

POLIO NETWORK NEWS

Spring 1986

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An international newsletter for polio survivors and support groups, physicians and health professionals, and resource centers, in order to exchange information, encourage research, and promote networking among the post-polio community.

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SOCIAL SECURITY ADMINISTRATION ON POLIO

"The Social Security Administration's (SSA) Office of Disability, responsible for developing and implementing medical criteria and other disability-related policies for determining an individual's eligibility for disability benefits under Social Security, is concerned about the new functional problems some polio survivors are experiencing.

"SSA wants to ensure that all medical and other professional personnel who adjudicate or review disability claims are fully aware of how to evaluate the late effects of polio on an individual's ability to perform basic work activities.

"Accordingly, a national reminder highlighting the guidelines for evaluating the late effects of polio will be issued to all personnel directly involved in the disability decision process. A draft of this reminder has been sent to selected polio researchers, clinic directors, and advocate groups for comment. Based upon those comments, the issuance will be revised, as appropriate, and then issued nationally to all personnel who adjudicate or review disability claims.

"The Office of Disability will also be meeting with Marge Torre, of the Philadelphia Post-Polio Support Group, and Gini Laurie, of G.I.N.I., to discuss polio issues. At this meeting, Torre plans to share with SSA the medical records and case histories she has collected to illustrate the types of new problems polio survivors are encountering.

"SSA is looking forward to this opportunity to discuss polio-related concerns and to take any action which may be necessary to ensure that the medical evaluation guidelines for evaluating polio under the Social Security disability program are as complete and accurate as they can be."

MEDICAL RECORDS NEEDED FOR SOCIAL SECURITY ADMINISTRATION MEETING

Marge Torre of the Philadelphia Post-Polio Support Group needs more case histories substantiated by medical records from polio survivors to document the effect of post-polio problems on polio survivors and their jobs. Torre will meet with representatives of the Social Security Administration later this summer.

The records can be anonymous. Torre CANNOT solve individual problems. Please send copies of case histories and medical records to Torre at 7921 Fairfield St., Philadelphia, PA 19152.

TED KENNEDY, JR. KEYNOTER AT 1987 POLIO CONFERENCE

Ted Kennedy, Jr., will be the keynote speaker at G.I.N.I.'s Fourth International Polio and Independent Living Conference, June 4-7, 1987 at the Sheraton St. Louis Hotel.

Kennedy will highlight civil rights for disabled individuals and celebrate the 10th anniversary of the implementation of the 504 regulations.

Gini Laurie, chairman of G.I.N.I., met Kennedy when they both participated in the First International Rehabilitation Conference in Beijing, China, in January 1986.

Laurie also met with Deng Pufang, son of Deng Xiaoping, the Chinese leader. Deng Pufang, who is paraplegic due to a spinal cord injury, is director-in-chief of the China Welfare Fund for the Handicapped. Deng Pufang is expected to attend the 1987 conference.

MICHIGAN SUPPORT GROUP OFFERS PSYCHOTHERAPY

The Polio Survivors' Support Group in Lansing, Michigan, offered a 10-week therapy group led by two psychotherapists focusing on the emotional stresses of the late effects of polio.

Everyone talked about the psychological trauma of his or her initial bout with polio 30-40 years ago and of coping with disability in the years that followed. The therapists pointed out that resolving the past is important because people tend to deal with current problems in the same way they dealt with problems in the past. If the previous pattern was depression or denial, the pattern may be repeated.

The polio survivors who participated in the group did not have severe disabilities. All but one were able to walk and otherwise function without any assistive devices, yet were having serious, long-standing emotional problems related to their initial polio experience.

Russell Scabbo, Ph.D., Michigan State University in East Lansing, concluded in his doctoral dissertation that persons with less severe physical disabilities suffer from stresses largely unrecognized and caused by a capacity for denial, high expectations of performance from others, and lack of belonging in either the nondisabled world or the disabled world.

For more information write Charlene Bozarth, 4815 Arapaho, Okemos, MI 48864.

POST-POLIO RESEARCH

Easter Seal Research Foundation will review five proposals on post-polio in May. The grants begin July 1, 1986.

