daily life and may also help slow the progression of symptoms in the future. The P.T. may also recommend the use of certain appliances during activities of daily living (A.D.L.) that might make it easier for a person to function.
- ◆ Finally, the most common reason for polio survivors to seek the services of a P.T. is because they have noticed pain or functional decline in strength, flexibility, endurance, ability to walk, climb stairs, etc. Physicians must rule out the possibility that conditions other than polio are responsible for problems such as these. However, it is the P.T. who has special skills to implement programs to address the symptoms noted above.

### How does one obtain access to a P.T.?

In some states, physical therapists are permitted to evaluate, or to evaluate and treat patients without referrals from physicians. In other states, referrals from physicians are required by law. In either case, almost always a referral from a physician to a physical therapist is needed for third party payers (insurance companies) to cover physical therapy services.

For people who live in relatively close proximity to one of the established post-polio clinics around the country, evaluation by a physician at one of these clinics is certainly ideal. A physician from one of these clinics can write a referral for physical therapy. However, if polio survivors do not live in close proximity to one of these established post-polio clinics or must wait a long time to obtain an appointment at such clinics, referrals to physical therapy in their

own locale from their family physicians can certainly be appropriate.

Family physicians are sometimes hesitant to write physical therapy prescriptions because of lack of knowledge about polio or about specific instructions to write on the referral. However, all states accept simply-written referrals such as "physical therapy to evaluate and treat." A diagnosis must be written on the referral. If a physician feels comfortable making the diagnosis of the "late effects of polio," this should be written on the referral. Otherwise descriptive diagnoses such as, "postural dysfunction," "back pain," "gait disturbance," or "muscle weakness" may be listed.

Specialists such as physical medicine specialists, orthopedists, or neurologists may prefer to write more specific instructions on the physical therapy referral. Hopefully, however, they have a good rapport with the P.T. with whom they are going to refer, and they will trust them enough to also write "evaluate and treat" on the referral in addition to their specific instructions. This allows the P.T. to use his/her expertise fully to address the patient's problems.

### Choosing a P.T.

If you live near a physical therapist who is listed in the directory published by **International Polio Network**, of course attempting to obtain services from such a person would be optimal. If you do not live in close proximity to a P.T. listed in the directory, I suggest that you look in the *Yellow Pages* in a phone book under "PHYSICAL THERAPY" and call several offices in your area to determine if anyone is knowledgeable in any way about the late effects of polio. Most hospitals will also have the capacity to treat outpatients, and you may also consider calling a hospital physical therapy department.

If you are unable to find a physical therapist in your vicinity who has any knowledge of treatment of the late effects of polio, my next suggestion is that you inquire if there is anyone who is willing to learn about this problem. If you sense that a P.T. has a willingness to learn about the late effects of polio, share any polio-related information you have access to and share the information contained in this article with him/her. Then request that an evaluation be conducted and a program implemented based on this or similar information. You may also direct P.T.'s to an article in the October, 1991, issue of *Physical Therapy* magazine by Elizabeth Dean, P.T., entitled, "Clinical Decision Making in the Management of the Late Sequelae of Poliomyelitis."

## Reasonable Expectations

Nearly every polio survivor comes to health care providers initially with the hope — whether clearly evident or secretly buried — that someone will be able to “make me as I was.” Because of this hope, some survivors are initially reluctant to hear about suggestions a P.T. may make regarding lifestyle modifications, equipment options, etc. Often, polio survivors consider accepting changes such as these as an act of “giving up.”

I would encourage survivors to consider that the only true act of “giving up” is refusing to participate in activities and retreating from society. Any suggestions for changes in lifestyle or use of equipment should be viewed as suggestions for how to “get on with life,” and survivors should attempt to look at these suggestions as a means of continuing their participation in society to the fullest extent possible.

Reasonable goals that *may* be possible to achieve via physical therapy intervention can include the following. However, the survivor and P.T. should work together to choose which goals should be worked on at any given time.

- ◆ pain reduction
- ◆ edema reduction
- ◆ improved skin integrity
- ◆ improved endurance for activity
- ◆ improved flexibility
- ◆ improved ability to move in bed/transfer
- ◆ stabilization of balance/gait
- ◆ possible reduction of rate of strength loss and improved ability to use existing strength

Polio survivors should recognize that their bodies may be especially sensitive to even subtle changes. Sometimes small interventions may result in huge positive benefits. For example, the provision of 1/4-inch internal heel lift in one shoe may be enough to greatly minimize low back pain.

Other times small interventions may result in negative outcomes. For example, if the therapist would recommend providing a low back support to stabilize the pelvis and minimize back pain, the patient's ability to use the pelvis to assist with certain phases of the walking cycle might be impaired. Therefore, the survivor must be able to communicate fully any negative results that occur when interventions are implemented.

