

POLIO NETWORK NEWS

International Polio Network

Winter 1992 ■ Vol. 8, No. 1

Post-Polio Problems Featured in Prosthetic- Orthotic Publication

International Polio Network provided information about polio's late effects to Robert Kidd & Associates of 836 Riverside Ave., Suite 1, Jacksonville, FL 32204 USA (904/350-0300) for inclusion in a P & O newsletter which was mailed to their clients across the country. With their permission, we reprint one article.

W.P., 76, is in many ways a classic post-polio syndrome patient. Afflicted with polio at 14 months, he experienced total paralysis of the lower extremities and partial paralysis of the trunk and neck. After "a lot of surgery," he first walked with the aid of crutches at age 6 but did not receive his first braces for another 16 years. Though those initial steel-and-leather orthoses were heavy and cumbersome, W.P. built a successful career as a plant chemist, demonstrating the fierce drive to achieve a normal existence that characterizes what some clinicians have come to call "the polio personality."

But at age 46, long after concluding he had polio licked, the patient began experiencing new muscle weakness, pain, and fatigue, to the point that he was compelled to give up his chief chemist position in favor of a less-physically demanding job. Unfortunately, the year was 1961 — it would be another 22 years before doctors could tell him what was behind his polio symptoms resurgence or begin to deal effectively with it.

With his advancing muscle weakness, W.P. adopted an exaggerated four-point stance, relying on his upper body for stability and support on two straight canes. This unnatural posture exacerbated his back and shoulder pain and seriously limited his mobil-

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Vaccine Related Issues

NATIONAL VACCINE INJURY COMPENSATION PROGRAM

Compensation Awards Continue

Despite calls for a moratorium on awards being paid in the federal compensation system for vaccine injuries and deaths which occurred before 1988, awards continue to be made by the U.S. Claims Court. Of the 4,236 petitions which have been filed with the Court, 611 have been fully processed. Of these, 230 have been awarded compensation, 305 dismissed and 76 were denied compensation.

To date, only 2,478 of the 4,236 petitions filed have been examined by the Department of Health and Human Services (DHHS) to determine the type of claim submitted. The U.S. Claims Court anticipates they will need an additional two years to process all claims.

Of the 2,478 petitions which have been examined by DHHS, 1,719 are for deaths and injuries following DPT/polio vaccination; 440 following MMR vaccination; 277 following polio vaccination and 42 following other vaccinations. Of the 230 awards, 51 were for deaths and 42 out of the 51 deaths were initially misclassified as sudden infant death syndrome (SIDS). Awards have ranged from \$48,000 to \$2.9 million.

The U.S. Claims Court continued to accept petitions after the January 31, 1991 deadline for vaccine injuries and deaths which occurred before October 1988. However, these petitions are ultimately being dismissed by the Court because they were late. Whether or not these petitions will be reconsidered in the future will depend upon examination of the deadline issue by the U.S. Supreme Court.

Reprinted with permission from National Vaccine Information Center, Dissatisfied Parents Together (NVIC/DPT), 128 Branch Road, Vienna VA 22180 (703/938-DPT3).

Polio Vaccine Options

Much has been reported lately about the potential danger of vaccines. If your family and friends ask you, as a polio survivor, about the polio vaccine

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Post-Polio Problems Featured

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ity and ability to carry out customary daily activities. Compounding his progressive physical deterioration was what W.P. describes as his growing frustration at having to confront polio again.

By the mid-1980s, the patient's prospects began to improve significantly. First, medical science "discovered" post-polio syndrome and began to develop effective approaches to treatment. Moreover, after a 30-year virtual lull in brace development, the orthotics industry experienced a surge in new technology and materials, leading to lighter, more functional leg braces for polio patients.

As his PPS debility worsened, W.P. became a patient of an area polio clinic, where a determined team collaborated on design and fabrication of bilateral lightweight plastic KAFOs (knee-ankle-foot orthoses) with the goal of reducing pain, improving his ambulatory posture and reducing the energy required for donning and walking.

The team's certified orthotist constructed the orthoses with ischial weight-bearing rings — "I virtually sit in them," the patient notes — to provide added protection and support for his knees, which are also affected by arthritis. The braces feature plastic thigh shells, bail-type knee locks, and spring-actuated ankle dorsiflexion joints to counter drop foot.

With his new advanced braces, W.P. now stands more erect than at any time in his life. His pronounced "shoulder slouch" is diminished, he does not tire as easily, his functional capabilities are improved, and his psychological outlook is substantially brighter. "I now feel solid on my legs —

I didn't before," he says. "That gives me a better sense of security, which enables me to do more and cuts down on my frustration level." His only complaint with the braces is itching and irritation brought on by perspiration, a problem ameliorated somewhat by absorbent clothing worn between his skin and the plastic brace components.

A distinct benefit of W.P.'s new KAFOs — "the coupe de grace" as he describes it — is easier donning and doffing of the braces. Smooth plastic interface has replaced soft leather, and velcro straps now do the job of long laces, which he found "excruciating" and tiring to use.

This patient demonstrates the potential of new approaches to orthotic design and componentry for PPS patients, whose ability to function in older-style braces is deteriorating. Custom measurement, design and fabrication, close attention to patient needs and capabilities, and the skill of a certified orthotist can now provide an orthosis that can maximize the wearer's function capacity.

Seventh World Congress of the International Society for Prosthetics and Orthotics June 28 to July 3, 1992

For more information contact:

Moorevents, Inc.
400 N. Michigan Ave., Suite 2300
Chicago, IL 60611 USA
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Resource Unit Provides P&O Information

The Resource Unit for Information and Education at **Northwestern University's Rehabilitation Engineering Program** provides information in prosthetics and orthotics to a wide audience of consumers, researchers, and service providers. The RU was formed under a grant from NIDRR in 1987/88.