Easter Seal awards \$25,000 per year up to a maximum of three years. The next deadline for proposals is August 1, and should be submitted to Rita McGaughey, Associate Director, Easter Seal Research Foundation, 2023 W. Ogden, Chicago, IL 60612.

Easter Seal has awarded grants to Dr. Theodore Munsat, New England Medical Center, to study TRH (thyroid releasing hormone) as a possible treatment for post-polio weakness, and Dr. Leonard Kurland, Mayo Clinic, to study polio survivors with and without polio problems.

March of Dimes Birth Defects Foundation will review four post-polio proposals in July. The grants are for a one-year period.

March of Dimes is funding Dr. Munsat's study also. Dr. Lauro Halstead of T.I.R.R. was awarded a grant to evaluate the medical, neurophysiological, and biochemical assessments in post-polio.

Grant applications are still being accepted and should be sent to Dr. Samuel Ajl, Vice-President for Research, March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605.

The proposals which are finally accepted by each foundation will be detailed in the Summer issue of Polio Network News.

POST-POLIO HIGHLIGHTED IN MEDICAL JOURNALS, ENCYCLOPAEDIA

Journal of the American Medical Association, March 21, 1986, Volume 255, No.11, featured two articles by Chris Anne Raymond, Ph.D., on post-polio problems: "Decades after polio epidemics, survivors report new symptoms," pp. 1397-1399, and "Polio survivors spurred rehabilitation advances," pp. 1403-1404.

New England Journal of Medicine, April 10, 1986, Volume 314, No. 15, pp. 959-963, featured an article by Marinos Dalakas, M.D., "A long-term follow-up study of patients with post-poliomyelitis neuromuscular symptoms." Co-authors are: Gregory Elder, Mark Hallett, John Ravits, Michael Baker, Nicholas Papadopoulos, Paul Albrecht, and John Sever.

The following article by Drs. Mary Codd and Leonard Kurland in the 1986 Medical and Health Annual published by Encyclopaedia Britannica is clear, concise, accurate, and an excellent summary of polio's late effects.

Epidemiological studies in Minnesota by Drs. Codd and Kurland cited in the article were supported by a grant from the Easter Seal Research Foundation.

Coverage in these most prestigious of American medical journals publicizes post-polio symptoms among the medical community. It also gives credence to what polio survivors have been telling their local physicians for the last few years. Kudos to JAMA, NEJM, and EB for highlighting the late effects of polio.

Polio's Late Effects

by Mary B. Codd, M.B., B.Ch., and Leonard T. Kurland, M.D., Dr. P.H.

For people of the Western world, mention of poliomyelitis evokes memories of epidemics of a dread paralytic disease that occurred unpredictably during summer months but "disappeared" miraculously about 30 years ago with the introduction of effective vaccines. That poliomyelitis is a relatively new disease has been proposed by some medical historians, since epidemics of the disease were unknown before the mid-19th century. There is, however, considerable evidence to suggest that the causative agent of polio was widespread prior to the occurrence of epidemics.

Historical perspective

In its endemic (preepidemic) form, poliovirus reached all susceptible individuals, usually in the early months of life while the infant was still protected by maternal antibodies, resulting mostly in asymptomatic infection with subsequent development of lifelong immunity. Among the relatively few with manifest illness, mortality rates were exceedingly high, though some individuals with paralysis survived. Reports of such sporadic cases exist from the 17th and 18th centuries, one of the most credible of which comes from an autobiographical account of Sir Walter Scott.

The emergence of polio as an epidemic disease coincided with changing ways of life, in particular better sanitation and rising standards of living and hygiene. The consequent reduction in exposure to infectious agents that had afforded immunity led to an increase in the proportion of the population susceptible to the viral infection. Epidemic poliomyelitis was simply a new manifestation of an existing infection, brought about by environmental change.

Probably the earliest recorded epidemics were those that occurred in the 1830s in Worksop, England, and on the island of St. Helena. The earliest reported outbreak in the United States occurred in West Feliciana, La., in 1841. These were the harbingers of the epidemics that swept through Europe and North America in the late 19th and early 20th centuries. A most feared aspect of polio in those years was the inability to predict the occurrence of epidemics either in time or in place. Polio, therefore, became "the Sword of Damocles" that hung over every child and young adult in summer and early fall.