What is the moral of this story? Survivors should attempt to be flexible and should attempt to look upon recommendations made with an open mind. However, survivors should also recognize that several interventions may need to be tried before one might be found that is beneficial.

## What should you expect in a physical therapy evaluation, and how should the results be incorporated into treatment?

### ◆ COMPREHENSIVENESS

In physical therapy school, students are taught all the components of the following type of evaluation. They are instructed to complete all of the components of the following evaluation on any body part that is affected by problems that the patient is being sent to physical therapy for.

Because polio is a systemic disease that initially invades the body from head to toe, polio survivors are at risk for dysfunction of multiple body parts. Therefore it follows that all these components of a physical therapy evaluation should be performed on all body parts for polio survivors. Comprehensive evaluations of this type can take as long as three to four hours

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## Becoming an Intelligent Consumer

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spread out over three to four visits. (I am aware that some P.T. departments are not set up to allow this much time per patient. This may be another factor in your decision as to which P.T. to choose.)

Most polio survivors envision that certain of their body parts were minimally or not at all affected by polio. However, I think it is very helpful to survivors when a P.T. can evaluate the whole body and possibly confirm that certain body parts were relatively spared from dysfunction. Conversely, the P.T. may point out to survivors that certain body parts have been affected perhaps more than they thought. If this is the case, measures can be taken to minimize the effect of abnormalities.

After an evaluation such as that described below, the P.T. should sit down with the survivor (and family or other significant people, if the survivor so desires) to explain the results. A thorough explanation with a proposal of treatment options can take up to an hour. The survivor and others in attendance should be encouraged to ask questions they may have regarding the results and the proposed treatment options. The survivor should then decide which option to pursue.

The therapist should compose a report detailing the specifics of the evaluation and the therapist's recommendations for approval by the referring physician. The therapist should work in conjunction with the physician to implement a program based on the results of the evaluation.

### ◆ INTERVIEW PRIOR TO PHYSICAL ASSESSMENT

- What is the survivor's complete medical history?
- What is the survivor's vocational social history?
- What is the survivor's perception of function in each major body part?
- Has any decline of function occurred in recent years?
- Are there symptomatic areas of pain?
- Are there body parts at circulatory risk, i.e., is there cold intolerance, presence of swelling, discoloration of skin, etc.?
- Are there any problems with sleeping?
- Are there any problems with breathing or swallowing?
- What activities are common for the survivor on a regular basis?
- How is endurance for activities?
- How accessible is the survivor's home?
- How are the survivor's abilities to move in bed, get up and down from a chair, or to walk?

Does the survivor use any special equipment? (i.e., braces, crutches, canes, wheelchairs, feeding devices, breathing devices, etc.) Have these devices changed in recent years? Are there any problems using the current equipment?

### ◆ CARDIOPULMONARY

**EVALUATION.** The components of a basic cardiopulmonary evaluation should be under consideration throughout the physical assessment. The survivor's resting blood pressure, heart rate, and respiratory rate should be evaluated. Some description should be made of the survivor's ability to adequately oxygenate each lung lobe and of the survivor's ability to cough and breathe deeply. In conjunction with coughing and deep breathing, a description of the use of abdominal muscles and chest muscles for forces should be included. The P.T. should also describe any abnormal use of the neck or chest muscles for breathing purposes.

During the rest of the physical evaluation, repeat measurements of the resting heart rate, blood pressures, and respiratory rate and quality should be periodically recorded to let the therapist, survivor, and attending physician know how the survivor responds to mild activity such as is conducted during a physical assessment.

Some P.T.'s have the kind of equipment to give the survivor a modified aerobic exercise test using a treadmill or a stationary arm or leg cycle. (Of course, if the survivor has a history of heart or lung disease, it is not wise to do a test of this kind without proper cardiopulmonary monitoring in an office with access to a physician.) An eight- to 12-minute test of this type may be performed to determine how the survivor responds to this kind of more vigorous, sustained activity, as compared to the intermittent, lower-level activity performed in the rest of the evaluation.

A word of caution here is that performing a sustained aerobic activity before knowing the survivor's true strength as noted below under "STRENGTH TESTING" could be hazardous. Survivors can overexert themselves in the cardiopulmonary testing and suffer pain, muscle tremors, or temporarily increased muscle weakness as a result afterwards.

**TREATMENT.** If cardiopulmonary abnormalities are found in the evaluation, vital signs should be monitored during any treatment involving exercise. Almost all polio survivors will show a generalized deconditioned cardiopulmonary response to exercise. They can benefit from instruction in work simplification techniques, energy conservation techniques, body mechanics, etc., to reduce their daily cardiopulmonary demands.

All polio survivors, even in the absence of true lung function impairment, can benefit from instruction in abdominal-diaphragmatic and segmental breathing.

