

POLIO NETWORK NEWS

Spring 1987

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

IPN is coordinated by Gazette International Networking Institute (GINI), which has maintained a worldwide polio network since 1958.

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SELF-HELP GROUPS: A DEFINITION by Gini Laurie

Since January, 1987, I have been active on the Surgeon General's Planning Committee for a national workshop in September, 1987, at UCLA on self-help groups and public health.

The Planning Committee defines self-help support groups as a collection of individuals who share a common concern, provide emotional support to each other, govern themselves, and charge little or no fees for their involvement in the group.

In most groups, there are three basic types of activity: emotional support, information exchange, and coping strategies. The degree of activity in each of these areas will vary dependent upon the needs of the group's members.

This definition allows the involvement of professionals (voluntary agencies, etc.) so long as the group is in control and the professionals serve at the wish of the group. One of the purposes of the Surgeon General's workshop is to explore the nature of the relationship between self-help groups and professionals.

Professional human services agencies and mutual help groups sometimes have a tense and competitive relationship. Group members sometimes believe themselves to have been ill-served by professional helping systems, and members may be encouraged to only consult one another.

Historically, professionals have sometimes tried to co-opt mutual help organizations, and they are often regarded as intruders. When groups turn to agencies for assistance, a struggle for control may result.

Most mutual help organizations are not anti-professional and collaboration is possible if there is mutual respect and understanding.

Self-help groups are a powerful and constructive means for people to help themselves and each other. This exciting movement involves about 15 million persons in more than one-half million self-help groups. The basic dignity of each human being is expressed in his or her capacity to be involved in a reciprocal helping exchange.

LETTERS TO THE EDITOR

Rotary International's
PolioPlus Campaign

"As coordinator of a post-polio support group in New York, I was recently asked to speak at a District Conference of Rotarians. They were grateful for the first-hand perspective on polio.

"No one knows better than we do why it is important to prevent this disease, and perhaps our experiences can help Rotary succeed in its goal of wiping out polio in the next 5 years. Support groups can contact local and regional Rotary organizations to offer services as speakers or resource people. While we are supporting this important campaign, we will also be helping to educate Americans about the late effects of polio."

Barbara McManus
5 Chester Dr.
Rye, NY 10580

"Keep Up the Good Work"

"I have recently read the Polio Network News...and I have to commend you in putting together a "short and sweet" informative bulletin.

"My interest in subscribing and keeping current with post-polio needs is twofold: primarily as an orthotist serving the Dallas/Ft. Worth area, and secondly as the son of a polio survivor. I hope these facts serve as a vote of confidence in your actions to pass important information along to this group of people.

William Rodgers, C.O.
Baylor Univ. Med. Center
Dallas, TX 75246

Chicago Polio Swim Club: 1936

Polio survivor C.J. Lamos, former resident of Chicago now living in Florida, sends news of a visit with friends in the Chicago Polio Swim Club:

"Almost all are in their sixties or seventies. The oldest is 88, still walking with braces and crutches, but in a nursing home because he has outlived his younger brothers and sister, all able-bodied.

"Second oldest is James Hall, 85, founder of the club in 1936, which flourished for 30 years until the neighborhood changed and some of us couldn't get in and out of the pool. Hall suffered a siege of depression when he retired at the age of 75 from a long career as a jeweler and gemologist. He recently had an elevator put in his house: Hall had climbed stairs to his bathroom and bedroom for 80 years on crutches. Some complaints of arm problems, but as sharp as ever.

"Warren Bell, our old swimming instructor, close to 75, is using an Amigo because his arms are tired after 65 years of crutching. A few years ago the Amigo shot out from under him and left him on the floor with a broken hip. It also shot off the pier into the lake with him while he was on vacation, but he is still riding the Amigo.

"The members who were high school kids when I joined the swim club in 1941 are retiring now. This gives a sample of polio tenacity in Chicago. In Florida, these people could add maybe another 20 years. I have."

C.J. "Connie" Lamos
925 N.E. 122nd St.
N. Miami, FL 33161

Send your "Letters to the Editor" to International Polio Network (IPN), 4502 Maryland Ave., St. Louis, MO 63108 by July 31, 1987.

THE ORTHOTIC DILEMMA: ANOTHER VIEW
by Linda Terrill

Polio survivor Linda Terrill describes her experiences with braces made by Glenn Ham-Rosebrock, C.O., whose article on a new design for plastic braces appeared in the Winter 1987 issue of Polio Network News.

"I was born in San Francisco in 1948 and contracted polio in 1949. The polio left me paralyzed from the hips down. At age 3, I wore braces, but refused to use crutches until age 5, preferring to push a doll buggy with bricks in the bottom to stabilize me.