The development of effective vaccines represented the culmination of the 20th-century crusade against this devastating disease. In the years just preceding their introduction, reported cases of paralytic polio in the U.S. totaled 10,000 to 20,000 per year. Inactivated polio vaccine (Salk) was approved for general use in 1955, and its widespread use brought about a steady and dramatic reduction in the incidence of paralytic polio. Live attenuated polio vaccine (Sabin) became available in 1961, leading to a further reduction in annual incidence. From 988 paralytic cases in 1961, the average toll dropped to 20 per year by the mid-1960s.

Over the ensuing 20 years interest in this disappearing disease waned. New generations of physicians emerged with only textbook knowledge of the disease; healthy children no longer faced the prospect of being suddenly stricken by a crippling disease and, in the Western world, polio was relegated to oblivion, a chapter of medical history.

New perspectives on an "old" disease

In 1979 the *Rehabilitation Gazette*, an international publication established in 1958 as an advocate for rehabilitation and independent living for disabled persons, carried an article by a former polio victim entitled "Those Passing Years," in which he chronicled his increasing fatigue and muscle weakness of recent years. As reactions poured in, it became apparent that many other postpolio individuals were experiencing similar difficulties. Having achieved a maximal functional recovery level in the months and years following the acute infection, they had successfully maintained this level for many years but more recently had begun experiencing a gradual deterioration in functional capacity. This was a new perspective on an "old" disease, a disease survivors believed they had conquered through sheer willpower and endurance.

What is now being described in the aftermath of paralytic poliomyelitis is not, however, a new disease. The occurrence of additional muscle weakness and atrophy many years after an acute episode of paralytic polio was first reported in the medical literature in 1875. Well-documented cases were reported in 1903, 1935, and at various other times up to the present by many investigators. Why, then, have postpolio prob-

lems become recognized more widely only in recent years?

Examination of the annual incidence rates of reported poliomyelitis from 1900 to 1955 reveals a generally increasing trend, most marked in the '40s and '50s and culminating in an unprecedented rate in 1952, when 56,000 cases were reported to the U.S. Public Health Service. Concomitant with the rising incidence rate was an increase in survivorship, due predominantly to refinement of respiratory equipment over time. Thus, thousands of individuals affected by polio as children or young adults are now entering their middle years. Some are experiencing new polio-related problems, and simply by weight of numbers they are providing a new perspective on a problem that has been documented in the medical literature for over a century.

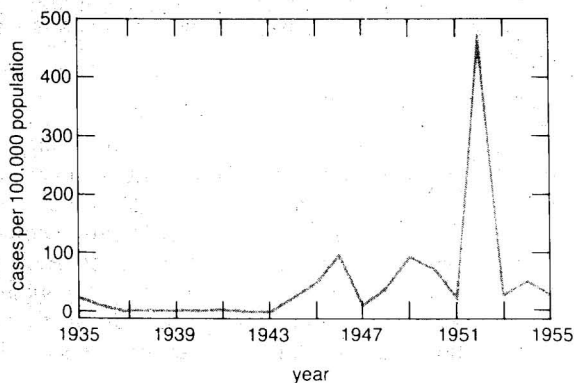
Postpolio symptoms

There is some diversity of opinion among health professionals as to whether postpolio symptoms represent a clinical entity sufficiently specific and sufficiently different from other neurological or systemic disease entities to be characterized as distinct. The designation "distinct clinical entity" demands that certain specifications be established and met. Thus, the entity should have certain characteristic features, deserves a specific title, and should have established criteria by which the diagnosis can be made. Having thus established the unique nature of the disorder in question, epidemiological and pathological features should be explored and the composite information channeled into the development of effective treatment regimens.

