

Polio Network News

Fall 1985

Vol.I. No.1.

A national newsletter for post-polio support groups, physicians and health professionals, and resource centers to exchange information, to encourage research, and to promote networking among the post-polio community.

Editors: Robert Gorski, Deborah Brewer. Guest Columnist: Harriet Bell.
Publishers: Gini Laurie, Judith Raymond, Gazette International Networking Institute (G.I.N.I.)

COMING TO TERMS WITH MEDICAL TECHNOLOGY

By Richard Owen, M.D. & Jennine Speier, M.D., Sister Kenny Institute

The Post Polio Task Force chose the term "post polio sequelae" to identify the variety of new experiences associated with additional disability in people who had acute poliomyelitis years ago. There is a wide range of probable interacting origins to these new problems.

In some instances, there seems to be nothing more than a gentle decay of function with change in life-style and/or aging. Marginal muscles underused and under-challenged become weaker. Overused and abused musculature may suddenly weaken in response to repeated stress beyond the limiting strength and endurance of the muscles.

Compensatory and adaptive mechanisms may be vulnerable to aging and deconditioning. Muscle shortening and contracture may restrict mobility, cause pain, and unbalance delicate adaptations in paretic limbs. Cardiopulmonary decondition predisposes to poor endurance, muscle fatigue, and pain.

Bulbar involvement may result in disturbed breathing, swallowing, and sleep patterns. Loss of chest wall elasticity may result in need for ventilatory assistance in people who were once on a respirator. Theoretically, latent or lurking viruses, genetic predisposition to additional neurologic disease, distorted immune mechanisms, and premature aging have all been implicated.

We have had the opportunity to review medical records on many of the patients seen in our clinic. In spite of the rather wide margin of error associated with manual muscle tests, we have found that most additional weakness occurs in previously documented involved musculature. Muscles graded as normal manually in post-polio people often showed quantitative values that were actually 25-40 percent below expectations for age, sex, and activity.

With these facts in mind, we believe that current baseline evaluations should be obtained and remedial problems addressed. X-rays, electromyography, pulmonary function test, sleep tests, and stress tests might be required to shed additional light on new disability. New technology in

adaptive equipment, bracing, wheel-chairs, ventilators, and environmental controls may be introduced in order to reduce the impact of the additional disability.

The creation of support and network groups across the country should facilitate the development of understanding of "post polio sequelae" and encourage dissemination of research and management information.

Address: 800 E. 28th St. at Chicago, Minneapolis, MN 55407. (612) 874-4492.

LATE RESPIRATORY COMPLICATIONS

By D. Armin Fischer, M.D. Rancho Los Amigos Medical Center

Respiratory complications in polio survivors can and should be anticipated. If individuals had respiratory complications at the onset of polio, they are at greater risk for late complications. The simplest way of assessing this risk is by periodic measurement of the vital capacity.

Ideally, this should be obtained both in the upright position and in the recumbent position. When vital capacity drops below one liter, more frequent measurement may need to be obtained, and if one's cough is weak (due to poor abdominals), closer follow-up and greater awareness may be needed to anticipate problems.

One sign that has been observed in recent years in post-polios is "sleep-disordered breathing," also called "sleep apnea." This is associated with periods of obstruction of the throat during sleep by flabby throat muscles or sometimes by periods when the breathing center at the base of the brain shuts off for a minute or two.

Often the person who develops these symptoms may not be particularly aware of the problem, but may feel they had a restless night and may be tired and sleepy

at times during the day. If a spouse is present during the night, he or she may be aware of snoring and reduced breathing manifested by their bed partner. Once a diagnosis is established, a successful treatment program is usually available.

Evaluation of this problem may involve detailed sleep studies in a special laboratory environment which can measure the amounts of oxygen and carbon dioxide in a person's breathing, as well as record chest and abdominal movements during sleep. Sleep laboratories have facilities for very elaborate evaluations, but they are also very expensive. At times, however, they may be essential in making a correct diagnosis.

