

# POLIO NETWORK NEWS

International Polio Network

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## A Look at Carpal Tunnel Syndrome

Charlotte Gollobin, M.S., L.N.

The approach to carpal tunnel syndrome varies, so we have studied some of the recent medical literature to determine standard as well as newer treatment. Alone and in combination, the recommendations include wrist splints, anti-inflammatory drugs, rest, diuretics, local steroid injection, surgery and vitamins B6 and B2.

In August 1989, the *Washington Post* carried an article on carpal tunnel syndrome reporting the possible cause to be repetition and stressful motions of the hand and wrist. It quoted results of a California study which suggested the number of people suffering from this disorder may be far higher than recognized; that health professionals may not be trained to detect it which compounds the problem according to the Centers for Disease Control.

Thirty-three patients with long-term histories of poliomyelitis and diagnoses of CTS were surveyed in another study (2). There was no significant resolution of symptoms in the patients who had surgery or were currently using wrist supports compared to patients without such treatment. In ten patients who used a single cane or ten who use crutches, there was a direct correlation between the hand holding the cane or crutch and the hand in which CTS developed. It was concluded that the chronic use of cane and crutch predisposes these patients to development of CTS and caution was suggested when considering wrist surgery.

According to the most recent issue of *Harrison's Principles of Internal Medicine*, the indispensable reference for medical students and many practicing physicians, carpal tunnel syndrome is defined as "an entrapment neuropathy of the median nerve at the

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## A Ten Year Experience

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Post-Polio Clinic, San Francisco, CA

The following paper was prepared for **Post-Polio Conference III — Perspectives for the Nineties** held February 1-2, 1991, at the Oakland Hyatt Regency in Oakland, CA USA.

### THE ORIGINAL EFFECTS OF THE POLIO VIRUS

To more easily understand the late effects of polio, it is important to understand the original effects of the poliomyelitis virus. The portal of entry for the polio virus was oral, and the infection in its first stage was in the gut cells lining the intestine. Many people infected with the virus at this stage thought they simply had gastrointestinal flu with symptoms of diarrhea and nausea. For a significant percentage of the people infected, the disease ended at this point.

But for some, the virus continued to multiply and spilled over into the blood stream, signaling the viremia stage of the infection. Symptoms then were not unlike a more generalized influenza, with fever, chills, malaise and achiness. Once again, for a significant percentage of patients, the disease process ended there. However, in a small percentage of the patients, the virus crossed over into the central nervous system and infected the anterior horn cells. These individuals contracted "paralytic" polio.

The distribution of weakness or paralysis depended on which anterior horn cells were involved. Spinal anterior horn cell involvement resulted in weakness or paralysis in the arms, legs, and trunk to one degree or another. Bulbar (brainstem) anterior horn cell involvement resulted in visual, swallowing, or breathing difficulties in any combination.

It is this period of fever, weakness, paralysis, and muscle pain that many polio survivors (or their parents) remember. This was the time when infected motor neurons were dying, leaving all the muscle fibers they innervated orphaned (or denervated). If all the motor neurons that supplied a particular muscle died, the result was complete paralysis of that muscle. If only a percentage of the motor neurons died, the muscle was only weakened, but not completely paralyzed.

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Many polio survivors remember having muscles completely paralyzed that started to move again, although weakly, after a period of a few weeks. That occurred because some of the anterior horn cells were simply shocked when neighboring anterior horn cells died. These nonfunctioning anterior horn cells were not dead but stunned by the swelling caused by adjacent nerve cell destruction. As days and weeks passed, the swelling subsided and the surviving anterior horn cells revived. Kenny hot packs and stretching helped control the pain and contracture of the denervated muscle. With time and exercise, the muscle got stronger.

Over the course of months and years, many polio survivors got stronger in a previously weakened or paralyzed muscle and were able to discard braces or wheelchairs. This was not only because of hard work and exercise but also because of a phenomenon called *sprouting*. Denervated or orphaned muscle fibers within the same muscle sent out a chemical distress signal that caused tiny sprouts to grow from the terminal nerve branches of neighboring, surviving motor neurons. Very slowly these sprouts grew over to the orphaned muscle fibers and reinnervated them, causing the motor unit to grow in size. In fact some motor units sprouted to innervate three to four times as many muscle fibers as Mother Nature had originally intended. As a result polio survivors felt stronger, and this pattern of strength and weakness remained stable for the next twenty to thirty years.

## THE LATE EFFECTS OF POLIO

Since 1981, four hundred eighty-three (483) post-polio patients have been seen at **St. Mary's Hospital Post-Polio Clinic**. When the data collected by **Barbara L. Bammann, M.D.**, at **Alta Bates-Herrick Rehabilitation Hospital** and by **Michael Berlly, M.D.**, at **Santa Clara Valley Medical Center** are added, there is a wealth of statistics and information. In all, seven hundred eleven (711) patients have been examined in the Bay Area Post-Polio Clinics. The ages range between thirty and seventy-six. The following material is based in large part on these statistics.

**FATIGUE:** The most frequent symptom was unaccustomed fatigue (79%). During the past decade, a number of investigators have looked at the problem using a variety of research tools, including muscle biopsies, electromyography, single fiber electromyography, immunologic and metabolic blood studies, biomechanical and gait analysis, and psychometric testing. The picture that has emerged from this data suggests that after thirty years, the metabolically overburdened surviving motor neurons appear to have become incapable of supporting the integrity of all the distal nerve terminals, resulting in defective neuromuscular transmission.