The specific complaints of those postpolio individuals experiencing new health problems show remarkable consistency. Usually insidious in onset, a gradual

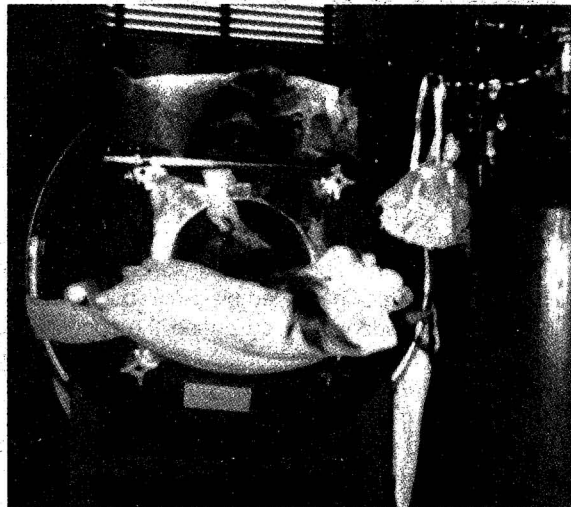
An epidemiological study of annual incidence of polio in residents of Rochester, Minnesota, revealed rising rates in the 1940s and early 1950s, culminating in an unprecedented peak in 1952, prior to the availability and use of vaccines.

Annual polio incidence in Rochester, Minnesota



Mayo Clinic, Rochester, Minnesota

Courtesy, Barbara Whitney



(Above) Polio patient in iron lung in 1949. Many survivors of polio epidemics are now experiencing symptoms such as fatigue, weakness and pain of joints and muscles, and respiratory difficulty some 25-30 years later.

deterioration in functional capacity is characterized by excessive fatigue, slowly progressive muscle weakness with or without some decrease in muscle bulk, and occasionally muscle pain and/or troublesome muscle twitching (fasciculation). The additional weakness usually involves muscle groups or limbs bearing residual weakness from acute polio, though unaffected muscles or those originally involved but recovered may also be affected. Persons with involvement of their respiratory muscles may become aware of increasing difficulty with breathing, particularly during sleep or with exertion. Other complaints include increased joint pain and increased joint or skeletal deformity with its attendant problems.

Classifying the symptoms

The question of appropriate nomenclature for the late effects of poliomyelitis now being observed has yet to be resolved. Various terms have been proposed, among them progressive postpoliomyelitis muscular atrophy (PPPMA), postpolio syndrome, late effects of polio, or postpolio sequelae. None of these accurately describes or encompasses the constellation of symptoms reported by affected individuals. Currently a classification of symptoms according to clinical manifestations may be the most useful.

Symptoms that may be related to previous poliomyelitis and its sequelae appear to fall into two categories. The first of these includes those with a definable cause, perhaps related to deformities of joints, limbs, or trunk (for example, scoliosis), which may cause degenerative arthritis, pain, nerve entrapment, or mechanical problems. The second category of symptoms involves those without a readily identi-

able underlying mechanism, manifest as a new, slowly progressive muscular weakness with or without additional muscle pain, atrophy, or fasciculation. Evidence of a systemic disease or neuromuscular disorder other than polio, the symptoms of which may mimic or exacerbate postpolio problems, should be sought. These latter conditions may be amenable to effective forms of therapy.

The most appropriate nomenclature for any disease entity is one that evolves over time, accommodating changing concepts about the disease. The term poliomyelitis was itself preceded by generations of terms, each of which adequately described the condition for a time but was found inadequate in the light of subsequent discoveries. Thus, early terminology described the outward manifestations of the disease. In 1789 it was described as a "debility of the lower extremities." In 1843 it was called "morning paralysis." French authors of the 1850s described "*paralysie essentielle chez les enfants*," later anglicized to "infantile paralysis." With the recognition of the underlying pathological processes, involving certain anterior cells of the spinal cord, came the term acute anterior poliomyelitis. As with the evolution of the term poliomyelitis, the recognition of the pathological processes involved in late manifestations of the disease, which are currently being recognized and described, may ultimately suggest more appropriate terminology than that to which we are presently confined.

Diagnostic criteria

What are the criteria by which the diagnosis of so-called PPPMA, postpolio sequelae, or late effects of poliomyelitis can be established? The following have been proposed: (1) a credible (and preferably documented) history of poliomyelitis; (2) partial recovery of function; (3) a minimum ten-year period of stabilization of this recovery following acute polio; and (4) the subsequent development of progressive muscular weakness for which there is no identifiable cause other than polio.