Many survivors have trunk abdominal weakness that results in binding down of the soft tissues of the body, making it difficult to move the chest wall well during breathing. Proper breathing techniques can help address these problems. Survivors who have postural problems that impair oxygen flow will also be helped by using these techniques. Finally, normalizing respirations is known to reflexively activate the part of the nervous system that promotes bodily relaxation.

Of course, for survivors who do have true respiratory impairment, learning all the above can be potentially life-saving or life-prolonging. These survivors should also learn assisted coughing techniques.

#### ◆ FLEXIBILITY TESTING

**EVALUATION.** Flexibility testing refers to how far into a given movement a person can move a body part. In medical jargon, this is referred to as range of motion (ROM). ROM tests should be performed of all joints in all places. These measurements should be taken accurately with an instrument called a goniometer, which is a standard piece of equipment in all physical therapy departments. (A goniometer is a device similar to a protractor with arms on it that can measure precisely in degrees, the amount of movement present at any joint in any plane.) Simply "eyeballing" the available movement at the joints is not acceptable.

There are many texts that cite "normal" values for ROM at each joint in all planes. These various sources disagree on what "normal" is. P.T.'s should define whatever values they have chosen to use as representative of "normal," in light of whether or not the chosen values are at the upper end or at the lower end of those noted in the available resources.

In interpreting ROM values, the P.T. should show survivors a ratio of their values over the value that the therapist is considering normal. For example, if the normal ROM that the P.T. is considering for straight leg raising is 80 degrees and the survivor's ROM is 60 degrees, the ROM should be expressed at 60/80. This is helpful so that both the survivor and the therapist are aware that the survivor has a 25% deficit in flexibility.

**TREATMENT.** The importance of adequate flexibility in all patients, but especially in polio survivors, cannot be overstressed. It is well-documented by people active in the acute phase of polio treatment during the epidemics earlier in this century (Sister Kenny and current lecturer Dr. Thomas P. Anderson, for example), that muscles affected by polio easily become "stiff," and must undergo continual stretching to maintain adequate flexibility. Without adequate flexibility, it becomes very difficult for a person to use whatever strength is available in that body part. Poor flexibility can also cause pain and deformity. Too much flexibility on the other hand can cause what

Florence Kendall refers to as "stretch weakness." This, too, makes it difficult to use the available strength.

In general, I have always used the "normal" values as a firm target to shoot for in most people to assure as normal a biomechanic force at a joint as possible. Surgeries, arthritis, or bony deformities may impair a person's ability to achieve "normal" ROM. However a good passive stretching program performed by a friend or family member goes a long way toward minimizing pain and normalizing movement patterns. Self-stretching is usually difficult to perform due to pain, weakness, and substitution patterns.

In certain cases amongst polio survivors, some degree of "tightness" in certain muscles may assist function. For example, in a patient with weak forearm and finger muscles, a certain degree of tightness selectively permitted in these muscle groups can allow the patient to have the appearance of more "strength" than he/she would otherwise have. Another example might be if a patient has weak knee extensor muscles and weak buttock muscles, a certain amount of tightness in the inner aspect of the thigh may make it easier for the patient to use the available strength in the thigh. However, these examples are quite variable and extremely dependent on all the symptoms that present in a given patient. Only a well-trained therapist can discern, in conjunction with the patient's physician, if certain areas of selected tightness might be adaptive for a particular person.

*The conclusion of this article by Marianne T. Weiss, P.T. will be published in Vol. 9, No. 2, Polio Network News.*

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## Medigap Policy Choices

New Federal Medigap policy requirements became effective July 30, 1992. As a result, Medicare's 35.5 million beneficiaries may choose to supplement their Medicare insurance with one of the newly available Medigap policies with standardized benefits and simplified wording. Under the new requirements, every Medigap policy must offer basic benefits. The new law does not require that beneficiaries buy one of the standardized policies. If you have a policy you're satisfied with, and it is guaranteed renewable, there is no need to change.

More information about the new standardized plans is available in the HCFA-NAIC publication, Guide to Health Insurance for People with Medicare. Single copies may be ordered free of charge from the Consumer Information Center, Pueblo, Colorado 81009. Specify the title and publication number 518-Y.

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## One Year without Polio

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The task was made possible thanks to the joint backing of various collaborating agencies, at a cost of approximately 542 million dollars (US). The governments from the countries have provided around 430 million and the rest has come from the collaborating agencies that include the Agency for International Development from the Government of the United States (USAID), Rotary International, UNICEF, the Inter-American Development Bank (IDB) and the Canadian Public Health Agency (CPHA).

In addition to the national vaccination days, mass communication was used extensively to inform the public and mobilize the population. Also, a laboratory network was used for diagnostic support. PAHO has established an impressive surveillance system of acute flaccid paralysis that includes more than 20,000 health units that report cases on a weekly basis.