To better understand this, visualize what happens at the junction of the nerve and muscle under the usual circumstances. The electrical impulse travels from the anterior horn cell, down the nerve fiber to the tiny terminal nerve endings, which contact the individual muscle fibers. The arrival of the electrical impulse at the terminal nerve ending causes the release of a chemical (acetylcholine), which in turn causes the electrical impulse to penetrate into the muscle fiber,

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resulting in contraction of that tiny muscle fiber. In polio survivors, repeated discharges of the large reinnervated motor unit results in a failure of some of the muscle fibers to fire, thereby not contributing to the force of contraction. Polio survivors experience this as fatigue or a loss of stamina.

Interestingly, all polio survivors have defective neuromuscular transmission, but not all survivors complain of decreased stamina, so clearly other factors must be playing a role. The number of surviving motor units is probably an important factor, as well as the force generated during a particular task. Improper pacing during day-to-day activities and deconditioning following illness, surgery, or trauma are also factors to be considered. Finally, some polio survivors complain of sleepiness as well as decreased stamina, and this "mental fatigue" may result from the stress of chronic pain or the stress of dealing with secondary disability.

**WEAKNESS:** Four hundred ten (58%) of the polio survivors examined in the Bay Area's Post-Polio Clinics were found to have new or increasing weakness. This was based on the patient's history including his or her functional abilities, the physical examination, and appropriate laboratory studies, including electromyography (EMG), x-rays and CT scans, Magnetic Resonance Imaging (MRI), metabolic or electrolyte studies, and pulmonary function testing with blood gases. Usually, we were unable to track down old manual muscle testing records, but they were used when available.

A significant number of the patients had new or increasing weakness for reasons not directly related to their polio residuals. Radiculopathy (pinched nerve root) accounted for forty patients (10%) of the total with new weakness. Compression neuropathy (pinched peripheral nerve, as in carpal tunnel syndrome) accounted for thirty-one patients (8%) of the cases of progressive weakness. A few other cases were not at all related to old polio residuals and included three individuals who developed multiple sclerosis, three with peripheral neuropathy, one with brachial plexitis, and one with lithium toxicity. All of these cases underscore the importance of careful examination in order to rule out other treatable causes of weakness. Not every ill can be blamed on the late effects of polio!

Having stated that, we note that there were a large number of patients who did have increasing weakness which was directly attributable to the late effects of polio. One hundred fourteen patients (28%) of the total with new weakness had *acute* overwork weakness, while two hundred eleven (48%) were diagnosed with post-polio muscular atrophy (PPMA). Some clinicians would argue that *acute* overwork weakness

and post-polio muscular atrophy are one and the same. We have chosen to separate them for record keeping purposes and for prognostic reasons.

The idea of overwork weakness is not a new one. Dr. Bennett, the former medical director of Georgia Warm Springs, described it clinically in 1958, and there are other less well-articulated references in the medical literature to worsening weakness in polio survivors going back nearly one hundred years. Clinically, polio survivors who have engaged in excessively strenuous activities like tennis, weight lifting, stair climbing, etc., have noted the sudden onset of weakness in particular muscle groups overused in that particular activity. The muscle may lose more than a full grade of strength on the manual muscle test. Even though it may take months and with proper rest, the strength may return nearly to the level it was prior to the strenuous activity. This reversible weakness is what we refer to as *acute* overwork weakness.

Cumulative research suggests that the old overburdened motor neuron, which has been driving many more muscle fibers than it was meant to drive, is so metabolically exhausted by the strenuous activity that some of the terminal nerve endings die back, leaving many of the muscle fibers of the same motor unit orphaned again. If the weakened muscle group is allowed to rest (by stopping the offending activity or bracing, for example), new sprouts will grow and recapture the lost muscle fibers. The number of surviving motor units in a particular muscle, the pattern of muscle substitution, and the force generated by that muscle are crucial variables.

*Chronic* overwork weakness, or what has been called post-polio muscular atrophy (PPMA), differs inasmuch as there is no singular event of strenuous activity or exercise that signals the onset of increasing weakness. Rather there is a very slow and gradual loss of strength with accompanying atrophy of a particular muscle group. And no amount of rest will reverse the weakness. It appears, once again, that the overburdened motor unit is the common problem. The variables appear to be the intensity of work imposed on a particular muscle group by the function required of it over a long period of time. The overburdened motor neuron is unable to send out new sprouts to capture the orphaned muscle fibers, which have become denervated slowly from "pushing" in order to complete ordinary day-to-day activities.

**RESPIRATORY PROBLEMS:** Of the total number of patients seen in the Bay Area's Post-Polio Clinics, only one hundred fifteen (16%) were classified as having worsening respiratory problems. This included people who required increased mechanical assistance like

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intermittent positive-pressure ventilation (IPPV) during the day, more effective mechanical assistance necessitating a change in type of ventilator, and those who began using positive pressure by mouth ventilation at night. There were other respiratory problems, but these were not included in the statistics. Recurrent bronchitis was a frequent enough problem to warrant mentioning, even though the patients for whom it was a problem had a perfectly adequate cough and no difficulty handling secretions. Except for two patients, there were no immune abnormalities. The problem seems to be more of a chemical bronchitis (as opposed to infection) caused by night-time aspiration of tiny amounts of stomach acid, which refluxes from the stomach into the esophagus because of hiatus hernia. Fully one hundred sixty-seven polio survivors (23%) have symptomatic indigestion secondary to hiatus hernia. The figure may be so large in polio survivors because of the high percentage of scoliosis, which is usually associated with chest wall rotation. There are other effects of scoliosis on breathing, especially people who have any residual weakness of the deep breathing or coughing muscles. Despite reports of sleep apnea in polio survivors, we have seen only one documented case.