It may not always be necessary to go to the sleep laboratory, especially if a spouse can describe the sleep problems that occur. Sometimes a less detailed sleep study can be done with an ear oximeter and observation in a hospital environment over night. (An ear oximeter clips to the ear and - painlessly - measures oxygen in the blood flowing through the skin.)

Treatment for "sleep-disordered breathing" may require oxygen to be used during the night. Occasionally, a medication is found to be helpful. For people who continue to have upper airways obstructed, the use of continuous positive pressure applied over the nose has been useful.

For some people, a rocking bed may help. The use of a tank or shell at night can, however, aggravate the problem if the rate is too fast, causing a collapse of the upper airways during the negative pressure cycle. If obstructive sleep apnea does not respond to these approaches, a tracheostomy may be necessary. This would be necessary only as a last resort. Most night breathing problems do respond to one or more of the above remedies.

Address: 7601 E. Imperial Hwy., Downey, CA 90242. (213) 922-7556.

POST-POLIO CLINICS: ESTABLISHED AND EMERGING

Spalding Hospital, Denver

Dr. Y. S. Franotovic, a specialist in physical medicine and rehabilitation, directs post-polio services at Spalding, and is a clinical instructor in the Department of Physical Medicine and Rehabilitation at the University of Colorado Health Sciences Center.

"I've treated acute polio patients in Europe and, consequently, I've taken a special interest in providing information and treatment for this new rehabilitation issue with post-polio persons," Franotovic said. "During the past year we've found that there's a great need for both inpatient and outpatient programs. I hope that in the future medical insurance companies will provide adequate coverage, as many post-polio persons would benefit."

Beginning in August 1984, Spalding sponsored several support group meetings to determine how many people in the Denver area needed services and how best to help them. Monthly screening seminars started in March, and these seminars teach about the cause, symptoms and treatment of polio's late effects. Participants meet with a physician, and occupational therapist, and a physical therapist for assessment and receive written evaluations of their physical condition and recommendations for improvement, if appropriate.

For people referred from the seminars, Spalding offers a series of four workshops to help with coping mentally as well as physically. Workshops address problems most commonly associated with late effects and how to prevent them; proper body mechanics for reducing risk of injury and for conserving energy; postural and breathing exercises; nutrition; and how to cope emotionally.

According to Jenny Weis, a physical therapist at Spalding,

"The latter part of July is the target date for beginning a post-polio reconditioning program of swimming sessions and exercise classes. Therapists will supervise participants for three or four sessions depending on individuals needs. After that we hope everyone will continue on their own with what they've learned in the program." Address: 1919 Ogden St., Denver, CO 80218. (303) 751-9800.

The University of Wisconsin Hospital at Madison (From COPH Bulletin, April 1985)

The long-term care needs of the post-polio population are of special interest to the Rehabilitation Center multidisciplinary team at the Hospital Rehabilitation Services of the University of Wisconsin. In response to individuals with post-polio, the Rehabilitation Center offers outpatient clinic services designed to meet special needs.

The Polio Clinic evaluation includes assessment of current medical status and functional level. The professional staff providing these services include a physiatrist (a physician specializing in physical medicine and rehabilitation), a nurse clinician, a registered respiratory therapist, and a physical therapist.

Specific procedures and services include: scoliosis X-rays, muscle testing, mobility evaluation, joint contracture measurement, chest X-rays, pulmonary function studies, equipment evaluation, and influenza and pneumonia vaccination.

After assessment is completed, each individual case is reviewed and findings discussed with the patient. Also, recommendations regarding health care program changes or additions are discussed and included in a written summary report sent to each patient.

Follow-up appointments are scheduled as needs require, usually on an outpatient basis.

It is the multidisciplinary team's objective to provide clear and appropriate medical information and care to all individuals attending this clinic.

Address: Highland Avenue, Madison, WI 53792. (608) 263-6542.

The National Rehabilitation Hospital, Washington, D.C.

(From P-POLIO Newsletter, May 1985)

The post-polio community received good news this spring. Dr. John Goldschmidt, medical director of the new National Rehabilitation Hospital, expressed strong interest in developing a model treatment center for the care of persons with post-polio. Our organization has

requested that the program provide a complete work-up to include neuromuscular, cardiovascular, and respiratory evaluations.