The challenge now is to maintain the impetus by increasing the vaccination coverage, consolidating the gains made in eradication and achieving control and elimination of other childhood diseases, PAHO has named a Poliomyelitis Eradication International Certification Commission that will verify the interruption of wild poliovirus transmission. It is estimated that the Commission will conclude its work in 1995. In the meantime, high levels of coverage and surveillance should be maintained and three years should pass by without confirmed cases of polio before the Region of the Americas can be certified as free of wild poliovirus. One of those three years has already passed; PAHO will continue the effort and write history!

**Source:** EPI newsletter, *Expanded Program on Immunization in the Americas*, Vol. XIV, No. 4, August, 1992.

**Editor's Note:** The last wild poliovirus detected in the Americas to date was on September 5, 1991, still over a year ago.

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## Polio Outbreak

*In September 1992, the Netherlands reported an outbreak of polio among members of a religious group that refuses immunization services.*

Since this religious group also exists throughout the Americas and its members frequently travel back and forth, countries of the Western Hemisphere are on alert for importations. Attempts to educate and immunize members of this religious group are being made. The 1979 outbreak in the United States and Canada clearly illustrated the risk for unvaccinated members

of religious groups who have direct or indirect contact with members of Dutch religious groups among whom poliovirus is circulating.

**UPDATE.** The outbreak in the Netherlands of poliomyelitis among unvaccinated persons who are members of religious groups that generally do not accept vaccination is continued (1). From September 17 through December 5, 1992, 54 cases of poliomyelitis were reported to the Netherlands' Office of the Chief Medical Officer of Health. All of the reported cases have occurred among unvaccinated (n=53) or inadequately vaccinated (n=1) persons belonging to a religious denomination that routinely does not accept vaccination. Patients range in age from <1 month to 56 years (mean age: 18.9 year). Of the 12 provinces in the Netherlands, seven have reported cases of poliomyelitis; the most severely affected provinces are South Holland and Gelderland.

The risk for acquiring poliomyelitis while in the Netherlands is considered small because of the excellent sanitation in the country and because transmission of the poliovirus has been limited primarily to unvaccinated religious groups. Nonetheless, the polio immunity of travelers to the Netherlands should be evaluated, and persons with inadequate protection should complete a primary vaccination series with three doses of poliovirus vaccine before departure, especially if extensive travel in the Netherlands or contact with persons in the affected religious groups is anticipated.

**Source:** *Morbidity and Mortality Weekly*, 1992; 41:775-8; 41:917-9.

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## Polio in the U.S.

*No cases of suspected poliomyelitis have been reported in 1993. Four cases of suspected poliomyelitis have been reported in 1992; 6 of the 9 suspected cases with onset in 1991 were confirmed, and 5 of the 8 suspected cases with onset in 1990 were confirmed; all were vaccine associated.*

### THE U.S. VACCINE DISTRIBUTION DEBATE

Fewer than 60% of U.S. children are properly immunized by age two. Federal health objectives for the year 2,000 say 90% should be vaccinated.

Some blame rising vaccine costs and propose a national vaccine program with a single, government purchaser. It would reduce costs to private physicians. Currently, half the children who receive vaccination get them from private physicians who pay manufacturers' catalog prices, or get small discounts. The other half are vaccinated in public clinics that receive substantial discounts through a Centers for Disease

Control and Prevention grants program. (The oral polio price through the grant program is \$2.09 per dose; manufacturers' catalog price is \$9.91).

Physicians and child advocates argue that lower costs would improve access and boost immunization rates. The drug industry counters that forced discounts would curtail research and development and low costs do not always yield higher vaccination levels. The government is investigating.

**Source:** Extracted from *American Medical News*, January 18, 1993.

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## Accessible Worship

Elizabeth Reeves, Chicago, IL

*Some people take going to church for granted. However, if you have a disability, this simple activity can be a luxury, sometimes impossible.*

This was made very clear to me recently, as leader of the Northwestern University Polio Support Group. One of our members revealed her frustrations with this problem. She requires a scooter, just as I do, and explained that during the past year she has not been able to attend her family's church of 30 years. Her legs and arms have gotten progressively weaker, and she can no longer "struggle" up and down her church's many steps. She shared her sadness over losing her human-powered mobility, as well as her church experience which had been an important source of comfort in the past.

Listening to my friend I suddenly realized that I too had given up life in my protestant church — the place where my daughter was married, my granddaughter christened.

At first I wrote letters to my church, almost begging them to provide even the most minimal accessibility. The responses were always polite, assuring me that within the next five years changes would be made.

Sec. 307 of the Americans with Disabilities Act exempts "religious organizations or entities controlled by religious organizations, including places of worship," except for the employment provisions.

Following my dream to find accessible church services for myself and the support group, I found an answer until we can comfortably enjoy our own churches.