**JOINT AND MUSCLE PAIN:** Various musculo-skeletal aches and pains were a problem for five hundred fifty-nine polio survivors (74%). Many people had more than one site of pain and had been bothered by one pain or another for many years. As you can see from the statistics that follow, most polio survivors suffer from chronic pain, which for some can be quite disabling. Our statistics break down the different sources of pain.

Nearly all polio survivors (99% of our patients) had scoliosis. Scoliosis per se does not hurt, but the long standing effects of rotation and curvature of the spine have been associated with conditions that do hurt. We found that one hundred seventy-eight people (34%) had facet arthropathy or wear and tear arthritis of the little joints of the spine. Two hundred sixteen (41%) had degenerative disc disease, sometimes in combination with facet arthropathy. Sixty-seven (12%) had pain in the back and legs or in the neck and arms due to radiculopathy (pinched nerve root). Fifty-nine patients (11%) had lumbar spinal stenosis, all of whom were over the age of sixty. Twenty-three (4%) had a problem with sacroiliac joint pain. All but one of these people were long-time wheelchair users with pelvic obliquity associated with scoliosis. Three patients had piriformis syndrome.

The other joints in addition to the ones of the spine showed signs of wear and tear arthritis. As in the case of the back, abnormal biomechanics and overuse (or sometime abuse) caused wear and tear of degenerative arthritis. The shoulder was affected in one hundred sixteen people (22%), while the knee was affected in one hundred eleven (21%). Degenerative arthritis was present in the hip in fifty-eight (11%), in the ankle/foot in thirty-one (6%), and in the wrist in twenty-one (4%). Interestingly, if a leg was braced because of weakness, the arthritis generally developed on the unbraced side, which had been the side of major weight bearing for many years.

In addition to joint pain, there were a number of soft tissue sources of pain. Bursitis/tendonitis was generally associated with underlying arthritic changes and was present in one hundred seventy-one patients (32%). Carpal tunnel syndrome was present in one hundred seventeen polio survivors (22%) and was usually associated with crutch or cane walking or pushing a wheelchair. Fibrositis or myofascial pain syndrome, usually associated with underlying degenerative changes in the spine, was present in sixty-eight patients (13%). Fifty-nine individuals (11%) complained of muscle tension headaches, which was associated with degenerative cervical changes. Fifteen (3%) patients complained of burning and tingling in the hand and arm due to ulnar compression neuropathy from leaning their elbows on the wheelchair armrests. Other compressional neuropathies causing pain and discomfort included tarsal tunnel syndrome (not unlike carpal tunnel syndrome, but in the foot) and lateral femoral cutaneous neuropathy. Finally, there were eleven cases of thoracic outlet syndrome, associated with chronic slumped shoulders. We did not collect statistics on fractures.

**COLD INTOLERANCE:** Forty-one percent of the polio survivors complained of worsening cold intolerance. For nearly everyone it was not a new problem, but one that had been present since the onset of polio to a less bothersome degree. There seem to be two manifestations of the problem. One we have dubbed the "purple foot syndrome," which is characterized by painful coldness in one or more limbs, usually in the limb most affected by residual atrophy. Spouses also complain of this problem, especially in the middle of the night! It appears that some of the sympathetic nerve fibers were affected originally, and these fibers are the ones that constrict the blood vessels of the skin in response to cold. Normally, when we are exposed to cold, the blood vessel of the skin constrict to shunt blood away from the surface of the skin down to the underlying bone and muscle where heat can be conserved and the core body temperature maintained

at 98.6 degrees. Some polio survivors have lost that ability to shunt blood away from the skin, and so heat radiates away from the affected limb and it cools down. The best treatment is an elastic stocking and good woolly socks, foot warmers at the bottom of the bed, and an insensate spouse!

The other part of the problem is decreased muscular performance in the presence of cold. Many polio

survivors find they are unable to swim in an unheated pool, or they find that they have more trouble walking in cold winter weather. This is explained by the fact that when muscle is cooled, defective neuromuscular transmission is made worse. If you suffer from cold intolerance, you can only be advised to try to avoid cold exposure and "button up your overcoat."

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## A Look at Carpal Tunnel Syndrome

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wrist producing paresthesias\* and weakness of the hands. The syndrome is caused by pressure on the median nerve where it passes in company with the flexor tendons of the fingers through the tunnel formed by carpal bones and the transverse carpal ligament."

This compression can be produced by any process that encroaches on the carpal tunnel. Premenstrual swelling or retention of fluid in pregnancy (3,4) may cause the same symptoms. Often, people engaged in activities which require repeated wrist motion may experience these symptoms. (CTS is reported to be an occupational disability of sign language interpreting associated with repetitive wrist movements and pinching) (5). Other cause of bilateral (in both wrists) CTS may be rheumatoid arthritis, diabetes mellitus, hypothyroidism and pregnancy. Sometimes unilateral (one wrist only) CTS may be due to some trauma, physical activity involving one wrist, gout or calcium deposition disease.

Symptoms may be described as numbness on the palmar surface of the thumb, index and middle fingers. Numbness or burning or tingling of the whole hand has been reported as well. This may be intermittent at first, becoming chronic with time (6). Pain may be experienced in the forearm as well as the shoulders and neck region, while the muscles of the fleshy part of the hand below the thumb can develop weakness or degeneration. Pain or tingling of the fingers often occurs at night.