These criteria are based essentially on the accuracy of historical records and personal recall, on the subjective interpretation of symptoms by the patient, and on their objective interpretation by the attending physician. There is no serological, electrodiagnostic, or other mode of investigation that, if positive, is regarded as definitive for the diagnosis of late progression of paralytic poliomyelitis. Yet criteria such as those outlined above, or modifications thereof, need to be established, accepted, and uniformly applied before comparisons between groups and individuals can be made.

Epidemiological features

What proportion of the survivors of the polio epidemics are experiencing new polio-related problems? Ideally, one needs to know the present health status of all

Dan Ford Connolly—Gamma/Liaison



Lauro S. Halstead, a rehabilitation specialist at the Baylor College of Medicine in Houston, Texas, is among the experts who are studying the so-called postpolio syndrome. Halstead himself is affected by late-occurring symptoms.

postpolio individuals in order to answer this question accurately. Estimates of the number of survivors of the epidemics in the United States vary, with 300,000 being the most commonly quoted figure. Determining the present health status of all 300,000 becomes an awesome task. A limited answer to the question has been provided by a population-based epidemiological study of polio conducted at the Mayo Clinic, Rochester, Minn.

By means of a centralized records-linkage system at the Mayo Clinic, all individuals who contracted paralytic poliomyelitis from 1935 to 1955 and who were residents of Rochester were identified and traced. Follow-up questionnaires, aimed at determining the present health status of those still living, indicated that about 25% have new health problems probably related to their previous poliomyelitis.

This and other surveys recently conducted suggest that symptoms occur an average of 25 to 30 years after acute polio and are probably directly related to the severity of initial involvement. The relationship of symptoms to gender, poliovirus type, age at onset of polio, or an individual's natural aging process is less clear.

Reasons for the late polio symptoms

The cause or causes of functional deterioration in postpolio individuals is unknown. Various pathogenetic mechanisms have been proposed. Speculation that there may be persistence of the poliovirus, with increasing symptoms being due to recrudescence of the illness, has not been substantiated by experimental studies. Limited evidence for a role of an immunopathological mechanism comes from a study by

investigators at the U.S. National Institutes of Health. These results have yet to be verified, however, in larger series of patients. Receiving some acceptance is the hypothesis that lifelong excessive demands on normal muscles to compensate for those weakened by polio may result in an overwork weakness or a new lesion of these muscles.

By far the most credible theory to date, however, is that symptoms may be a function of "premature aging" in the polio patient. A component of the aging process in normal individuals is attrition of motor neurons. This seems to occur throughout life, more slowly in early than in later years, to a total loss of about 30% of one's original motor neuron population. The effect in most people is imperceptible. In the postpolio person, however, the gradual loss superimposed on the original loss of motor neurons due to poliovirus infection may result in weakness hitherto unrecognized. A second possibility is that certain anterior horn cells (the cell bodies of motor neurons) of the spinal cord, although they survived and remained functional after the acute attack, may have been damaged, rendering them less able to withstand the ravages of time and age. It is conceivable that present observations on the proportionate frequency of new polio-related symptoms may represent the "tip of the aging phenomenon" among the postpolio population. Thus, as the population of former polio patients ages, the present estimate of 25% may change. Reappraisal of this estimate requires that prospective evaluations be conducted, preferably utilizing some objective measurements of changes over time.

Treatment and prognosis

An essential component of the management of postpolio problems is general medical evaluation. Although there is no evidence to suggest that common medical conditions occur with greater frequency in postpolio individuals than in the general population, an additional medical problem may contribute to reduced functional capacity.

While early recognition, corrective procedures, and increased usage of assistive devices can do much to alleviate the distress caused by certain musculoskeletal residua of poliomyelitis, effective treatment regimens to arrest or reverse progressive muscle weakness are less clearly defined. Development of such regimens is contingent upon recognition of underlying pathogenetic mechanisms and identification of suspected risk factors. Nonetheless, promising results have been obtained by clinicians and researchers with expertise in the area of exercise physiology and rehabilitation.