In addition, the model treatment center would evaluate the effectiveness of different treatment plans, track common patterns of symptoms, and refer appropriate candidates to research projects on the late effects of polio.

The opening of the hospital is scheduled for November, 1985. Located on the campus of the Washington Hospital Center, the National Rehabilitation Hospital will incorporate and deliver the most advanced concepts in rehabilitation medicine, and it will also be a teaching facility to train students, residents, and allied health professionals in rehabilitation medicine.

Address: 106 Irving Street, NW, Suite 101, Washington, DC 20010. (202) 726-6100.

POLIO INFORMATION CENTERS

SUPPORT GROUP LISTINGS AVAILABLE FROM G.I.N.I.

An updated list of all the support groups, post-polio clinics, and resource persons knowledgeable about post-polio problems is available from Gazette International Networking Institute (G.I.N.I.).

The number of support groups has increased and spread since the Gazette's polio conference in May 1985.

Readers are asked to send names of new groups, clinics, etc. to Judith Raymond at G.I.N.I. Corrections are also appreciated.

The list is computerized, and easily and frequently updated. Anyone requesting the list is asked to send a stamped,

self-addressed envelope to G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. (314) 361-0475.

WARM SPRINGS

The Roosevelt Warm Springs Foundation is developing a national polio registry to enable the Foundation to keep polio survivors, medical personnel, and other interested persons informed on polio issues.

Registrants will periodically receive a newsletter with information on the late effects of polio, research and studies, and polio survivor groups.

The registry will also serve as a database for clinicians and

researchers, but only if the registrant is willing to be contacted by them.

There is no charge for this service. To have your name included, write or call Betty Baxter, 3384 Peachtree Rd., N.E., Suite 306, Atlanta, GA 30326. (404) 655-3321, ext. 3462.

An alumni association is being formed at Warm Springs. Tamara Bibb is trying to locate former polio patients, family members, or staff members of the Roosevelt Warm Springs Institute for Rehabilitation.

The alumni association is also planning to hold a conference in 1986 on the late effects of polio.

To join the association, contact Marge Smith, Dir. of Special Services, RWSIR, Box 1000, Warm Springs, GA 31830, (404) 655-3321.

WE'RE NOT ALONE ANY MORE

By Harriet Bell

After three international post-polio conferences, several regional conferences, the Warm Springs Symposium, several books and some research, we know a lot more than we did five years ago about the problems now being experienced by people who had polio.

Five years ago, individuals scattered across the country, were having problems and began looking for answers. Most people thought that they alone were in trouble. No longer was there the March of Dimes or any other organization to help them. People turned to doctors for help, but many of them had never treated polio.

Perhaps it was that segment on NBC Prime Time Saturday in 1980, about polio and the new problems people are experiencing that first convinced us that we were not alone.

Conferences now have generated interest at every level: individuals who had polio, physicians,

and health care professionals. We are reaching out to one another, and establishing support groups. More than 50 support groups are sharing information resources and new developments. It is encouraging, but it is not enough.

We need to reach more post-polio people and find out what their needs are and how they can be helped. Physicians and all health professionals need up-to-date information. Our support groups can help by distributing pertinent information through this newsletter.

I am completing a study intended to show the approximate number of people we are now reaching as well as the services being offered by support groups, information on funding, methods of reaching out, and suggestions for national organizations. Address: Polio Information Center 510 Main St., Suite A446, Roosevelt Island, New York, NY 10044. (212) 223-0353.

RESEARCH

EASTER SEAL FOUNDATION GRANTS FOR POLIO RESEARCH

Muscle weakness in post-polio individuals.

Theodore Munsat, M.D.
Dir., Neuromuscular Research
New England Medical Center
Boston, Massachusetts

Frequency/risk factors of individuals in Rochester with polio 30-50 years ago.