The pain is often described as aching or burning and is aggravated by use of the hand. Motor involvement occurs late in the course of carpal tunnel syndrome. Initially, it may be manifested by stiffness or clumsiness in the hand. Later, general weakness occurs, causing difficulty with pinch and grasp. But, complete paralysis is rare, even in advanced cases.

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\**abnormal tactile sensation, often described as creeping, burning, tingling or numbness.*

The accepted treatment of patients with only sensory symptoms and minor nerve conduction abnormalities consist of wrist splint to be worn mainly at night, anti-inflammatory drugs, and local injection with steroids. If symptoms persist or motor abnormalities are present, surgical decompression of the carpal tunnel is indicated. However, there are non-operative treatments which decrease the volume of the contents within the carpal tunnel by decreasing edema (accumulation of fluid) or inflammation. To help, diuretics are sometimes used.

Physicians can perform many simple tests to determine the extent of CTS, such as median nerve percussion, wrist flexion, and tourniquet tests. More sensitive tests include vibration and pressure threshold measurements with electrophysiologic testing.

Recently, 12 patients with CTS were studied (7). Estimates of vitamin B6 status by enzyme assays were made. Although no patients were found to have outright B6 deficiency, they nonetheless treated all with 150 mg of B6 daily for three months. The vitamin B6-dependent enzyme measured increased significantly in all patients. Six patients showed clinical and electrophysiological improvement and in these six, the target enzyme increased more than in the other six. The conclusion was reached that vitamin B6 supplementation can be recommended as adjuvant treatment in those undergoing surgery.

Another article (8) notes conservative therapy as first-line treatment unless the condition is severely advanced or immediate resolution of symptoms of CTS is essential. It recommends use of wrist splints, steroid injection, nonsteroidal anti-inflammatory drugs and vitamin B6 followed by reexamination in three weeks or earlier, if symptoms progress. For persistent or acute symptoms, surgical treatment may be necessary.

Yet another study (9) measuring B6 levels in patients concluded that vitamin B6 deficiency may accompany carpal tunnel syndrome.

Two recent articles (10, 11) further discuss the use of vitamin B6 in treatment of CTS. Drs. Karl Folkers and

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John Ellis and others have been publishing on this subject for many years. These reports described experiments conducted which identified cases of CTS treated with vitamin B6. Assays of the specific activity of a vitamin B6 enzyme determined the status of the patient as well as the efficacy of treatment. Three of the patients developed CTS during pregnancy while others were recommended for the study prior to surgery.

Of the 22 cases treated, 17 patients had bilateral and five had unilateral CTS. All were treated with vitamin B6 in amounts of 50-200 mg daily for minimum of 12 weeks. All hands were relieved of pain, tingling and numbness of median nerve distribution except one, for a rate much higher than that usually achieved by surgery alone. (Several medical books list CTS as the most common compression disease of the peripheral nervous system in the upper extremity of the body and note that from a few percent to as high as 20% fail to respond to surgery.)

Riboflavin (vitamin B2) is required for the first step in the activation of vitamin B6. When vitamin B2 was given together with B6 (11), treatment was more effective. Ellis and Folkers conclude that carpal tunnel syndrome is the clinical result of deficiencies of both vitamins B6 and B2.

With several options available, those with CTS now can choose from variety of treatments. If you wish to increase your B2 and B6 intakes, learning to eat foods which contain these vitamins may be beneficial.

Foods high in vitamins B2 and B6 are listed below:

<b>Vitamin B2</b>	<b>Vitamin B6</b>
Whole grains	Whole grains
Legumes	Legumes
Egg Yolks	Meats
Nuts	Green Leafy Vegetables

Avoid excess fluid retention by keeping salt intake down and potassium intake up. Foods high in potassium include whole grains, legumes, lean meats, vegetables, and dried fruits.

**Please note:** Whole grains (such as cereals, whole grain breads, rice, brown rice, barley, bulgur) and legumes (such as beans, peas, lentils) will give you all three of these nutrients.

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## RESOURCES:

**American Carpal Tunnel Syndrome Association**, P.O. Box 6730, Saginaw, MI 48608 USA.

**Charlotte Gollobin, M.S.**, Nutrition Consultant, Lower Level, 11510 Old Georgetown Road, Rockville, MD 20852 USA (301/365-1622). Charlotte is the immediate past president of the American Nutritionists Association.

## Dr. Siegel comments...

Carpal tunnel syndrome (CTS) is indeed a common condition, as noted in this excellent review. In addition to repetitive motion stress, CTS may be caused by alcoholism or gout, various endocrine abnormalities, including diabetes and hypothyroidism, tumors, hemophilia, any number of drugs, including Vincristine, Isoniazid, oral contraceptives and heavy metals, vascular disease, diffuse inflammatory diseases, and a variety of other diseases of unknown

etiology. A common condition to be ruled out in diagnosing CTS is radiculitis secondary to cervical spine osteoarthritis. Not infrequently, pressure on the peripheral nerves in the neck, shoulder, or arm can mimic CTS. In addition to the tests listed, thermography is an excellent tool for diagnosing CTS.

Concerning therapy, first-line treatment should be to change or modify those repetitive motions which put the wrist at risk for CTS. As suggested, conservative therapy should be given every chance before turning to surgery. The use of Vitamin B2 and B6 as adjunctive treatment is intriguing and may indeed prove of value. Comments by: Irwin M. Siegel, MD, 4640 Marine Drive, Chicago, IL 60640 USA (312/275-3200).