The RU maintains databases which contain information on amputation management, amputee support groups, state-of-the-art research, recreational resources, self-help groups, P&O schools,

service providers, P&O publications, and manufacturers' information. The RU's quarterly news-letter, *Capabilities*, provides state-of-the-art research information, consumer interest articles, publication reviews, and other items of interest to persons involved with P&O.

Polio survivors can call the RU's **Help-Line 312/908-6524** and ask for information and receive helpful materials which are free of charge. The Help-Line also refers callers to alternative resources; however, no recommendation or endorsement is made. If you prefer, write to: Northwestern University, Rehabilitation Engineering Program, Resource Unit for Information and Education, 345 E. Superior St., # 1441, Chicago, IL 60611 USA.

New Braces Do Not Always Mean Ugly Shoes

Marge Torre, Philadelphia, PA

Approximately a year and a half ago I, like many of you, was told that going back into braces was the only answer to my unstable ankle and feet problems. I was not surprised.

What I did not expect was my emotional reaction the first day that the braces were put on. My mind was filled with memories — memories of childhood and early teens; memories of operations, and most of all, the pain. They all came rushing back and I had to pull the car over to the side of the road four times because of the tears.

When I finally returned home, I threw my braces as far back into my closet as I could. For the next 24 hours I cried. I cried myself to sleep and I woke up crying. Then the phone calls started from my polio survivor friends who had already faced new bracing. Not long after the supportive calls, I realized that I was not being fair to my braces or to myself. I kept telling myself I would walk better with my new braces. While I was trying to convince myself I was really fortunate, I suddenly realized I had to find shoes for my braces. More memories of ugly, orthopedic shoes.

I thought the challenge of finding shoes for my braces was going to be a long and tedious job. I was very delighted to find I was wrong. Recently having purchased a pair of sneakers at a neighborhood orthopedic shoe store, I purposely returned so I could find the salesman who had been so pleasant and helpful.

He was busy with another customer when I walked in carrying my braces. I looked at the shoes on display and found a pair that I liked but was sure

they would be a “no no” for my braces. The shoes were the wrong size, wrong color, made by a company out of business, and the only pair of that style left in the store. Thanks to Jim Dodd (**L&E Comfort Shoes**, 8026 Frankford Ave., Philadelphia PA) I later owned those same shoes that were now black and comfortable including a strap lined with velcro for support (see Photo I). The most wonderful thing of all was the realization that braces did not always have to mean ugly shoes, and that I now had a pair of shoes that I would feel comfortable wearing with a skirt.



When it was determined that my new braces were adding to my fatigue, new and lighter ones were made. This time they were not attached to the heel of my shoe, but featured a footplate that would fit inside any shoe with the correct heel size.

For me, though, the problem still was finding my small shoe size. So again, I returned to Jim, carrying my second set of new braces. I told him I would love to have a dress boot for the winter but I had never been able to find a company which made boots in my small but wide size. Jim found a boot wide enough and, once again performed his magic by making a boot small enough with the correct heel height (see Photo II).

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Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

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New Braces

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Many times since then I have sat in the shoe store, waiting for Jim to finish with other customers, and have watched him perform shoe magic with those who had bunions, callouses, hammer toes, diabetes, and other neuromuscular diseases besides polio.

A few weeks later, I realized that I was wearing my brace

because I liked my shoes, and that Jim and people like him are the world's best kept secret.

I asked Jim how he came to be so good at what he does. He explained to me he had been a shoe salesman for 20 years but had been a pedorthist for 15 years. The easiest way to explain the difference between a regular shoe salesman and a pedorthist is that a pedorthist is a "**foot pharmacist for doctors.**"

Foot Pharmacist for Doctors

PEDORTHIST — practitioner of pedorthics.

Pedorthics (pronounced "pe-door-thicks") is a unique foot-health professional service that specializes in prescription footwear, footwear modifications, and foot orthotics.

According to *Doorland's Medical Dictionary*, pedorthics is defined as "the art concerned with the design, manufacture, fit, and modification of shoes and related foot appliances as prescribed for the improvement of painful or disabling conditions of the foot and limb."

Pedorthics and Polio Survivors

The profession of pedorthics can greatly assist the polio survivor by reducing energy expenditure. This is accomplished by supporting the foot with proper footwear and providing a better biomechanical alignment through the use of shoe inserts and shoe modifications.

Because certain foot muscle groups are used in a repeated fashion, individuals can place undue pressure on one area of the foot. Certified pedorthists can remedy foot conditions and stabilize feet by using polymer resins, rocker soles and flares within the structure of the footwear.

The Certified Pedorthist

The individual who has served a period of internship and training, has fulfilled academic requirements, and who has been tested and credentialed by the Board for Certification in Pedorthics is known as a "board certified pedorthist." A certified pedorthist (C.Ped.) dispenses and provides medically related specialty footwear service that affect the ability of people to function.

The certified pedorthist works in concert with physicians and other allied health professionals such as orthotists, prosthetists, physical therapists, athletic trainers, and nurses in the "team approach to foot health care."

The physician provides the prescription from which the certified pedorthist designs and fits the prescribed therapeutic footwear for his or her patient.

Many physicians will refer their patients only to **board certified pedorthists**. Medical and allied health professionals look to certified pedorthists for quality and excellence in specialized footwear care.