I discovered that Sunday Catholic mass was held at Chicago's North Pier entertainment complex. I also learned that the Rehabilitation Institute of Chicago (RIC) offers Interdenominational Sunday services.

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## Accessible Worship

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I attended one of RIC's services and for the first time in a long while, I felt at home in a church setting. The ease and comfort of the accessibility and ministry was like a soothing balm. The warmth and caring of those around me quickly bridged the gap left by not seeing old friends at my church.

Encouraged, I wrote a letter to area Protestant churches requesting that they start a service at Chicago's North Pier entertainment complex. Dr. Eugene Winkler of the Temple Methodist Church, in the center of Chicago, picked up the challenge and met with me there. He then met with his church and the idea was approved.

I am happy to report that the first service will be Sunday, February 28.

Now, at last my quest for a Protestant church environment that I can freely enjoy on my scooter has become a reality. I don't have to be helped in and out of the service and I can "sit" anywhere I want.

I was amused at an announcement recently in our church newsletter that there is now an accessible bathroom in the church. If you physically cannot get into the church, who cares?

I still attend my church on special occasions leaving my scooter at the foot of the sanctuary stairs, and, with the help of my daughter, walk to my seat.

To be treated as an equal and enjoy access into any church is a dream I will never give up.

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## RESOURCES

***That All May Worship*** offers an interfaith approach to welcoming people with disabilities.

The purpose of the handbook, *That All May Worship*, is to assist congregations, denominational groups, and seminaries to welcome people with disabilities into all aspects of worship and religious life. The handbook is interfaith in scope and concerns people with all types of disabling conditions.

*That All May Worship* is a "coaching manual" written to change the ways people with disabilities are, or are not, included in their congregations.

Offered by **National Organization on Disability**, 910 16th St., NW, Suite 600, Washington, DC 20006 (800/248-2253, 202/293-5968 TDD, 202/293-7999 FAX), the handbook sells for \$10.00 postpaid. Special bulk rates are available.

The National Organization on Disability (N.O.D.) promotes the acceptance and full participation in all aspects of life, of America's forty-three million men, women, and children with physical, sensory, or mental disabilities.

**Joni and Friends (JAF)**, P.O. Box 3333, Agoura Hills, CA 91301 (818/707-5664, 818/707-2391 FAX, 818/707-7006 TDD) offers many outreaches. Each summer they hold retreats for families with a member who is disabled. Oregon, Florida, Pennsylvania, and California are the sites for the 1993 retreats.

Christian Fund for the Disabled (CFD) is a matching grant with a local church to fund equipment needs for a disabled person. Although Wheels for the World is still in the beginning stages, they plan to refurbish used manual wheelchairs and through churches match these chairs with a needy person.

JAF Ministries also offer the following: Disability Awareness Sunday materials, Disability Awareness Study Guide, Curriculum List for the Mentally Disabled, and Curriculum for Student Awareness.

For details, contact JAF Ministries at the above address.

**Healing Community/The Carling Congregation**, 521 Harrison Ave., Claremont, CA 91711 USA (909/621-6808, FAX 909/399-5552) has initiated Project Promised Land, a three year "Action for Access" program. They have materials to help congregations become accessible in attitude, architecture, and communication. Harold H. Wilke is the director.

**National Catholic Office for Persons with Disabilities (NCPD)**, P.O. Box 29113, Washington, DC 20017 (202/529-2933 v/TDD), provides many services, including representing to bishops the needs and concerns of persons with disabilities; providing workshops, retreats, presentations to pastoral ministers; developing and disseminating resource materials; sponsoring national training workshops, and publishing a quarterly newsletter, *NCPD National Update*.

The NCPD has also published several booklets and manuals and two videos entitled *We Are One Flock* and *Welcome One, Welcome All*. New projects include "Access to the Word" which will develop strategies and technology for bringing the good news to millions of Catholics with sensory disabilities. "Answering the Call" will encourage access to roles of leadership within the Catholic church. Contact the above address for a complete listing of services and materials.



**MOVING?**

**Please send both your old and new addresses to:**  
**International Polio Network**, 5100 Oakland Ave.,  
#206, St. Louis, MO 63110-1406 USA.

... when you move, *POLIO NETWORK NEWS* will not be forwarded by your post office. And, if you spend part of your year in the South, please notify us. We will mail to your current residence. Remember to notify us when you move back.





## NATIONAL LIBRARY SERVICE

The National Library Service for the Blind and Physically Handicapped of the Library of Congress publishes books and magazines in braille and in recorded form on discs and cassettes for readers who cannot hold, handle, or see well enough to read conventional print because of a temporary or permanent visual or physical handicap.

Through a national network of state and local libraries, the materials are loaned free to eligible readers in the United States and to U.S. citizens living abroad. Materials are sent to readers and returned by postage-free mail.