Leonard Kurland, M.D.
Chair, Dept. of Medical
Statistics & Epidemiology
Mayo Clinic
Rochester, Minnesota

SUPPORT GROUPS AROUND THE COUNTRY

Downey, California

Richard Daggett is the president of the Polio Survivors Association. 1985 is the tenth anniversary year of the Association. In his remarks in the January-February 1985 PSA newsletter, Daggett looks back at a decade of change in the disability community.

"Ten years ago, public awareness of the needs and rights of disabled persons was in its infancy. There were a few laws and regulations on public access, but they were not well known and seldom enforced. The independent living movement was just getting started. Since then we have seen the International Year of the Disabled, disability related events in the Olympics, and increasing coverage by the media. Some developments were superficial, but many advances have been made -- in substance, and in image.

In our own arena of post-polio, the changes have been even more pronounced. In 1975, unless you were directly involved, polio was something from the distant past. Most of the clinics and medical centers that had seen polio outpatients on a regular basis were closed, or concentrating on other endeavors. Doctors familiar with polio were retiring. And this was happening at a time when many of us were beginning to experience some new problems associated with long-term disability.

In addition, those with the most severe disability faced the strain of trying to live with dignity on insufficient funds and incomplete support programs. Programs for personal attendant care were inadequate, and in some areas were unavailable. There were few reliable or affordable transportation services that would handle wheelchairs and none for the respirator dependent. Shopping, banking, even visiting were virtually impossible.

This was the situation ten years

ago when a handful of post-polios, assisted by Richard Carman, a southern California businessman, met to form what has become the Polio Survivors Association. These first few were mostly "alumni" of Rancho Los Amigos Hospital, and the hospital staff helped to identify polios in the area. Most were severely disabled, and many were respirator dependent. The Board of Directors of the new organization succeeded in convincing government agencies that additional funds were needed if these respirator dependent individuals were to remain outside of the institutions. Special transportation was also begun. In 1978 the Polio Survivors Foundation was established to raise funds from the private sector to provide emergency assistance.

From the original handful of members the Association has grown to several hundred across the United States and Canada, and the special needs of those with long-term disability are beginning to be addressed. Many polio clinics are reopening, and research is being done at several locations. Conferences have brought together a large number of post-polios and health care professionals. This shared knowledge will benefit us all.

While much remains to be done, an increasing awareness and commitment is evident. Working together we can be a positive influence. I'm looking forward to our second decade."

Address: 12720 La Reina Ave.,
Downey, CA 90242. (213) 923-0034.

Philadelphia, Pennsylvania

On June 26, a press conference was held by the Delaware Valley Post-Polio Survivors Association and proposed legislation was announced to serve Pennsylvania citizens who have been affected by polio.

"The bill," reports Arnold Snyder

of the Association, "has now been introduced in the Pennsylvania legislature and stands an excellent possibility of passage."

The legislation aims at amending the state administrative code to include the following section:

"The Department of Health shall have the power and its duty shall be:

(a) To investigate the subject of post-polio muscular atrophy, a deterioration of muscular strength suffered by persons previously afflicted with polio after having been seemingly stable for a long time.

(b) To study the number of persons who suffer from post-polio muscular atrophy, their ages, sex and other relevant factors and the period of time after having been afflicted with polio that symptoms appear.

(c) To compile all available information relating to post-polio muscular atrophy and make such information available to victims, together with any education material deemed helpful.

(d) To establish a single, statewide toll-free telephone number for use by persons seeking information relating to post-polio problems."

Address: 530 E. Vernon Rd., Philadelphia, PA 19119. (215) 844-5500.

Milwaukee, Wisconsin

The Post-Polio Resource Group of Southeastern Wisconsin has held monthly meetings since April that were each attended by over 40 people, and the group has a mailing list of over 100.

"The purpose of the group," explains its public relations person, Jo Simon, "is to conduct education programs and to provide opportunities for post-polio persons to support each other."

Monthly meetings are convened at Curative Rehabilitation Center, part of Wisconsin Medical College.

The June meeting featured Dr. Jacqueline Wertsch who emphasized the individual nature of problems and the need for a team approach to evaluation - consisting of not only a physician but also a physical therapist, respiratory specialist, a social worker, and other allied health professionals.