A National Association

Most certified pedorthists belong to a national organization known as the **Prescription Footwear Association (PFA)**. PFA is a professional, non-profit group comprised of individuals from a variety of medical and retail disciplines who share an interest in pedorthics, its practice, treatment, research, and education.

Currently, Northwestern University in Chicago, Illinois, and Ball State University in Muncie, Indiana, are the institutions that offer basic training courses in pedorthics.

Literature Available

For a complimentary brochure explaining the profession of pedorthics, the function of a certified pedorthist, and a directory of board certified pedorthists located in the United States and Canada, please contact Cynthia Emmel, Director of Communications, c/o Prescription Footwear Association, 9861 Broken Land Parkway, Suite 255, Columbia, MD 21046-1151 or call 1-800/673-8447.

Update on ...

Americans with Disabilities Act (ADA)

As you know, the Americans with Disabilities Act was signed in July, 1990.

For more detailed information on ADA, write to the **U.S. Department of Justice**, Civil Rights Division, Coordination and Review Section, P.O. Box 66118, Washington, DC 20035-6118 or call 202/514-0301 or TDD 202/514-0381. You may also call **Equal Employment Opportunity Commission** at 800/669-3362 or **U.S. Department of Transportation** at 202/366-9305 or **Architectural Transportation Barriers Compliance Board** at 800/USA-ABLE.

Also, your closest independent living center (ILC) would also be an excellent resource. A directory of ILC's is published by ILRU Research and Training Center on Independent Living at TIRR, 2323 S. Shepherd, Suite 100, Houston TX 77019 (713/520-0232 or TDD 713/520-5136). The IPN office also has a copy of this directory if you prefer to call us.

In addition, Greg Larbes (G & L Consulting Services, 231 West 4th St., #620-A, Cincinnati, OH 45202 USA 513/381-8199) created the Disability/Civil Rights Resource Center (D.C.R.R.C.) with the intent to provide access to information regarding Section 504 of the Rehabilitation Act of 1973, the Fair Housing Act Amendment of 1988, the Americans with Disabilities Act of 1990, and other federal, state, and local laws that impact the lives of people with disabilities.

As a polio survivor and an advocate for people with disabilities, he writes, "We must take the responsibility to become informed of legislation that directly affects us. These laws were developed, written, and passed to protect our rights and to open doors to opportunities that have previously been denied us."

Greg informs us he will publish a quarterly newsletter. A \$10 per year membership will entitle you to four issues plus a complimentary consultation.

Update from ...

Germany

A post-polio support group with the goal of nationwide activities was established in Augsburg in October 1991. Its name is **Polio e.V.** (e.V. means officially registered non-profit organization). The group intends to join one of the big multi-disability associations in order to increase its effectiveness in dealing with government agencies, medical professionals, etc., as well as to get into contact with as many polio survivors as possible. Some 50 persons, most of them polio survivors from the Augsburg area, but also seven from the former East Germany, attended the foundation meeting. The board of seven is chaired by **Annegret Lamey**, Augsburg. For more information: **Gertrud Weiss**, Ebersbergstr. 33, 8200 Rosenheim, Germany or Annegret Lamey, Hofenstrasse, 4A, 8902 Steppach, Germany.

... National Cristina Foundation (NCF)

Barbara Miller, support group leader from Wichita Falls, TX, reports that she has received computer equipment from the NCF. The Foundation is the only not-for-profit organization directing commercially obsolete and surplus computers, etc., to educational and training facilities for people with disabilities. For more information, or to donate equipment, call 1/800-CRISTINA.

Health Promotion Program Manual Now Available

Stay Well! A manual for a health promotion program edited by Sunny Roller, M.A. and Frederick M. Maynard, M.D. has recently been completed.

The manual presents structured guidelines for starting and conducting a successful community-based wellness program for people who had polio. Designed to help participants alleviate, manage, and prevent a variety of secondary conditions that are associated with the late effects of polio, this wellness program presents three important strategies for staying well: Sound Nutrition, Individualized Exercise, and Lifestyle Enhancement Techniques (including stress management).

The contents of the manual were created by a national team of post-polio specialists to be user-friendly for **community organizers who will initiate the program and for the professional facilitators who will make it happen.** It includes step-by-step guidelines on how to start and organize a program, program curriculum guidelines, and extensive information on the late effects of polio. (For more detailed information on content, call Sunny Roller at 313/763-4485.)

For copies at \$35.00 each (postage included), mail check or money order to: Polio Network Serving Michigan, Inc., 2877 S. Ennis, Ithaca, MI 48847 USA. Allow six weeks for delivery.

The Three Types of Three Types of Polio

Polio has occurred for thousands of years in all parts of the world. The bone formation of an Egyptian skeleton of the period of 3700 B.C. indicates the effects of polio, as does an Egyptian plaque from 1300 B.C.

Polio has had many labels: poliomyelitis, infantile paralysis, Heine-Medin disease, and poliomyelopathy. Poliomyelitis is a combination of two Greek words: Polios or gray, denoting the gray matter of the nervous system, and myelos or marrow, denoting the myelin sheath around certain nerve fibers.

The recording of polio as a disease dates from the late 18th century. By the early 19th century it was reported as being widespread in Europe and India. It was regarded as ubiquitous and caused by teething, foul bowels, or fever.

Presently, it is known that the infection is primarily an inapparent one involving the alimentary tract, that paralytic polio is a relatively uncommon complication, and that silent infection in childhood provides long-lasting protection. The disease is spread by asymptomatic persons through the shedding of the virus from the throat and intestinal tract. Dissemination of the disease is enhanced by poor sanitation, crowding, and low standards of personal hygiene such as those that are common in many tropical and subtropical areas. It is still a widespread problem of endemic proportions in parts of the Eastern Hemisphere.