### BOOKS AND MAGAZINES

Readers may borrow all types of popular-interest books, including bestsellers, classics, mysteries, westerns, poetry, history, biographies, religious literature, children's books, and foreign-language materials. Readers may also subscribe to more than seventy popular magazines in braille and recorded formats.

Special equipment needed to play the discs and cassettes, which are recorded at slower than conventional speeds, is loaned indefinitely to readers. Headphones are provided on request. An amplifier is available for blind and physically handicapped readers who are also certified as hearing impaired. Other devices are provided to aid readers with mobility impairments in using play-back machines.

### ELIGIBILITY

You are eligible for the Library of Congress program if:

You are legally blind — your vision in the better eye is 20/200 or less with correcting glasses, or your widest diameter of visual field is no greater than 20 degrees.

You cannot see well enough or focus long enough to read standard print, although you wear glasses to correct your vision.

You are unable to handle print books or turn pages because of a physical handicap.

Or, you are certified by a medical doctor as having a reading disability, due to an organic dysfunction, which is of sufficient severity to prevent reading in a normal manner.

### HOW TO APPLY

You may request an application by writing NLS or calling toll-free 1-800/424-9100, and your name will be referred to your cooperating library.

## SCOLIOSIS

Since our feature on scoliosis, two of the three listed resources have moved. The new addresses are as follows: The Scoliosis Association, P.O. Box 811705, Boca Raton, FL 33481-1705 (407/994-4435); Scoliosis Research Society, 6300 N. River Rd., Suite 717, Rosemont, IL 60018. The National Scoliosis is still at 72 Mount Auburn St., Watertown, MA 02172 (617/926-0397).

## Readers Write ...

### MYOCLONUS

"My main problem in life remains the myoclonus. It started as a problem at night and now has developed into a 24-hour problem. I can't rest in the afternoon and every time my body settles down I start to twitch. Perhaps you could get used to it, but these are nerve spasms right on the boarder of pain, and it is a very unpleasant sensation. I have been through three sleep lab tests. Currently, the only way to stop these impulses is to walk, or some kind of constant activity, typing, sorting stamps, etc., and I cannot go 24 hours a day.

"Suggestions from physicians now have me trying several medications including Dopamin (for Parkinson's) who literally told me "to play around with them until I had some kind of result!" What kind of fooling around is this, but I guess this has been life all the way, figure it out yourself." Juliana Sawyer Stolle, Kaninchenbergweg 63, W-2400 Lubeck, Germany.

The following is from a brochure of the **Myoclonus Research Foundation, Inc.**, 220 Hardenburgh Ave., Demarest, NJ 07627 (201/585-0770, FAX 201/585-8114).

#### ■ What is Myoclonus?

Myoclonus is a neurological impairment characterized by sudden, shock-like involuntary jerking movements which can interfere with walking, speech, and manual activities. In the majority of patients, however, myoclonus is a serious and debilitating impairment.

Myoclonic jerks involve the motor system. Epileptic seizures are a common accompaniment of myoclonus, but intellect and sensation are spared unless affected by diffuse cerebral damage. Awareness of the motor deficits makes the myoclonus patient's life emotionally more difficult.

Myoclonus may occur in a variety of neurological disorders, such as toxic or vascular brain damage, degenerative cerebral disorders and brain tumors. Even more striking, myoclonus has been a complication of prolonged deprivation of oxygen. Myoclonus has been associated with epilepsy, vitamin deficiencies, metabolic disorders or can be a complication of a movement disorder, stroke or Alzheimer's disease. Myoclonus does not discriminate by age or sex. It occurs in children as well as in the elderly, and both women and men are its victims. At this time, only limited therapy is available.

#### ■ What Causes Myoclonus?

The brain mechanisms which cause this disorder remain an enigma. The fact that myoclonus can occur in several distinctly different neurological disorders

Continued on page 10

## Readers Write ... What Is Myoclonus?

Continued from page 9

confounds an understanding of its nature and impedes attempts to find its neurophysiological source. At this time, specific biochemical disturbances of the brain are suspected to be factors for this condition. While there is no known way to restore malfunctioning brain tissue, it may be possible to replace missing chemical agents in the brain, or to remove toxic materials from it.

Additional insights and information are needed to find a remedy which could significantly change the dependent life of the myoclonic patient.

The Myoclonus Research Foundation, Inc. was established to support clinical and basic research into the cause and treatment of myoclonus. To comprehend the complex nature of myoclonus, it is necessary for clinical and research neurologists, physiologists, biochemists, pharmacologists, anatomists, and members of other disciplines to share expertise and knowledge.

### Get on the road to freedom with the NextStep™ Rolling Walker from ...



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1-800-234-WALK (9255)

## SURVIVING WINTER

IPN has received several letters asking for suggestions on surviving winter. **Polio Network News** asks its readers to send their ideas, equipment suggestions, comments, etc. to IPN, 5100 Oakland Ave., #206, St. Louis, MO 63110 USA.