"I first entered Shriner's Hospital in San Francisco at age 5, and subsequently had 10 major surgeries by the time I reached age 14. I was told not to accept changes, but to accept things as they were. I chose to swing through braces and Canadian crutches.

"At age 24, a fall shattered the femur in my right knee. Suddenly, I was in a wheelchair with pins in my knee. My leg finally mended.

"At age 30, I started experiencing pain in my left shoulder. The doctor said it was bursitis, and, not knowing anything about further polio problems, I worked out in a gym for 6 months and walked almost a mile every day for 5 years, suffering pain every day.

"Then came another fall, tearing a muscle from the rotator cuff of my left shoulder, and leaving me unable to support myself on crutches. I fought severe pain for 2 months before talking to Dr. Jacquelin Perry of Rancho Los Amigos Medical Center in Downey. Finally, I accepted the wheelchair and graduated to a walker and a wheelchair for another year and a half.

"I had tried to get the old braces fixed many times, but they were 12 years old, bulky, cumbersome, heavy, and caused pressure sores on my thighs. The ortho-

pedists and orthotists couldn't or wouldn't make them comfortable and more supportive. After a major adjustment from hopping for 30 years to walking with a walker, my right knee became even more unstable and leaned to the left. Every step was painful.

"Following Dr. Perry's advice to change my lifestyle and accept the limitations caused much frustration and depression. I gradually realized that I didn't have to give up, but could look for alternatives.

"At this time, circumstances brought me to Glenn Ham-Rosebrock, an orthotist in Los Angeles who had trained under Dr. Perry. He had polio about the same time I had, and had had similar experiences. His methods differed from those of other bracemakers. Plastic and aluminum was the structure, but total body contact was the method.

"He made me new braces which weighed only 8 pounds, and I walked out of his office with underarm crutches and no walker. The change was immediate. My feet now point straight ahead, supported at the thigh. My right knee is no longer unstable but straight. There are no more pressure sores or pain, and I can stand comfortably. I'm much more stable and haven't fallen. When I move, the braces feel a part of my legs.

"I hope that Mr. Ham-Rosebrock's method will be studied before this last polio generation passes."

Address: Linda Terrill, 2714 W. Keller, #1, Santa Ana, CA 92704.

POST-POLIO RESEARCH

Post-Polio Syndrome and the Poliovirus

by Raymond Roos, MD

One of the most exciting events in virology was the development of the poliovirus vaccine. It is surprising to realize that no one really understood why it worked. Sabin discovered years ago that if he grew poliovirus many times in tissue culture, the virus would no longer cause paralysis -- although it still could trigger an immune response and protect against natural poliovirus infection. For more than 25 years, countries have used the Sabin vaccine with no real idea as to why these living polioviruses do not paralyze.

Sabin's strains have been cloned using recombinant DNA techniques and the sequence of every component (nucleotide) of the genes has been compared to natural poliovirus. The Sabin strains are mutants that differ very subtly from natural poliovirus; a change of only one nucleotide of the total 7000 nucleotides of the virus gene can make the difference between whether the virus will paralyze someone or just immunize them without any observable effect. We understand the virus better now and can construct a better vaccine -- one that is nearly perfect.

What does poliovirus have to do with PPS? Perhaps I should first give my definition of PPS. I define PPS as a new difficulty in carrying out certain functions that occurs years after acute polio. PPS can be classified into two entities that at times can overlap and that frequently involve fatigue. In one process, patients have pain that limits their functioning or so-called musculoskeletal PPS. Most of the time this seems to be caused by tendonitis, bursitis, and similar problems that are related to a weakened muscle. The second process involves a loss in motor functioning that is not explained on the basis of pain or so-called post-polio muscular atrophy (PPMA). At times, patients with this problem have evidence of new muscle atrophy due to ongoing motor nerve damage. The cause of PPMA is unknown.

Poliovirus caused the original paralysis, but could it also be a cause of PPMA? We know that viruses can behave in very unusual ways. Some viruses can infect a person, not cause disease until three decades later, and then persist for decades. These viruses are not infectious at the time that they cause these delayed diseases, and therefore, do not spread. There is no evidence at present that poliovirus is able to cause any persistent type of infection; however, viruses similar to poliovirus can produce a persistent nervous system disease. Although it is understandable that PPS individuals do not like to consider the possibility that poliovirus could still be present years after acute poliomyelitis, it is nevertheless important scientifically to keep an open mind with respect to the cause of PPS. It is also important to remember that PPS is a slow process that, at times, can plateau and stabilize; if poliovirus is involved in PPMA it clearly is not causing a disease at all related to the original paralysis.