1 Immunological Types of Virus

The poliomyelitis virus is an obligate intracellular parasite which has been classified into three main types: **Brunhilde** — named after the Rhesus monkey in which the virus was first identified, **Lansing** — isolated from a fatal case of bulbar polio in Lansing, Michigan, and **Leon** — identified in a child named Leon during the Los Angeles epidemic. Because of these three separate immunological types, in theory, you can get polio three times.

2 Types Based on Severity of Infection

Probably the most common type of poliomyelitis is the form least identified by the general public. It is known as **abortive polio** and is difficult to diagnose, since the symptoms are often overlooked. These symptoms may consist merely of headache, fever, vomiting, sore throat, or an upset stomach. There are no evidences of paralysis. It is this form that helps to bring about lifelong immunity for a vast number of persons. It is not known how many mild

cases of this disease occur, nor the ratio of these mild abortive cases to paralytic cases.

If, on the other hand, the virus on reaching the central nervous system carries on pronounced activity, it will bring on identifying symptoms of recognized poliomyelitis. First, it may cause merely a stiffness of the neck and back, but no clinically evident paralysis. This type is known as **non-paralytic poliomyelitis**. The nerve cells involved are not sufficient in number to result in clinically evident weakness. It is known that those with recognized and definite poliomyelitis, at least one-half get entirely well without any significant paralysis.

The most familiar and more dramatic, but fortunately the least common, form of the disease is **paralytic poliomyelitis**. Here large numbers of the nerve cells are rendered useless and the muscles which they innervate are unable to cause motion. A person may become paralyzed in the arms, the legs, or in other parts of the body. The disease may affect the muscles of respiration that cause the breathing action of the lungs.

3 Types by Location in the Central Nervous System

At times the virus may settle in the region of the medulla, or "bulb," the thickened collection of nervous tissue at the upper end of the spinal cord. It is in this bulb that many of the vital nerve centers of the body are lodged. When the infection localizes in this region, it is known as **bulbar polio**. The virus, lodging here, may affect the nerves controlling the muscles of the throat, thus making it impossible to swallow or to speak plainly. Lodging in the medulla, the virus could affect the breathing "centers." Bulbar poliomyelitis is very serious. However, this form of polio is fortunately relatively rarer than the spinal polio, where the infection localizes lower down in the spinal cord. Spinal polio is divided into two types: **high spinal polio** because the nerves controlling the muscles of breathing — diaphragm and intercostals — are located in the high spinal area; **low spinal polio** which involves the lower limbs.

All these forms — spinal and bulbar — are the same illness, the only difference being in the location and the extent of damage done to the nerve cells which control the various muscle activities.

SOURCES: *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* edited by Gini Laurie, Frederick M. Maynard, M.D., D. Armin Fischer, M.D., and Judy Raymond.

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Update on Vaccine Related Issues

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options, the following organization can provide information.

The **National Vaccine Information Center** is a national, non-profit educational organization representing parents and healthcare professionals concerned about childhood diseases and vaccines, especially whooping cough (pertussis) and the DPT (diphtheria, pertussis, and tetanus) vaccine. The NVIC is dedicated to: (1) informing the public about childhood diseases and vaccines in order to prevent vaccine injuries and deaths; (2) assisting those who have suffered severe reactions to vaccinations; (3) representing the vaccine consumer by monitoring vaccine research and development, vaccine policymaking, and vaccine related federal and state legislation; (4) working to obtain the right of parents to choose which vaccines their children will receive; and (5) promoting the development of safer and more effective vaccines. The NVIC is operated with private donations and does not receive federal or corporate funds. The Center publishes a newsletter and other pertinent booklets.

Other sources for related information are Kathryn Todd, R.N., RR #2, Box 31, Industry, PA 15052 and the **Morbidity and Mortality Weekly Report** (Nov. 15, 1991/Vol. 40/No. RR-12) "Update on Adult Immunization: Recommendations of the Immunization Practices Advisory Committee (ACIP)." This volume on pages 29-31, discusses both live OPV (oral polio vaccine) and eIPV (enhanced inactivated polio vaccine) as they relate to adult immunization. In general "a primary vaccine series need not be given to adults living in the United States who have not had a primary series as children. However, for adults who have not had a

Three Types (continued from page 6)

Poliomyelitis, a Source Book for High School Students, published by The National Foundation for Infantile Paralysis, Inc. *Treatment of Acute Poliomyelitis*, edited by William A. Spencer, M.D.

With special thanks to ... Ernest W. Johnson, M.D.

Dr. Johnson, the former chairman of the Department of Physical Medicine and Rehabilitation at The Ohio State University Hospitals was awarded the 1991 Henry B. Betts Award recognizing his work with people with disabilities. He continues in his medical practice and much of his work involves assisting polio survivors.

EDITOR'S NOTE: A few sources list six types: inapparent infection, abortive poliomyelitis, non-paralytic poliomyelitis, spinal paralytic poliomyelitis, bulbar paralytic poliomyelitis, and encephalitic manifestations.

primary series and who are at greater risk of exposure than the general population to wild polioviruses because of foreign travel or health occupation, eIPV is preferred because the risk of OPV-associated paralysis is slightly higher among adults than among children. Poliovirus vaccine is not routinely recommended for persons older than high school age (greater than 18 years old)." To obtain a copy, send \$3.00 to Massachusetts Medical Society, P.O. Box 9120, Waltham MA 02254-9120 USA.