Handi-Trak, Inc., 1521 S. 85th St., Milwaukee, WI 53214 (800/726-7718) USA makes Sno-Traks, special chains for wheelchair tires. They are designed to keep wheelchairs moving through snow, ice, and slush and are for powered and manual chairs, as well as three-wheeled scooters.

## OTHER QUESTIONS AND COMMENTS

All medical problems of polio survivors cannot be and should not be blamed on polio. We know that. We also know that sharing problems, and, ultimately, solutions, is a very important part of networking.

We have been asked to collect information about survivors who have had a problem with rash. A few readers report a rash which is migratory, very itchy, never completely disappears and, at times, is very widespread and severe; other times less so. They have been unable to obtain a diagnosis from dermatologists.

Additionally, we have been asked to collect information from survivors about an allergic reaction to corn, or an allergic reaction to Premarin.

Robert Vaughn, of Lubbock, TX, reports "Seven years ago, I was having major depression over my declining health. Prozac (fluoxetine) was prescribed. Recently, when I switched insurance companies, I received a more complete brochure about the drug I was taking. Once I read the information about Prozac's possible side effects — joint or muscle pain; tiredness or weakness; trembling or quivering — symptoms similar to my polio problems, I began tapering off the drug and have since stopped. Within two months, my pain level dropped. I encourage all survivors to investigate the side effects of any medication they are taking. Do not assume that your physician will point out possible side effects if he/she feels your medicine puts you at risk for any further complications with post-polio syndrome."

## RESEARCH EFFORT

**International Polio Network** thanks its readers for supporting the Polio Society's efforts to secure more funds for research through Congress. The 1992 effort educated many more legislators about polio and its late effects.

Plans for 1993 include a postcard campaign in conjunction with Congressional hearings. Individuals who signed up for the Coalition will receive information soon, as will support group leaders.

## Potpourri

### ILLINOIS

*A Directory of State Services for People with Disabilities*, published by the Illinois Department of Rehabilitation Services (DORS), lists a wide range of services provided by 23 different state departments and provides a quick and handy reference, complete with addresses and phone numbers, on all agencies providing assistance to people with disabilities. Individuals or groups interested in obtaining a copy of the *Directory* can contact DORS' Disabled Individual's Assistance Line at 1-800/233-DIAL (Voice/TDD/TT).

### OHIO

Winnie Walker, polio survivor from New Philadelphia, reports that their survivor group, along with other volunteers, have compiled and published an *Access Guide to Tuscarawas County*. It contains 80 pages of information and covers about 140 buildings including churches, public buildings, restaurants, and stores. To find out how their group coordinated the effort, contact Winnie at 132 9th St., S.W., New Philadelphia, OH 44663.

### MICHIGAN

**The Polio Collection Library**, formerly at the Brandon Township Library, has moved to 4291 Squires Road, Quincy, MI 49082 USA. Nancy A. Miller, the new librarian, informs us an answering machine is on at times she is not available. Video and audio cassettes, periodicals, pamphlets, and book loans cost \$5.00 handling fee for health care professionals and out-of-state requests. Loan periods and charges to individuals in Michigan and members of the state organization are different. For more information about the collection and prices, contact Nancy at 517/869-2996.

### NEW YORK

Polio survivors in New York state are still collecting information about the **Shaw Act**. Interested survivors should contact Janis Wolpin, 713 Mosley Rd., Fairport, NY 14450.

Wheelchair accessible, one bedroom East 25th Street, New York co-op apartment on twentieth floor of luxury, 24-hour doorman building. Fully modified for wheelchair use by physician owner; roll in shower, lowered kitchen counters, etc. \$195,000 (maintenance \$884). Please call 203/966-5261 after 6 p.m.

### WISCONSIN

In the Spring of 1991, a barrier-free log cabin was constructed and gifted to the Department of Natural Resources (DNR) by the Telephone Pioneers of America, Wisconsin Chapter 4. The cabin is located in Mirror Lake State Park in the heart of the Wisconsin Dells area. Since the campground cabin is the only cabin of its kind in the state park system, rules have been established for its use. Applications for reservations may be made by writing Department of Natural Resources, Box 7921, Madison, WI 53707-7921, or by calling Mirror Lake State Park, 608/254-2333.

## Maynard Accepts New Position



Frederick M. Maynard, M.D., has been appointed clinical director of the Department of Physical Medicine and Rehabilitation and medical director of MetroHealth Center for Rehabilitation in Cleveland, Ohio. MetroHealth Center for Rehabilitation, the largest provider of inpatient and outpatient rehabilitation services in northeast Ohio, has long been regarded as the innovative leader in the field of medical rehabilitation.

Dr. Maynard will join the faculty of Case Western Reserve University in Cleveland and will continue his clinical and research activities on the late effects of polio and on aging with a disability.