## Repetitive Motion Disorders Lead Increase in Job Illnesses

The Labor Department said that 32,000 more cases of repetitive motion disorders were reported in 1989 than in 1988, making it the leading cause of increases in job-related illnesses. Such illnesses result from repeating the same motions with arms and hands throughout the day, as frequently occurs on assembly lines and at computer terminals.

Repetitive motion disorders, such as carpal tunnel syndrome, rose from 115,000 in 1988 to 147,000.

Source: OT WEEK, Dec 13, 1990.

## Research Potpourri

### APPEAL FOR FEDERAL FUNDING FOR RESEARCH

**Lauro S. Halstead, M.D.**, testified before the U.S. Senate Appropriations Subcommittee for Departments of Labor, HHS, and Education on Wednesday, April 24, 1991. He also appeared before the U.S. House of Representatives Appropriations Subcommittee for Departments of Labor, HHS, and Education on Thursday, May 9, 1991. The purpose of his appearance was to request the Subcommittees to direct significant funds for post-polio research.

Below is the entire text of his testimony:

"Good morning, Mr. Chairman. My name is Lauro Halstead. I am a physician and Director of the Post-Polio Program at the National Rehabilitation Hospital here in Washington, DC. I also serve on the Board of Directors of the Washington-based Polio Society, and am a polio survivor myself.

"There are over 650,000 persons like me in the United States who contracted paralytic polio during the 1940s and 1950s and are still alive today. Many of you remember the poster children of yesterday, one of whom is shown here (March of Dimes poster). Today, however, as many as half of these polio survivors have begun to experience new disabling health problems known as "post-polio syndrome." These survivors are being seen in doctors' offices all across the nation with severe fatigue, new muscle weakness, new muscle and joint pain and respiratory problems. These health changes affect their ability to work, be active with their families, and generally live full productive and independent lives. As a physician I see the physical

and emotional problems every day. For example, a CEO at age 48 who can no longer run his company, a mother in her mid-30s who has difficulty taking care of her three children, and an immigrant woman in her late 20s who lost her job because she could no longer stand at a cash register due to new weakness and pain in her legs.

"Because of the lack of public attention to the post-polio issue, there has been very little organized research. We need to find out what is causing these new problems now so we can help treat the half million Americans who will suffer from post-polio syndrome over the next few decades.

"You may be asking the question: Why bother doing research and spending scarce dollars on a problem that will disappear in 50 years? Let me answer. First, the post-polio problem offers a unique scientific opportunity to study the effects of aging on the nervous system; second, lessons learned from studying polio may be important in understanding other similar neurological diseases; and third, there is a moral obligation to the 650,000 polio survivors who have led the fight for disability rights and the Americans with Disabilities Act (ADA), and struggled hard to overcome adversity in their own lives.

"We request this committee to direct the National Institute of Neurological Disorders and Stroke and the new National Center for Rehabilitation Research to issue specific requests for proposals (RFPs) in the amount of \$2 million and \$1 million dollars, respectively, to: (1) investigate the causes of post-polio syndrome; and (2) support research on the most effective treatments.

"With funding from the NIH, the U.S. scientific community can once again be the international leader

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## Research Potpourri (continued from page. 7)

in eliminating the unexpected and painful aftermath of a crippling disease once and for all.

"I would be pleased to answer any questions you may have."

### Your Help Is Needed

**As a polio survivor, or an individual interested in post-polio issues, you are strongly encouraged to write to, or call, the Senator and Representative of your choice.** In your letters or calls, briefly document why you feel major funding is urgently needed to "investigate the causes of post-polio syndrome and support research on the most effective treatments." We request that your letters be mailed prior to July 15, 1991. Please see the following phone number and addresses.

Letters to Members of the House of Representatives should be addressed:

The Honorable (Name of Member)  
United States House of Representatives  
Washington, DC 20515

#### **A listing of the Members of the U.S. House of Representatives, Appropriations Committee Subcommittee for Departments of Labor, HHS, and Education:**

William Natcher (D-KY), Chair  
Neal Smith (D-IA)                      Carl Pursell (R-MI)  
David Obey (D-WI)                      John Porter (R-IL)  
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Joseph Early (D-MA)  
Bernard Dwyer (D-NJ)  
Steny Hoyer (D-MD)

Letters to Senators should be addressed:

The Honorable (Name of Senator)  
United States Senate  
Washington, DC 20510

#### **A listing of the Members of the U.S. Senate Appropriations Committee, Subcommittee for Departments of Labor, HHS, and Education:**

Tom Harkin (D-IA), Chair  
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Phone calls to any Member of Congress can be made through the Capitol switchboard — 202/224-3121.

## POST-POLIO BIBLIOGRAPHY

"Recognizing Typical Coping Styles of Polio Survivors can Improve Re-Rehabilitation (A Commentary)." **Frederick M. Maynard, M.D., and Sunny Roller, M.A.** *American Journal of Physical Medicine and Rehabilitation*; April, 1991; Vol. 70, No. 2, pp. 70-72.

"Evaluation, Treatment, and Follow-up Results of Post Polio Patients with Dysphagia." **Alice K. Silbergleit, M.A., William P. Waring, M.D., Michael J. Sullivan, M.D., and Frederick M. Maynard, M.D.** *Otolaryngology — Head and Neck Surgery*; March 19, 1991; Vol. 104, No. 3, pp. 333-338.

"Dysphagia in Patients with the Post-Polio Syndrome." **Barbara C. Sonies, Ph.D., and Marinos C. Dalakas, M.D.** *New England Journal of Medicine*; April 25, 1991; Vol. 324, No. 17, pp. 1162-1167.

According to a press release provided by the National Institute of Neurological Disorders and Stroke (NINDS), one of the 13 National Institutes of Health in Bethesda, MD, the article states ...