Polio Vaccine Ruling

Marc S. Moller, Esq., 100 Park Ave., New York, NY 10017-5590 and Stanley P. Kops, Esq., 210 W. Washington Square, Philadelphia, PA 19106, shared with the **International Polio Network** information on a September 1991 ruling by U.S. District Court Judge J. Frederick Motz. The essence of the decision was that the government is liable for injuries caused over several decades by oral polio vaccine.

The case asserted that the Federal Division of Biologics Standards (DBS) — now known as the Office of Biologics Research and Review — violated its own regulatory standards by not following its own neurovirulence standards and also by allowing attenuated (weakened) vaccine viruses to be put through more tissue cultures than the regulations allowed during manufacture. The Government is appealing the ruling.

Vaccination Rates Improve Worldwide, Uncertain in United States

Eighty percent of the world's children younger than one year old have been vaccinated against six common — and sometimes deadly — childhood diseases, the World Health Organization (WHO) announced. Though the statistic masks wide differences in vaccination rates between the industrialized and developing worlds, it represents a major advance in public health. Vaccination now prevents the deaths of about 3.2 million children per year, according to WHO estimates. Started in 1974, Expanded Program on Immunization (EPI) — a worldwide campaign — vaccinates infants against measles, polio, diphtheria, pertussis (whooping cough), and tetanus. In most non-industrialized countries, children also receive a vaccine against tuberculosis.

The United States is the only country in the world that has no official figures on immunization rates of one or two year old infants, because it stopped counting in 1985. The official explanation was that data collection was costly and the methodology was suspect, but critics contended that the Reagan

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Update on Vaccine Related Issues

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administration was embarrassed by the contrast between improving immunization rates throughout the Third World and five consecutive years of decline in the United States. However, in the wake of the 1990 measles epidemic — nearly 28,000 cases were reported, more than 18 times the number reported in 1983 — the government has begun to collect immunization data again.

SOURCE: OT week/November 7, 1991.

I am interested in information from **Polio Network News** readers on any research medication [Mestinon (pyridostigmine), Symmetrel, Prednisone, Eldepryl, etc.] they may be taking or have tried in the past. Please write to me and share the following: How long you have taken or tried the medication? Dosage? Consequences? If you discontinued the medication, why? Were you told the possible long and short term effects of this drug before taking it? I will compile the information and share it with all of you in a future issue.

I would also be interested in hearing from anyone who has tried a new or different treatment for their polio problems. An example could be a new exercise program, unusual injection, nerve stimulation, vitamin or mineral therapy, new equipment, etc. Please share what the treatment consisted of, what good or bad effects you noted from having the treatment, and who prescribed the treatment and their credentials (MD, PT, RN, OT, interested person, etc.). This information will also be reported to you at a later date.

Send your experiences to:

Roberta Simon, R.N., 7835 Pine Parkway,
Darien, IL 60559 USA.

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Ventilator Considerations: Lease vs. Purchase

Roberta Simon, R.N., Darien Park, IL

After being monitored over the past four to five years for respiratory and sleep difficulties related to the late effects of polio, it was decided last fall that assisted night-time ventilation was necessary. I was advised by my pulmonologist that prior to a scheduled sleep study I should obtain a letter of necessity from both my cardiologist and my pulmonologist to submit to my insurance company for their review and approval. I was also told to investigate what the insurance company would and would not consider for payment. All of this information turned out to be very good advice and was something I had not even considered.

I obtained the letters, sent them to the insurance company, and, after obtaining approval from their review board, I received a letter of approval prior to the sleep study. I learned that all insurance companies review non-emergency ventilator use to consider payment and necessity. Their decisions are based upon various considerations of symptoms and diagnosis.

Following up with a telephone call to the insurance company, I learned that they would pay the monthly rental fees up to the purchase price at which time I was responsible for paying the rental fees myself or pay the the outright purchase price and subsequent repairs and service as needed. I was glad to learn this, because if I had not, I may have been shocked when my coverage became exhausted after 18 months to two years. (That would have been very costly as I plan to live to be 100 and go skiing on my birthday as my great-grandmother did!) Anyway, I purchased the ventilator, after renting one for two months.

It was nice renting the ventilator for the first month or two because the respiratory therapist from the small medical equipment company stopped by frequently to check on my progress and assist me with problems. The primary reason for renting was to give Bi-PAP another try. I had tried Bi-PAP in the sleep laboratory but it did not ventilate me adequately, and I was swallowing large amounts of air due to pharyngeal weakness. Alas, Bi-PAP was not for me, although many individuals are having wonderful experiences with Bi-PAP.

There were numerous problems with the rental ventilators, including one which set its own breath rate during the night. Needless to say, this caused

unpleasant pain and fatigue in my chest. Remember that rental equipment is rarely new and for the most part has been serviced and rebuilt many times.

For the last ten months, I have been using a PLV-100 ventilator with a nasal mask, and know the quality of both my sleep and my life have improved tremendously. I look at my ventilator as a friend and in the same context as the other assistive devices I use. For me, purchasing a ventilator has caused few difficulties.

The main difficulty was related to nasal masks, and many of you know that finding a mast that fits correctly and fits comfortably is a challenge at best. Having been raised in a family with several siblings, I soon discovered that all the doors, toys, elbows, etc., that had connected with my nose through the years had definitely made an impact.

I tried an ADAMS circuit, but a bony prominence in my nose made that very uncomfortable and impossible. I tried a Respironics mask and a Healthdyne mask, but discovered that the anatomy of my face was again defective. The space between my upper lip and nose was smaller than average so that during the night the mask would slip over my lip and leak, sounding the ventilator alarm. After fighting the battle for several months, I had a custom mask fabricated for me by the staff of my pulmonologist. What a relief — difficulty solved!