Dr. Maynard's involvement with polio and its late effects dates back to the early 80s. He has lectured extensively to both professional and consumer audiences. His many polio-related publications include several professional journal articles and book chapters describing the physical and psychological challenges facing polio survivors as post-polio sequelae occur, a research report that identifies secondary conditions in polio survivors, a videotape on coping successfully with the late effects of polio, and a manual for establishing health promotion programs designed for polio survivors, titled *Stay Well!* He also co-edited IPN's *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*.

Dr. Maynard is a fellow of the American Academy of Physical Medicine and Rehabilitation, an active member of the American Congress of Rehabilitation Medicine, and the American Spinal Injury Association. He is currently a member of the Board of Directors of Gazette International Networking Institute (G.I.N.I.).

He will assume his new duties in March 1993. His new address will be: Department of Physical Medicine and Rehabilitation, 2500 MetroHealth Drive, Cleveland, Ohio 44109-1998.

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### MASSACHUSETTS

Wheelchair accessible home available for summer vacation rental after June 1, Chatham-Cape Cod. Two-story with fully accessible first floor, including modified bath. Three bedrooms, living room, dining room, outdoor deck, double garage. Short distance to shopping and beach. Weekly rentals from \$675, depending on dates. Contact: Sylvan Realty, 508/432-2344.

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serve as a reminder.

## CALENDAR

If you are planning a conference, please supply information to *Polio Network News* for inclusion in the Calendar. Yearly deadline dates for our quarterly publication are: January 15, April 15, July 15, and October 15.

◆ **Meeting The Challenges of Aging with a Disability: Lessons Learned from Polio and Stroke**, Long Beach, CA, March 19-20, 1993. Contact: Mary Marquez-Ackerman, Rehabilitation Research and Training Center on Aging at Rancho Los Amigos Medical Center, 7600 Conuelo St., Downey, CA 90242 (310/940-7402).

◆ **Post-Polio Syndrome Conference**, Ramada Renaissance Hotel, Regina, Saskatchewan, April 23-25, 1993. Contact: Saskatchewan Awareness of Post-Polio, Inc., Box 22237, Regina, Saskatchewan, S4S 7H4, Canada. Canadians send a stamped, self-addressed, business sized envelope for registration materials.

◆ **First Annual Forum Luncheon** with Frederick Maynard, M.D., Allentown, PA, April 24, 1993. Contact: Phyllis Kennedy, 524 New York Ave., Whitehall, PA 18052 or Beverly Solomon, 924 N 33rd St., Allentown, PA 18104.

◆ **Second Annual New Jersey State Symposium**, Princeton Marriott, Princeton Forrestal, NJ, April 25, 1993. Contact: New Jersey Polio Network, P.O. Box 537, Martinsville, NJ 08836, or call Jean Brodgon, 908/356-9447.

◆ **1993 Post-Polio Update Conference**, Holiday Inn Denver Southeast, Aurora, CO, September 10-12, 1993. Contact: Julia Beems, 303/233-1666, or Bev Holst, 303/423-1179.

◆ **Copenhagen Post-Polio Conference**, Copenhagen, Denmark, September 23-24, 1993. Contact: Gertie E. Larsen, PTU (National Society of Polio and Accident Victims), Tuborgvej 5, DK- 2900, Hellerup, Denmark (45 3162 9000).

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## **International Polio Network Post-Polio Directory - 1993**

*The Post-Polio Directory - 1993* is now available. This international directory contains clinics and health professionals knowledgeable about the late effects of polio, as well as support groups. The directory is available from International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 at \$3 for consumers and \$6 for others. Canada, Mexico, and overseas surface add \$1. Overseas air, add \$2.

## **POLIO AWARENESS WEEK**

For the past several years IPN has initiated the process to declare June 1-7 National Polio Awareness Week. Every year it has gotten more and more difficult to obtain the needed number of co-sponsors because many overwhelmed legislators refuse to co-sponsor commemoratives. They cite time and money and sometime the inaneity of the commemoratives as reasons. Once again, Congressman Dave McCurdy has submitted legislation to move commemoratives from Congress to a commission.

Consequently, other avenues will be explored this year. The Spring issue of *Polio Network News* will feature the results of those efforts.

## **PERSONAL ASSISTANCE SERVICES**

Gazette International Networking Institute's January, 1993 *Rehabilitation Gazette* (Vol. 33, No. 1) features an examination of personal assistance services. Articles are authored by Cynthia Brown, Ira Holland, Bob Kafka, Alma Krekus, Margaret Nosek, Penny Reed, Max Starkloff, and Leah Welch.

The June, 1993 issue will continue the discussion.

Single copies are available for \$6 postpaid. To receive both the January issue immediately, and the June issue when published, send the subscription rate of \$12. International surface add \$2; International air add \$4.