"Previous reports have demonstrated that post-polio syndrome weakens the muscles of the arms and legs — causing patients difficulty when walking, lifting, or reaching. The recent study shows that this progressive weakness also affects the bulbar muscles of the tongue, mouth and throat and triggers swallowing problems — called dysphagia — in most patients.

"During the study, scientists examined swallowing among 32 patients randomly chosen from a larger group of post-polio patients (*Ed. Note:* Survivors diagnosed as having post-polio syndrome). Using specialized imaging techniques, including videofluoroscopy and ultrasonography, they detected dysphagia in 31 patients, but only 14 were aware of this problem.

"Typical signs of dysphagia included excessive tongue movements, a delay in the swallowing reflex and constriction of throat muscles, and uncontrolled flow of food from the mouth into the throat. These problems were often more severe on one side of the mouth and throat.

"Dr. Dalakas and his colleague Barbara Sonies, Ph.D., of the National Institutes of Health also detected dysphagia using an index that assesses oral motor function based on 10 tests of muscle strength and motion, such as strength of tongue and lips, voice quality, and swallowing ability. 'As the index score rises, the patient's risk of choking also goes up,' Dr. Dalakas said. 'Using this index, physicians can predict which patients are likely to choke.'

"Dr. Dalakas suggested that patients with post-polio syndrome visit their physician for a check of dysph-

agia and, in some cases, change eating routines to reduce choking risk.”



“A Review of Swallowing Difficulties in Post-Polio Individuals” by **Roberta Simon, R.N.** was published in the Fall 1990 (Vol. 6, No. 4) *Polio Network News*. The article, written for survivors, lists problems our readers reported, discusses the swallowing process and what can go wrong, and includes some common sense suggestions. The article was reviewed by **Carl Coelho, Ph.D.**, Wallingford, CT, who is also researching swallowing problems in polio survivors. Send a self-addressed business-size, stamped envelope to IPN, 4502 Maryland Ave., St. Louis, MO 63108 USA, if you would like a copy.

## RESEARCH — IS IT FOR YOU?

*Roberta Simon, RN, Darien Park, IL*

Research is an important aspect for the medical community in dealing with any health difficulty which has no previous history of known causes or treatments. Unfortunately, as we are all aware, post-polio syndrome falls into this category. Since many of us have been or will in the future be asked to participate in research, I think it is wise for us to consider a few questions and options.

Of course, the first consideration is what the physician conducting the research hopes to learn. You would also want to know if there is a risk to you by participating in the research and if there would be any charges to you or your insurance company. Most research is funded totally by either a grant or the institution conducting the research. All research plans must be reviewed by that institution's review board for the use of human subjects so that they can evaluate the ethical use and the amount of risk to the prospective participant. These results should be available to you if you inquire.

You will also want to know how many visits the research will require and evaluate your personal situation to see if this is a possibility for you. Some research programs require only yearly evaluations. Others may require weekly or even more frequent visits. If this is the case, are you willing and able to cooperate? This follow-up is extremely important to the physician or institution, so try to be fair in evaluating this aspect.

Would the results of this research benefit your treatment in any way? Would it improve your function and slow the progression of post-polio syndrome? Or would it give clinical information that would be of benefit only to other clinicians trying to determine the

cause of the problem? I don't mean to imply that this is not important, because answers often come from the knowledge gained by understanding the case.

Last, but certainly not least, is the consideration, “Is this procedure invasive?” Muscle biopsies or spinal fluid studies are invasive and increase the risk to the subject. If you participate in such a study, you might want to be informed not only of the risks, but also who will finance the treatment and costs if complications occur. Exposure to radiation is also an important consideration. If this type of study is proposed, be certain to discuss it with your family physician or primary caregiver. If you are having numerous x-ray studies for other health problems, this may not be the study for you.

Research holds the key to understanding and treating post-polio syndrome, and we should all try to contribute in some small way to finding these answers. If you feel uncomfortable with participation in one research study, do not feel guilty or embarrassed to say no. There will be other possibilities, and perhaps another would be better for you. Remember: **you are in control, and the decision is yours.**

Reprinted from *Polio Network News*, Winter 1990 Vol. 6, No.1

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## Where to Get Info on Your Info

Since access to medical records varies from state to state, the first step in obtaining your own records begins with asking your personal physician. After that, the following resources are available.

For a copy of the free brochure *Your Health Information Belongs to You*: Send a stamped self-addressed business-size envelope to the American Medical Record Association, 919 N. Michigan Ave, Suite 1400, Chicago, IL 60611 USA.

For a copy of the 52-page booklet *Medical Records: Getting Yours*, which provides information and advice on obtaining your medical records and includes a state-by-state survey of the laws governing patient access: Send \$5 to Health Research Group, Publications Manager, 2000 P Street NW, Suite 700, Washington, DC 20036 USA.

For a copy of your Medical Information Bureau (MIB) record (if one exists): Contact MIB Information Office, PO Box 105, Essex Station, Boston, MA 02112 USA (617/426-3600); Canadian residents contact MIB at 330 University Ave, Suite 102, Toronto, Ontario, Canada M5G 1R7 (416/597-0590). If you find an error, you can ask MIB to correct it. — W.H.

Source: *Modern Maturity* April-May, 1991

## Polio Network of Illinois

Polio Network of Illinois (PNI) dissolved in February, and we think it is important to highlight what was accomplished.

As a result of their efforts, clinics and medical resources are in place which will continue to provide services and diagnoses for the survivors of Illinois, as well as education for medical residents and students who attend the state's medical institutions.