Recently, for the benefit of other ventilator users, I decided to investigate the rental vs. purchase conundrum. I called three national home health care agencies for their opinions. My first surprise was their reluctance to share any opinions or information with me.

The first company I called connected me with a respiratory therapist, but when I asked my question, the therapist put me on hold for several minutes (knowing I had called long distance on day rates), then rang an answering machine which asked for my name and telephone number. I have yet to receive a return call.

The second company stated that the advantage of rental was that service for the equipment would be available any time of the day or night, and that ventilators were high service equipment — meaning they break down frequently. When asked if they would service a purchased ventilator at any hour or replace it with a rental, they stated they would — for a charge. The therapist with whom I was speaking then transferred me to the manager of the respiratory therapy section. I was told he was too busy but would call me later. I am still waiting for that return call.

The third company stated they made no follow-up visits after a purchase, and any problems other than equipment-related ones covered by the warranty would have to be taken care of by a home health care company. The advantage of rental from this company was stated to be that they serviced the equipment and the patient and all necessary supplies were included in the rental fee. This latter statement fascinated me because the home ventilator company I had dealt with for two months had managed to run up considerable charges with supplies — over \$500.

I guess that by their anxiety in answering questions, they answered them. Subsequently I had a lengthy talk with my insurance company regarding home ventilator use. They stated that the reason they no longer paid for rental equipment was because they felt they were being gouged by home health care companies. Sleep laboratories are now diagnosing and treating sleep apnea with nasal C-PAP; thus nasal mask and home ventilation are more widely used, and these companies have seen big opportunities for profit. The cost has more than doubled in the past five or six years. Granted, the companies do need to pay respiratory therapists to service both the equipment and the clients, plus provide 24-hour coverage for equipment failure or client difficulties which may justify some of the expense.

To me, purchase of ventilation equipment for an individual with a chronic longterm need does make more sense from an economical point of view, as long as the insurance company is willing to pay for repairs and a temporary replacement while a unit is being serviced. The disadvantage, of course, is that you may have no backup unit in your home for emergency coverage.

I was fortunate to have a physician knowledgeable about ventilators or I could have faced some serious difficulties. I hope all of you will be able to investigate the services, regulations, and rules of your insurance company now so that more decisions and stress will not be facing you in the months to come.

Reprinted from *I.V.U.N. News*, Fall 1991, Vol. 5, No. 2., a publication of Gazette International Networking Institute.

RECENT, RELATED PUBLICATION: "Pulmonary Dysfunction and Sleep Disordered Breathing as Post-Polio Sequelae: Evaluation and Management" by John R. Bach, M.D. and Augusta S. Alba, M.D. *Orthopedics*, December, 1991, Vol. 14, No. 12. Pages 1329-1337. This article discusses "Pathophysiology of Late-Onset Pulmonary Dysfunction," "Evaluation of CAH (chronic alveolar hypoventilation) and Sleep Disordered Breathing," "Pulmonary Managements," and "Preparing for Surgical Intervention."

Update on ...

National Polio Awareness Week: 1992

International Polio Network has asked the **Hon. John T. Doolittle (R-CA)** to introduce a joint resolution designating **June 1 through 7, 1992** as **National Polio Awareness Week**. As in previous years, designation requires 218 co-sponsors. Therefore, it is imperative that you write or call (202/224-3121 — the Capitol switchboard) your legislators asking them to co-sponsor Congressman Doolittle's resolution. (As we went to press, we did not have the resolution number but should have it by the time you receive this copy. If you want it, please call our office).

Your letter should contain near the beginning, the phrase "request support of Congressman John T. Doolittle's resolution designating June 1 through 7, 1991 as National Polio Awareness Week" and, since our major goal is to familiarize them with the problems we are facing, it would be helpful if you gave a brief reason why increased polio awareness is important to you as their constituent.

Following is a list of co-sponsors from 1991. If your legislator is listed, please thank him or her and request renewed support. Jim McDermott, William Lipinski, Carlos Moorhead, Cardiss Collins, Marge Roukema, Raymond McGrath, Bob Clement, Ike Skelton, Jerry Lewis, Larry Smith, James Hansen, Charles Rangel, Amo Houghton, Frank Riggs, Jaime Fuster, Matthew Martinez, James Quillen, Floyd Spence, James Walsh, Charles Wilson, Jose Serrano, Steven Schiff, William Jefferson, Wayne Owens, Bruce Vento, Glenn Poshard, John LaFalce, Mike Espy, Gus Savage, Martin Lancaster, George Brown, Eliot Engel, Eleanor Norton, Glenn M. Anderson, Scott Klug, Jolene Unsoeld, Tom Bevil, Bob Stump, Marty Russo, Gerald Kleczka, Elizabeth Patterson, James Bilbray, Jim Slattery, George Hochbrueckner, Bill Sarpalius, Robin Tallon, Sid Morrison, Albert Bustamente, John Conyers, Ron de Lugo, Ronald Dellums, Jamie L. Whitten, George (Buddy) Darden, Hamilton Fish, Richard Gephardt, Joe Kolter, Nick Rahall, Larry Smith, Bill Emerson, Peter de Fazio, Norman Mineta, William Gooding, Beverly Byron, Barbara Boxer, Mel Levin, Bart Gordon, Leon Panetta, Paul Henry, Thomas Petri, Don Sundquist, Peter Kostmayer.

Several members of Congress may tell you they cannot, in good faith, spend public funds in this manner. Many have signed on as a co-sponsor to Rep. David McCurdy's, (D-OK) bill which would remove the consideration of commemorative resolutions from Congress and place them in the hands of an independent, bipartisan commission. So be it. But, your letter of request will have served the purpose of educating your legislator about the current problems of polio survivors. Please take the time to do this now!