There is a recent claim that PPMA patients have an abnormality in the antibody (a component of the immune response) in their spinal fluid. It is uncertain what the cause of this abnormal response is, but some investi-

POST-POLIO RESEARCH (continued)

gators suggest that the poliovirus triggers an abnormality of the immune response. We now know that viruses can cause disturbances of the normal immune response and, at times, lead to autoimmune diseases. In autoimmune diseases, the patient's immune system no longer recognizes the body as "self" and attacks it like a transplant patient rejects a foreign organ. Again, although we do not have evidence that poliovirus can trigger immune abnormalities, I think it is important to consider this possibility and its relationship to PPMA.

My research is directed toward a better understanding of the relationship of poliovirus to PPMA. I am specifically searching for subtle evidence of the virus' presence in PPMA tissue. In addition, we are trying to confirm the report claiming an abnormal antibody response in the spinal fluid of PPMA patients. If we find this antibody, we will use new techniques to try to find the target against which the antibody is directed. Lastly, we are studying a mouse virus closely related to poliovirus which causes a persistent nervous system infection. We hope we will understand more about the biology of poliovirus by studying this experimental mouse model.

It is only through basic research that diseases can be understood and treated. Burnet, a famous immunologist, summarized the extreme pessimism regarding control of poliovirus by writing in 1945 that "the practical problem of preventing infantile paralysis has not been solved. It is even doubtful whether it ever will be solved." Research breakthroughs and the development of the polio vaccine in the early 1950s made acute poliomyelitis a rarity. We hope that similar breakthroughs will make PPS a treatable and preventable entity.

Address: Raymond Roos, MD, Post-Polio Clinic, University of Chicago, BH Box 425, 5841 S. Maryland Ave., Chicago, IL 60637. 312/702-6221.

Easter Seal Awards New Grants for Post-Polio Study

In April, the Easter Seal Research Foundation awarded a \$25,000 grant to Augusta Alba, MD, Goldwater Memorial Hospital, New York, to study the treatment of sleep disturbances in polio survivors with the use of intermittent positive pressure ventilation.

It also awarded Raymond Roos, MD, University of Chicago Medical Center, a \$25,000 grant to analyze neuromuscular function of polio survivors diagnosed with PPMA.

August 1 is the next deadline for submitting grants to the Easter Seal Research Foundation, Rita McGaughey, 2023 W. Ogden, Chicago, IL 60612.

Motor Unit Size in PPMA

Mark Bromberg, MD, PhD, Neuro-muscular Fellow, University of Michigan Medical Center, received a fellowship from the World Rehabilitation Fund for a one-month study with Erik Stalberg, MD, of Uppsala, Sweden.

Bromberg investigated single fiber EMG, macro-EMG, and scanning EMG techniques to study motor units and why these units fail in persons with PPMA.

Address: Mark Bromberg, MD, PhD, University of Michigan Medical Center, 1500 E. Medical Center Dr., 1C327/0032 University Hospital, Ann Arbor, MI 48109.

NEEDED: USED ORTHOPEDIC AND VENTILATORY EQUIPMENT

Douglas Hewitt, a volunteer with Project Projimo, a nonprofit organization working with people with disabilities in Western Mexico, is collecting all types of orthopedic and ventilatory equipment to be redistributed and reused by people in rural Mexico.

Any kind of brace, cane, crutch, or other orthotic device, pneumo-belt, or chest cuirass in good condition, but no longer needed or used, may be sent or shipped to Hewitt at 14695 Poncho Conde Circle, Box 128, Rancho Murieta, CA 95683. 916/354-2924.

POST-POLIO BIBLIOGRAPHY

Recently published:

"Vaccine-Associated Paralytic Poliomyelitis" by Benjamin Nkowane, Steven Wassilak, Walter Orenstein, Kenneth Barth, Lawrence Schonberger, Alan Hinman, and Olen Kew. Journal of the American Medical Association, March 13, 1987, Vol. 257, No. 10. Pages 1335-1340.

"The PolioPlus Challenge." The Rotarian. April 1987, Vol. 150, No. 4.

"After the Epidemic: The Long-Term Impact of Poliomyelitis" by Joseph Kaufert and Patricia Kaufert in Health and Canadian Society by Coburn, et al. Fitzhenry & White-side, c1987.

**NATIONAL ODD SHOE EXCHANGE
BACK IN BUSINESS IN PHOENIX**

Write or call Jeanne Sallman,
P.O. Box 56845, Phoenix, AZ
85079. 602/246-8725.

87-YEAR OLD BRITISH POLIO SURVIVOR

(Reprinted from The Bulletin of the British Polio Fellowship, February, 1987.)

Betty Harris was born on January 1, 1900, and contracted polio at 6 months old. After nine operations and a long time in the London Orthopaedic and Great Ormond Street Hospitals, she was left with her left leg completely paralysed from toes to hip, a weak right leg, and curvature of the spine.