They coordinated two medical conferences to provide education for polio survivors, spouses, and medical professionals. In addition, a separate pulmonary conference was held for physicians in Illinois and the surrounding area to educate them about respiratory and sleep difficulties.

The medical schools within have been provided with copies of video tapes of their second conference and

folders of information on post-polio. In addition, all libraries in the state now have information on post-polio and where to obtain help. A notebook of re-printed medical and lay information was also sent to Project SLICD for availability to anyone from Illinois by request from their local library.

Numerous seminars were presented to organizations such as the Illinois Department of Rehabilitation Services, Districts of the Illinois Nurses Association, Department of Social Security Determination Services, and to the Lions and Rotary, as well as local hospitals.

Their support groups will continue to function and have been provided with an extensive notebook of state and local resources for both polio and disability issues.

When they dissolved, they felt they had accomplished their original goals. We agree, and IPN looks forward to continued networking with the survivors of Illinois.

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## 1991 Post-Polio Directory Changes

*Please add the following:*

### CLINICS

Robert Shields, M.D.  
Department of Neurology, S90  
Cleveland Clinic Foundation  
9500 Euclid Ave.  
Cleveland, Ohio 44106  
216/444-0855

Lisa Barr, M.D.  
DePaul Medical Center  
Post Polio Multidisciplinary  
Evaluation Program  
150 Kingsley Lane  
Norfolk, Virginia 23505  
804/889-5201

### HEALTH PROFESSIONALS

Ben Weinstock, P.T.  
8121 23rd Avenue  
Brooklyn, New York 11214  
718/373-9004

### SUPPORT GROUPS

RIL  
Ramona Garcia, RN  
1211 H St., Suite B  
Sacramento, California 95814  
916/446-3074

Rancho Los Amigos Polio  
Survivors SG

Patti Strong  
11860 E Cog Hill Dr.  
Whittier, California 90601  
213/692-8163

Elgin Polio SG  
Simona Rhodes  
Fox River Valley CIL  
730B W. Chicago St.  
Elgin, Illinois 60123  
708/695-5818 (Voice/TDD)

Polio Survivors SG of W. NY  
Don O'Connor  
56 Woodlee Lane  
Grand Island, New York 14072  
716/883-2326

Post Polio SG  
Mary Winkenson  
P.O. Box 70  
St. Stephens Church, Virginia  
23148

*Please make the following changes:*

### CLINICS

Northwestern Univ Med School  
Michael Minieka, M.D.  
James Silwa, D.O.  
Rehab Institute of Chicago  
345 East Superior St.  
Chicago, Illinois 60611  
312/908-7950

### HEALTH PROFESSIONALS

Michael A. D'Anton, Ph.D.  
Linda L. D'Anton, P.T.  
Rehabilitation Associates of NJ  
280 Route 46  
Denville, NJ 07824

Brian M. Ernstoff, M.D.  
Forbes Metropolitan Health  
Center  
c/o Forbes Back Institute  
225 Penn Avenue (2nd Floor)  
Pittsburgh, Pennsylvania  
19141

Kam-Fai Pang, M.D.  
Physical Medicine &  
Rehabilitation  
136 Rebecca Drive  
Pittsburgh, Pennsylvania  
15237-1239

### SUPPORT GROUPS

State of Florida's Polio Network  
Thomas Marshall, Jr.  
1846 Powell Drive, Lot #38  
North Fort Myers, FL 33917  
813/543-4242

Sarasota Post-Polio SG  
Frank Leakey  
5707 Westwind Lane  
Sarasota, FL 34231  
813/922-6523

Northwestern Hospital Polio  
Support Group  
Elizabeth Reeves  
215 East Chestnut, No. 1601  
Chicago, Illinois 60611

Lehigh Valley Polio Survivors  
Assoc  
Phyllis Kennedy  
524 New York Ave.  
Whitehall, Pennsylvania 18052  
215/436-7639

*The 1991 Post-Polio Directory is available from International Polio Network, 4502 Maryland Avenue, Saint Louis, MO 63108 USA. The following fees are postpaid: \$2 for survivors; \$15 for professionals; \$25 for institutions.*

## Leaders & Readers Write ...

### FROM CALIFORNIA

"Having worn leg bracing for over 35 years I feel like I am a bit of an expert on the topic. Through personal experience and observation as a social worker it is evident that there are very few orthotists in the field that have experience in specifically working with polio survivors. I am extremely satisfied with the quality of work and the patience one particular orthotist has shown me: Howard Smith, Orthotist/Prosthetist, Stockton Orthopedic, 440 West Harding, Stockton, CA 05204 (209/466-2546)."

**Judy Credille**, 2500 Kathrine Avenue, Modest, CA 95350 USA.

### FROM FLORIDA

"The **State of Florida's Polio Network** is now organized. In addition to reaching and informing polio survivors about the late effects of polio, we also want to address the insurance problems of polio survivors in our state, as well as issues pertaining to handicapped parking. Office hours are Tuesday, Wednesday and Thursday, 10 a.m. until 4:00 p.m." **Thomas S. Marshall, Jr.**, State of Florida's Polio Network, 1846 Powell Drive, Lot No. 38, North Fort Myers, FL 33917 USA (813/543-4242).

### FROM KENTUCKY

**PRIORITIES OF POLIO SURVIVORS**, continued:

1. We think one of the top priorities should be getting information to the medical field. Most family doctors seem to have very little information concerning the late effects of polio and proper treatment.
2. We like access to the articles on research and the updated information from completed research.
3. We like the St. Louis conferences held every other year. We think they are very important for both the medical field and the survivors.
4. We would like to continue receiving information on medication, treatment, and new equipment.