1992 Call for Congress to Fund Post-Polio Research

NATIONAL POLIO RESEARCH COALITION CREATED

The National Polio Research Coalition, co-sponsored by the **Polio Society** in Washington, DC and **International Polio Network**, St. Louis, MO, is forming to consolidate efforts to appeal to Congress to appropriate specific National Institutes of Health (NIH) funds for investigating the cause(s) and treatment of post-polio syndrome. The Polio Society will coordinate efforts in Washington DC and IPN will maintain a national database of organizations, polio survivors, family, and friends who are committed to writing, calling, and establishing personal contacts with their legislators to teach them about post-polio issues and the immediate need for post-polio research funds.

An Update: Recent Efforts with Congress

For the past three years the Polio Society in Washington, DC has led efforts to get Congress to appropriate funds for research. In 1990 and again in 1991, **Lauro Halstead, M.D.** testified before Congress asking that NIH, especially the National Institute of Neurological Disorders and Stroke (NINDS), set aside specific research dollars to study the cause(s) and treatment of post-polio syndrome.

Halstead told the Senate and House Appropriations Committees, "We need to find out what is causing this disturbing situation (post-polio syndrome). The cause or causes of these new health problems are not known. We do not understand the basic mechanisms of the problem. Aging undoubtedly plays a role, although it is unlikely that it is the only explanation. Most polio survivors with these new problems are between 40 and 60 years old but many are only in their 30s or late 20s ... We need to research possible treatments and medications. Now we are doing the best we can based on the experience of the past few years, but we do not have any research efforts to help in this process."

As a result of his testimony, and the 1991 letter writing campaign, the Appropriations Committees encouraged NIH and NINDS to increase its efforts in the area of post-polio syndrome, and to report on its activities prior to the hearings to be held on next years appropriations hearings.

Each year Congress must decide how much money will be appropriated (money actually made available) for NIH, its 13 research institutes, and related offices and agencies. Over \$8.9 billion was approved last year, an increase of over \$700 million. Although Congress does not like to micromanage the Institutes, it will suggest that attention be paid to certain issues, as it did with post-polio in 1991. In unusual cases, Congress will **direct** NIH to fund specific research activities. That is our goal for 1992.

Dr. Halstead has requested an opportunity to testify again this spring on the need for research related to post-polio.

What can you do to help?

Congress does listen. The success the Polio Society has had thus far is a direct result of its testimony, its contacts with many members of Congress, and the 1991 letter writing campaign in which some of you participated. If Congress is going to take stronger action, they will need to hear from many more polio survivors, their family, and friends.

While the key members of the Appropriations Committee (see listing) need to hear the message directly from their constituents, this year, **all** members of the House and Senate should be contacted. If you are not from the state or district of a member of the committee, you should still write or call asking them to relay your concerns to the Appropriations Committee. It is especially important for the Chairs and Ranking Minority members of the Appropriations Committee to be contacted.

What should you ask for ?

We need the Appropriations Committees to direct the National Institute of Neurological Disorders and Stroke (NINDS) to issue specific requests for applications to:

- investigate the cause(s) of post-polio syndrome, including neuromuscular transmission, neuromuscular overuse, and muscle cell breakdown.
- research the best treatment including the use of non-steroidal drugs, and the therapeutic effectiveness of exercise regimens.

This year, for the first time, NINDS will testify before Congress about what it is doing to support post-polio research. When this happens it is essential that the polio community respond to NINDS' comments immediately. Using the National Polio Research Coalition database, you will be contacted with information about their comments and suggestions for informing your legislators about the crucial need for specific funds to be allocated for post-polio research.

If you want to become part of a national effort to urge Congress to appropriate funds for research, first send your name, address, and phone number to IPN/ National Polio Research Coalition (IPN/NPRC), 5100 Oakland Ave., #206, St. Louis, MO 63110 to be included in the database. Second, send a letter immediately to your Senator and Congressman (with a copy to IPN/NPRC) to let them know that Dr. Halstead will be giving testimony in April or May to both Appropriations Committees. Your letter should express that the need is immediate for NIH funds to be allocated for post-polio research, and why it is personally important to you as a voter. Third, be prepared to respond in the Spring as a follow-up to Dr. Halstead's testimony and to respond to NINDS' comments. If you already have an established rapport with the key legis-

lators listed below or if your legislators need further information, contact Jessica Scheer, c/o the Polio Society, 4200 Wisconsin Ave., N.W., Suite 106273, Washington, DC or call 301/897-8180.

Key Congressional Committees for Post-Polio Issues

U.S. House of Representatives

Appropriations Committee: Subcommittee for Departments of Labor, HHS, and Education

William Natcher (D-KY), *Chair*
Neal Smith (D-IA) staff: Tom Dawson
David Obey (D-WI) staff: Anne Georges
Edward Roybal (D-CA) staff: Jorge Lambrinos
Louis Stokes (D-OH) staff: Anita Estell
Joseph Early (D-MA) staff: Rick Lane
Steny Hoyer (D-MD) staff: Johnnie R. Hemphill, Jr.
Robert J. Mrazek (D-NY) staff: Steve Goose

Carl Pursell (R-MI) Ranking Minority Member, staff: (vacant)
John Porter (R-IL) staff: Mike Myers
Bill Young (R-FL) staff: Douglas Gregory
Vin Weber (R-WI) staff: Jane Williams

Subcommittee Staff

Mike Stephens, Staff Director
2358 Rayburn House Office Building
Phone: 202/225-3508