Muscles deconditioned by years of underuse can be effectively reconditioned by exercise regimens carefully tailored to the individual's requirements and functional ability. Even within these conditioning programs, individuals are advised to exercise within their limits of

comfort and capacity. In addition, some people have gained from detailed attention to life-style, with adequate rest, prudent scheduling of both professional and social engagements, and avoidance of stress. There is no drug treatment that, to date, has proved to be effective.

These new symptoms described by some postpolio individuals do not represent a life-threatening illness. Neither does it follow that all postpolio individuals will eventually experience one or more of these symptoms. Most important, perhaps, there is no evidence, either from clinical or from experimental studies, to suggest that loss of function many years after polio is analogous to or suggestive of more serious motor neuron disease, such as amyotrophic lateral sclerosis (ALS) or other neuromuscular diseases.

Future perspectives

Research into late effects of poliomyelitis is in an embryonic phase. The first meeting of clinicians and scientists with an interest in postpolio problems was held in Georgia in May 1984. The objectives of the symposium were to establish current concepts about polio-related problems and to set forth research objectives for the coming years. Further epidemiological, clinical, and experimental studies, preferably prospective in design, will be needed for the accurate determination of the scope of the problem, potential risk factors involved, the most appropriate regimens of management, and the clarification of underlying pathogenetic mechanisms.

That poliomyelitis is an ongoing problem is true not only for those individuals in developed countries now experiencing new polio-related problems but also for the many thousands of people worldwide who contract paralytic poliomyelitis each year. Regarded as conquered in the Western and industrialized world, acute poliomyelitis remains a major public health problem in tropical and less developed areas. In 1981—the most recent tally—just over 47,000 cases of paralytic polio were reported to the World Health Organization from countries representing about 80% of the world's population. It is estimated that the number of unreported cases is several times that of reported cases, with a major toll in disability and death. A possible explanation lies in a shift from an endemic to an epidemic pattern of the disease, concomitant with the adoption by less developed countries of a "Westernized" way of life and analogous to what occurred with poliomyelitis in 19th- and 20th-century Europe and North America. To borrow a phrase from Albert Sabin, one of the polio vaccine developers, "The conquest of polio represents unfinished business." The objective of eradicating poliomyelitis presents a major challenge to the scientific and administrative resources of the world, a challenge that must be won if poliomyelitis is truly to become a curiosity of medical history.

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CALENDAR

G.I.N.I. is maintaining the calendar of polio seminars, workshops, conferences, etc. If you are planning anything, please check with Judith Raymond, (314) 361-0475, before you finally set your date - there have almost been conflicts in local and regional areas. Send Calendar notices to Judith Raymond, G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. (314) 361-0475.

1986

June 5-7. Polio Support Group Leaders' Workshop. Sheraton St. Louis Hotel, St. Louis, Missouri. Contact: Judith Raymond, G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. (314) 361-0475.

June 27. Second Annual Post-Polio Conference. Yale Inn, Meriden, Connecticut. Contact: Kathy Biglin, Gaylord Hospital, P.O.Box 400, Gaylord Farms Rd., Wallingford, CT 06492. (203) 269-3344.

August 9. Polio Polio Seminar. Holiday Inn-Haywood, Greenville, South Carolina. Contact: Gibson Bailey, Director of Continuing Medical Education, Roger Peace Rehabilitation Hospital, 701 Grove, Greenville, SC 29605. (803) 242-7814.

October 4. Post-Polio Conference. Sheraton-Airport, Pittsburgh Pennsylvania. Contact: Mike Kalogeras, 411 Anawanda Ave., Pittsburgh, PA 15228. (412) 344-7137.

October 11. Post-Polio Conference. Galt House, Louisville, Kentucky. Contact: Rita Whitt, 3200 West Muddy Branch, Ashland, KY 41101. (606) 836-2137.

1987

June 4-7. G.I.N.I.'s Fourth International Polio and Independent Living Conference. Sheraton St. Louis Hotel. Contact: G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108. (314) 361-0475.

Deadline for Summer 1986: July 4, 1986. Send news items to:
G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108, Robert Gorski, 1111 20th St., N.W., Room 600, Washington, DC 20036, or Deborah Brewer, 8905 Oneida Lane, Bethesda, MD 20817.