### FROM NEW JERSEY

"**Joyce Morgan Houser** and **Joan Lloyd Swain** are looking for Nancy Jenkins, a friend they have lost track of in recent years. The three, who lived in Westfield, N.J., had polio in 1949 and spent their isolation period in Muhlenburg Hospital in Plainfield. Nancy and Joan later went to the Hospital and Home for Crippled Children in Newark for rehabilitation.

"Joyce and Joan ask that anyone who knows Nancy's whereabouts help them find their friend. The last address they had for her was in Southern California." **Joyce Houser**, 1272 Oxford Road, Bridgewater, NJ 08807 USA.

### FROM NEW YORK

"I am interested in polio survivors with scoliosis (curva-

ture of the spine). 1) What are your problems? 2) How have you solved them? 3) Do you have a good back brace maker?" **Doris Benedict**, 201 Front Street, Deposit, NY 13754 USA.

### FROM OHIO

"The Chrysler Corp. has a program that allows a rebate of up to \$500 for the purchase and installation of hand controls, chair lifts, scooter hoists, and other adaptive devices. It works. I received a check for \$500 within a month after sending in the rebate form. Installation must be made within six months of the purchase of a new car, van, or truck. Forms are available at Chrysler, Plymouth, Dodge Dealers. For more information call the Physically Challenged Resource Center Information Network (800/255-9877).

"I have written to Ford Motor Company and General Motors Corporation asking them to consider a similar program. Maybe, if enough people write, it will come to be. Please write to: Mr. Roger Smith, President, General Motors Corp., 3044 W. Grand Blvd., Detroit, MI 48202 USA. and Mr. Howard Poling, President & Board Chairman, Ford Motor Company, The American Road, Dearborn, MI 48121 USA." **Earl Laycock**, The Polio Connection, P.O. Box 19810, Cincinnati, OH 45219 USA.

### FROM PENNSYLVANIA

**Lewis Gumerman**, 28 Unger Lane, Pittsburgh, PA 15217 USA will be starting a support group soon. Please contact him, if you are interested in participating.

### FROM TENNESSEE

"I am interested in the following information about polio survivors and myofascial pain syndrome, fibromyalgia, or fibrositis. 1) Do you have myofascial pain syndrome, fibromyalgia, or fibrositis? 2) Did it develop after an accident? 3) Did it develop after an illness?" **Ruby Halen Daugherty**, 319 Hialeah Drive #20, Knoxville, TN 37920 USA.

### FROM WASHINGTON

"My polio resulted in one leg shorter than the other, which caused my spine to curve possibly causing sciatica. Vitamin B12 was prescribed to relieve the pain. It has been the most effective medication I have tried for pain, and the relief has lasted from a month to six weeks. I hope this information may be of benefit to others as I believe it has been to me." **Teresa M. Weimer**, 3403 N.E. 86th Avenue, Vancouver, WA 98662 USA.

### FROM WISCONSIN

"I have written poems for many different occasions (birthday, wedding, thank you, etc.) and have printed them on parchment paper. They are suitable for mailing or for framing. Anyone who sends me a SASE envelope will receive a sample and the current prices." **Stephen P. Mickey**, 224 W. Main Street, St. Nazianz, WI 54232 USA.

## Self-Help Resources Corrections

**Handling Difficult Behavior at Meetings** is available from Marshall House, P.O. Box 918, Santa Monica, CA 90406 for U.S. \$4.45. Additional charge for overseas.

**The Self-Help Way: Mutual Aid in Health** is available from Canadian Council on Social Development, P.O. Box 30505, Station C, Ottawa, Ontario, K1Y 4G1, Canada for \$17.66, postpaid. A French version is also available.

## Back Issues of Polio Network News

All issues (Nos. 1-4) of Volumes 2, 3, 4, 5 and 6 are available for \$2 each. However, some volumes would be photocopied. Send your requests to: **International Polio Network**, 4502 Maryland Ave., St. Louis, MO 63108 USA.



The "foo" sign is a Chinese character which has long been a symbol of the **Gazette International Networking Institute (G.I.N.I.)**. It stands for health, prosperity and all good wishes.

We welcome items or articles for the **Polio Network News**. Please send them to Joan Headley, 4502 Maryland Avenue, Saint Louis, MO 63108.

## CALENDAR

**Fifth Annual Post-Polio Conference**, Pine Tree Camp for Handicapped Children & Adults, Bath, ME USA, July 20, 1991. Contact: Rick Meade (207/443-3341).

**Ohio Polio Network Post-Polio Conference**, Holiday Inn on the Lane, Columbus, OH USA, August 24, 1991. Contact: Betty Sugarman, Ohio Easter Seal Society, 2204 S. Hamilton Road, Columbus, OH 43232-0462 USA (614/868-9126).

**Mississippi Polio Survivors Association Quarterly Meeting**, Busey Auditorium, Baptist Medical Center, Jackson, MS, September, 14 1991. Contact: Richard Swanson at 601/563-8237 or Robert Thayer at 601/924-9284.

**Second Colorado Post-Polio Educational Conference**, Westin, Denver, CO USA, September 13-14, 1991. Contact: Alison Kron (303/233-1666).

**The Second Texas-Oklahoma Post-Polio Symposium**, Wichita Falls Ramada Inn, September 21-22, 1991. Contact: Barbara Miller, 4503 Allison, Wichita Falls, TX 76308 USA (817/691-3497).

## 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.