At the July meeting, the ABC-TV "Nightline" program was shown that focused on the late effects of polio and featured interviews with Dr. Albert Sabin, the developer of the oral polio vaccine, and Dr. Richard Bruno, researcher at Columbia University Hospital.

During August, the group discussed special shoes and adaptive clothing. According to Jo Simon, the first part of the meeting is the education program, after which people divide into small discussion groups. "Many people say they are relieved to find others who are experiencing symptoms of late effects of polio - and they often say 'I'm glad to know I'm not crazy.'"

Address: 1000 N. 92nd, Milwaukee, WI 53226.

Little Rock, Arkansas

An effort to develop a support group in central Arkansas commenced last month with a letter to post-polio persons in the area drafted by Delbert Lewis, Margie Loschke, and Donna Norvell Smith. The letter included a copy of the Newsweek article on the late effects of polio and a brief questionnaire. "Recipients were also asked," says Delbert Lewis, "to provide any names and addresses of people known to have polio, as this information is not available through public records."

According to Lewis, the Hot Springs Rehabilitation Center is planning polio clinics in conjunction with a new service program through the Hot Springs Rehabilitation Center Hospital. The coordinator for the polio clinic is Buddy Carmack and

the clinic's address is P.O. Box 1358, Hot Springs, AR 71901.

"Another positive development," says Lewis, "is the interest shown by a local television station in news about the late effects of polio. The station has contacted us about doing a series of television segments and we are providing them with information and leads of other people to contact." Address: 9010 W. Markham St., Little Rock, AR 72205. (501) 227-0758.

Washington, D.C.

The Post-Polio League for Information and Outreach is a support group formed to serve the Washington, D.C., metropolitan area. Small discussion groups meet in Virginia, Maryland and the District of Columbia, and once a month there is a large general meeting with an educational program. In July, Dr. John Toerge, from the National Rehabilitation Hospital, discussed the role of exercise in the lifestyles of persons with post-polio. September's meeting features a panel that will explore the psychological aspects of coping with post-polio sequelae.

The two major grocery chains in the area, Giant and Safeway, placed posters about post-polio in all their stores in Maryland, Virginia, and the District of Columbia.

"Since then our office phone has not stopped ringing," says Debbie Brewer, president of the League. "In three weeks we have added two hundred new names to our mailing list.

"We are pleased with the response - and also concerned because it is obvious that many people are having problems. We are working hard to line up resources to meet the needs of our community."

Address: 5432 Connecticut Ave., N.W., Suite 204, Washington, DC 20015. (202) 244-5700.

Libertyville, Illinois

"The Northeastern Illinois Post-Polio Support Group meets at the Easter Seal Society of Lake County in Libertyville the third Wednesday of each month," reports Holly Donohue. "There are five other branches of this support group which meet in other areas of northeastern Illinois. We are working on our charter for nonprofit status.

"Our goals include: awareness, educational materials, seeking interested and knowledgeable physicians in the area of the late effects of polio, and sharing and exchanging ideas with other support groups.

"We distribute educational materials to 104 libraries and we also are designing pamphlets for distribution to area hospitals, doctors' offices, pharmacies, health clubs, and Social Security offices to explain the late effects of polio. These pamphlets are similar to those published by the heart, cancer, and other health organizations.

"We plan to solicit more newspaper, radio, and TV coverage to promote awareness. Our hope is to reach all polio survivors in Illinois."

Address: 2308 Marshall Pkwy., Waukegan, IL 60085. (312) 336-8261.

Lansing, Michigan

The Lansing Polio Survivors Support Group has been meeting monthly with a different information program each month. In April, according to Charlene Bozarth, the group's newsletter editor, a speaker talked about the PAM Assistance Centre, an agency which provides information about assistive devices.

The May meeting featured Judy and Eric Gentile speaking about the spiritual issues of being disabled, and the June meeting was a potluck dinner and entertainment affair.

A psychotherapy group completed

its scheduled ten sessions, and participants decided to go on meeting in order to continue addressing unresolved emotions related to polio 30 to 40 years after the onset of the disease.