Betty started work at age 14 at a dairy firm with hours from 8:30am to 6pm daily, and 8:30 am to 12:30pm on Saturdays. After a bout with rheumatic fever, her doctor said she would not survive another English winter. An uncle in Cape Town provided her fare to stay with him and his family.

She stayed 12 years, only returning to England when spinal trouble set in. By then, she was using a wheelchair, but that did not stop her travelling. In 1972, she went to New Zealand, undaunted by a flight of 13,000 miles.

Arthritis has now caused much pain in her legs, hands, and arms, so Betty doesn't travel, content to live in a ground floor flat with a view of Torquay Harbour. She says, "I have never let disablement interfere with my life."

**AUDIO & VIDEO TAPES OF POLIO
CONFERENCE IN ST. LOUIS**

Order forms for audiotapes and half-inch VHS or Beta videotapes of G.I.N.I.'s Fourth International Polio & Independent Living Conference, June 4-7 in St. Louis, are available from G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108.

EXCERPTS FROM DR. JACQUELIN PERRY'S GENERAL INFORMATION LETTER
FOR POLIO SURVIVORS

The basic problem is that poliomyelitis destroyed some of the muscle fibers and thus the remaining musculature has had to function at a higher demand than normal. As a result, the muscles are wearing out earlier.

Qualitative measurements of different grades of paralysis demonstrated that our manual muscle tests have overestimated the amount of recovery.

The post-polio "normal" strength is at least 25% less than true normal and may even lack 40%. Similarly, the group graded "good" is only 40% of normal. These strengths are still adequate for a person to carry on customary activities in a normal fashion but at a demand that is twice the usual intensity. Hence muscles have been experiencing strain over all the years with gradual accumulation of stress.

The abrupt loss in the ability to function relates to two phenomena. First, all our physiological systems have a buffer zone that makes them able to accept strain for a considerable length of time without showing a frank loss. Once one exceeds the buffer limit, the loss is very prominent. Second, activity such as walking or lifting objects presents fixed mechanical demands. As long as one's muscle strength exceeds that demand even by 2% or 3%, a person can continue to perform in a usual manner, but if the strength goes below the essential limit - suddenly that function is lost.

The answer is redesigning one's lifestyle to avoid those activities that cause muscle strain, cramping, persistent fatigue, and, consequently, weakening.

Once the strain has been reduced, then cautious exercise may be of value. Do not take on the exercises, however, until a lifestyle that avoids the strain has been worked out. Also, if they cause any pain, persistent fatigue, or increased weakness, stop. This means just the mechanics of living are sufficient exercise for your muscles.

At the 1984 Warm Springs Research and Scientific Symposium on the Late Effects of Polio, Dr. David Bodian reported on the intensive polio research he did in 1945. He found that the poliovirus disappeared from the system in 3 weeks. Thus, there is nothing in the tissues to cause a second bout of polio. This again confirms the interpretation that today's problems are chronic strain of muscles whose strength was overestimated.

The advantage of having had poliomyelitis rather than some other disability is that it allowed one to resume very active and profitable lives for many years. Now it is necessary to recognize that excessive strain is being experienced and that lifestyles must be changed to accommodate this situation.

Address: Jacquelin Perry, MD,
Chief, Pathokinesiology Service,
Rancho Los Amigos Medical Center,
7601 E. Imperial Highway, Downey,
CA 90242. 213/940-7177.

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1987 CALENDAR

September 12. Post-Polio Conference. Oakbrook Marriott. Contact: Roberta Simon, RN, 7835 Pine Pkwy., Darien, IL 60559. 312/969-0287.

September 18-19. Post-Polio Conference. Westlake Holiday Inn, Cleveland, Ohio. Contact: Margaret Meyer, SIL, 25100 Euclid Ave., Suite 105, Euclid, OH 44117. 216/731-1529.

September 26-27. Crossing New Bridges II: Looking at the Effects of Polio Then and Now. Medical College of Wisconsin, Wauwatosa. Contact: Beth Fennigkoh, 5109 Russell Ct. East, Greendale, WI 53129. 414/421-9522.

October 2. Maine Post-Polio Conference. Contact: Dorothy Woods hmith, 188 Pride St., Westbrook, ME 04092. 207/797-5695.

October 9-11. Living Longterm with Disability. Los Angeles. Contact: Martha Griswold, ACSW, LIV Center, 943 E. Altadena Dr., Altadena, CA 91001. 818/798-5320.

October 20. Annual Meeting of the American Congress of Rehabilitation Medicine and American Academy of Physical Medicine and Rehabilitation: Post-Polio Seminar. Marriott's Orlando World Center, Florida. Contact: Fay Kaye, ACRM, 130 S. Michigan, Chicago, IL 60603. 312/922-9366.