U.S. Senate

Appropriations Committee: Subcommittee for Departments of Labor, HHS, and Education

Tom Harkin (D-IA), *Chair*
Robert Byrd (D-WV) staff: Joan Drummond
Ernest Hollings (D-SC) staff: Eddie Moore
Quintin Burdick (D-ND) staff: Mary Wakefield
Daniel Inouye (D-HI) staff: Patrick DeLeon
Dale Bumpers (D-AR) staff: Elizabeth Goss
Harry Reid (D-NV) staff: Karen Judge
Brock Adams (D-WA) staff: Tom Keefe

Arlen Specter (R-PA) Ranking Minority Member staff:
Douglas Loon

Mark Hatfield (R-OR) staff: Betty Lou Taylor
Ted Stevens (R-AK) staff: Jane Rosenquist
Warren Rudman (R-NH) staff: Christine Ciccone
Thad Cochran (R-MS) staff: Forest Thigpen
Phil Gramm (R-TX) staff: Ed Kivett

Subcommittee Staff

Michael Hall, Staff Director
186 Dirksen Senate Office Building
Phone: 202/224-7283

Phone Calls: All phone calls can be made through the Capitol Switchboard 202/224-3121. Ask for the office you are calling, i.e., the Member's office or the committee or subcommittee office. With the exception of the chair and ranking minority of each sub-committee, staff will be in the office of their member.

Letters: Room numbers are not necessary to write a Member of Congress; all mail goes through the Post Office at the Capitol. Letters to Members of the House of Representatives should be addressed:

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

Letters to Senators should be addressed:
The Honorable (name of Senator)
United States Senate
Washington, DC 20510

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Our label form is being changed to include the month your subscription is due.

◆ If you are not a subscriber to the **Rehabilitation Gazette** you may be interested in obtaining Vol. 32, No. 1 published in January, 1992, and Vol. 31, No. 2 published in June, 1991. Vol. 32 features articles by polio survivors **Larry Schneider** and **Hugh Gregory Gallagher**, author of *FDR's Splendid Deception*. It also includes several pages of disability resources.

Vol. 31 featured several views on the right-to-die issue. In Vol. 32, **Alice Mailhot** responds with "Ethics and the Old Polio: Will We Survive the 90s?" — an article expressing her personal view of the right-to-die issue as it pertains to persons with disabilities.

You may obtain both copies for the price of \$10 postage paid.

◆ **The Post-Polio Directory — 1992**, will be ready for distribution on March 1, 1992. This directory is a valuable resource for survivors, listing self-identified clinics, health professionals, and support groups in the US knowledgeable about the late effects of polio. It also contains an international section. *The Directory* is available to polio survivors in the US for \$3 postage paid. Canada and Mexico add \$1, overseas \$2.

Potpourri

As published in **Polio Network News** (Vol. 7, No. 4) Sandra Hughes Grinnell's insurance company pays for a certain amount of her physical therapy. We have heard from several individuals who have not been successful in obtaining approval. Are there others who have been successful? If so, please share your experiences so we can offer suggestions to others. (Your name and insurance company will remain confidential if you so choose.) Send your comments to IPN, 5100 Oakland Ave., #206, St. Louis, MO 63110.

International Polio Network is looking for a copy of Volume 1, Number 4 of **Polio Network News**. If you have a copy and would part with it, please mail it to IPN, 5100 Oakland Ave., #206, St. Louis, MO 63110. Your cooperation is deeply appreciated.

CALENDAR

The Late Effects of Polio, BEH Auditorium, Mercy Hospital, **Des Moines**, IA, March 27-28, 1992. Speakers include: Stanley Yarnell, M.D., St. Mary's Medical Center, San Francisco, CA; James Agre, M.D., Ph.D., University of Wisconsin Hospitals and Clinics, Madison, WI; Oscar Schwartz, M.D., Specialist Pulmonary Disease, St. Louis, MO; and two local physicians. Roberta Simon, R.N., Darien Park, IL, and Joan Headley, Executive Director, International Polio Network, will present the consumer perspective. Contact: Norma Cornelius, Iowa Polio Survivors Group, 1319 Johnson Ave., Ames, IA 50010 USA (515/232-7237).

New Jersey State Symposium, Princeton Marriott, **Princeton Forrestal**, NJ, April 4, 1992. Contact: Jean Brogdon 908/356-9447 for more information about the brunch meeting.

Understanding Post-Polio Syndrome: A Symposium for Survivors and Health Professionals, Center City Hilton Towers, **Philadelphia**, PA, May 30, 1992. Speakers include: Jacquelin Perry, M.D., Rancho Los Amigos, Downey, CA; Neil Cashman, M.D., Montreal Neurological Institute; and Joan Headley, International Polio Network. Local speakers include: Mary Ann Keenan, M.D., Albert Einstein Medical Center; Albert Esquenazi, M.D., Moss Rehabilitation Center. Call: 1/800/EINSTEIN or 215/456-6051.

Polio? What now, Holiday Inn/Bell Tower, **Fort Myers**, FL, July 17-18, 1992. Call 813/543-4242. Registration packets will be mailed February 1st.

Mike Dolliver, 1871 SW 37th Terrace, Fort Lauderdale, FL 33312 is interested in communicating with polio survivors in Florida who do not have a support group to attend or who find it impossible to travel to the meetings.

Polio Survivor **Stephen P. Mickey**, 224 West Main St., St. Nazianz, WI 54232 (414/773-2686) sells his original poetry on notecards, bookmarks, etc. Send a SASE for a sample bookmark and a price list.