A statewide organization called The Late Effects of Polio Coalition is planning an all-day conference for both health care professionals and polio survivors on October 21 in Lansing. The conference falls within "Polio Survivors Week, October 21-28," which has been approved by the state senate and awaiting action by the state lower house. In preparation for Polio Survivors Week, the Lansing group is planning educational exhibits at two area shopping malls. The exhibits are intended to tell the polio story, locate survivors, and encourage immunizations.

In another statewide development, the Senate Appropriations Subcommittee on Public Health has added \$10,000 to the budget of the Department of Public Health for assessing the needs of persons affected by the late effects of polio.

Address: 4815 Arapaho, Okemos, MI 48864. (517) 332-3789.

contradicts the long-held view that Roosevelt's disability is of small significance because it had little impact on his life following his rehabilitation in the mid-1920s. The prevailing view of Roosevelt, during his era and after, was that he was a "cured cripple."

With meticulous research, Gallagher looks behind the scenes at Roosevelt as governor of New York and as President for almost 13 years. FDR's Splendid Deception shows the tremendous influence that disability had on Roosevelt's physical abilities, emotional life, and daily activities. The book documents how the true extent and effects of Roosevelt's disability were assiduously and with practiced skill kept from the public.

It is Gallagher's premise, furthermore, that this "deception" was one in which the public fully participated and to which it assented. Writing of some of Roosevelt's acquaintances, Gallagher notes, "Many . . . will later deny that the President had much difficulty moving about."

Gallagher's many-faceted career has included studying at Oxford under a Marshall scholarship and five years as an aide to Senator Bartlett of Alaska, during which time Gallagher conceived and drafted the Architectural Barriers Act of 1968, the first such national law in this country and perhaps the entire world.

During the early 1970s, Gallagher was chief political officer for British Petroleum. He began his writing career with Etok: A Story of Eskimo Power and Advise and Obstruct: The Role of the United States Senate in Foreign Policy Decisions. Both books became book club selections.

Currently, Gallagher is a scholar at the Kennedy Institute of Georgetown University and is at work on a social history of disabled people.

A PERSON OF ACCOMPLISHMENT:
HUGH GALLAGHER

By Robert Gorski, Disabled USA

In spring 1985, a new book with a new perspective on Franklin D. Roosevelt called FDR's Splendid Deception was published by Dodd, Mead, & Co.

The author is Hugh Gregory Gallagher, a former Senate aide, and a person disabled by polio at age 19. Gallagher's 220-page book, with 18 rare photographs depicting the true extent of Roosevelt's disability, directly

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1985 CALENDAR

October 4-6. Living Longterm with Disability: Southern California '85. Holiday Inn Crowne Plaza LAX. Contact: Martha Griswold, Dir., LIV Center, 943 E. Altadena Dr., Altadena, CA 91001. (818) 798-5320.

October 21. The Post-Polio Experience. Sheraton Inn, Lansing. Contact: Kenny Michigan Rehabilitation Foundation, 21700 Northwestern Highway, Suite 1190, Southfield, MI 48075. (313) 569-8180.

October 26. Assessing the Needs of Post-Polio Persons: A Working Conference. Ramada Renaissance Hotel, Washington, D.C. Contact: Post-Polio League for Information and Outreach (P-Polio), 5432 Connecticut Ave., N.W., Suite 204, Washington, D.C. 20015. (202) 244-5700.

November 2. Post-Polio Sequelae. Registry Hotel, Minneapolis. Contact: Gail Olstad, Dept. of Research & Education, Sister Kenny Institute, 800 E. 28th St., Minneapolis, MN 55407. (612) 874-4300.

November 15. Polio Update: Strategies for-Coping with Severe Disability in Midlife. Howard A. Rusk Respiratory Rehabilitation Service, Goldwater Memorial Hospital. Contact: New York Easter Seal Society, 2 Park Ave., Suite 2000, New York, NY 10016. (212) 532-8830.

Deadline for Winter 1985/1986: November 15, 1985. Send news and articles to Robert Gorski, Disabled USA, 1111 20th St., N.W., Room 600, Washington, D.C. 20036. (202) 653-5011.
