

Polio Network News

Poliomyelitis, Disease Overview

Many polio survivors now experiencing the late effects of polio have asked for information about the poliovirus and acute poliomyelitis. The following article is copied with permission from "Information on Poliomyelitis and Poliovirus Vaccine Live Oral Systemic." All rights reserved. ©1999 The United States Pharmacopeial Convention, Inc.

Poliomyelitis is a contagious disease occurring worldwide. It is caused by three types (serotypes 1, 2, and 3) of poliovirus, which is an enterovirus. The three serotypes are not cross-protective, which means that the individual must develop immunity to each type for complete protection against the disease.^{1,2} In countries where poliomyelitis is endemic, the disease often is caused by poliovirus serotype 1, less frequently by poliovirus serotype 3, and least frequently by poliovirus serotype 2.¹

Poliomyelitis can be transmitted directly by fecal-oral contact or indirectly by contact with infectious saliva or feces (or by contaminated sewage or water).^{79,86} Polioviruses enter the mouth and replicate in the oropharynx and intestinal tract.^{1,2} From there, the viruses are carried by the blood stream into the central nervous system (CNS), resulting in cell destruction of the motor neurons of the anterior horn and the brain stem.^{1,2} (The exact mechanism by which the CNS becomes infected, however, remains uncertain and controversial. A study involving transgenic mice expressing the human poliovirus receptor suggested that poliovirus spreads from muscle to CNS by means of peripheral nerve muscle fibers, rather than directly from the blood stream.)³ Motor function of the individual is therefore impaired while the sensory function remains unaltered.^{1,2}

Paralytic symptoms usually occur 7 to 21 days from the time of

initial infection (range is from 4 to 30 days). The period of communicability starts after viral replication, continuing as the virus is excreted in oral secretions and feces. Communicability ends when replication and excretion of virus cease, which usually occurs 4 to 6 weeks after infection. More than 90% of susceptible contacts become infected after household exposure to the wild poliovirus.¹

Poliomyelitis can be diagnosed by recovery of polioviruses from throat secretions in the early phase of illness (first week), from feces (often for several weeks), and rarely from the cerebrospinal fluid (CSF). Virus isolates are classified as either wild-type (naturally occurring strains) or vaccine-like. Diagnosis also can be established by serologic testing to demonstrate seroconversion. Laboratory findings may include a normal or mildly elevated white blood cell count and CSF findings that are indistinguishable from other viral causes of aseptic meningitis.⁴

About 95% of poliomyelitis cases are asymptomatic and can be recognized only by the isolation of the virus from the feces or oropharynx or by a rise in antibody titer; however, these inapparent infections are still considered contagious.² Abortive poliomyelitis occurs in about 4 to 8% of infections and its manifestations include fever, headache, sore throat, listlessness, anorexia, vomiting, and abdominal pain. Neurologic examination is normal. The illness lasts from a few hours to about 2 to 3

days and is clinically indistinguishable from other viral infections; it can be suspected clinically during an epidemic. Nonparalytic poliomyelitis has more severe systemic manifestations than the abortive type, and with positive signs of meningeal irritation that make it clinically indistinguishable from aseptic meningitis caused by other enteroviruses.⁴

Paralytic poliomyelitis can be classified as spinal, bulbar, or spinobulbar disease. The development of paralysis is rapid (about 2 to 4 hours), is usually accompanied by fever and muscle pain, and rarely progresses after the patient's temperature has returned to normal. Spinal paralysis is usually asymmetric and more severe proximally than distally. Deep tendon reflexes are absent or diminished. Bulbar paralysis may affect respiration and swallowing. Many patients recover some muscle function after the acute episode. Prognosis can be firmly assessed usually within 6 months after the onset of paralytic manifestations.¹

Paralytic poliomyelitis may be confused with Guillain-Barré syndrome; in the latter, (a) the muscle weakness is more symmetric and ascending, with loss of sensation in about 80% of cases; (b) paresthesia is common; and (c) CSF findings consist of high protein content with normal or minimal

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pleocytosis.⁴ Other than Guillain-Barré syndrome, atypical/typical presentation of poliomyelitis may be mistaken for other clinical entities such as transverse myelitis, traumatic neuritis, or other paralytic conditions.^{5,74}

Risk factors for paralytic poliomyelitis include larger inocula of poliovirus, increasing age, pregnancy, strenuous exercise, tonsillectomy, and administration of intramuscular injections while the patient is infected with the virus, either during outbreaks or when intramuscular injections are given within 30 days after administering oral poliovirus vaccine.^{1,6,7,8,9} In developing countries, other factors to consider include a compromised environment (because of poor sanitation and high population density) that is a potential source of endogenous foci of poliovirus activity and the poor immune status of the community due to inadequate nutrition.^{80,81}

Poliomyelitis confers type-specific lifelong immunity. Carrier states (asymptomatic persons excreting poliovirus for more than 6 months after infection) are rare and have been reported only in immunodeficient persons.¹

A late-onset syndrome (post-polio syndrome) has been reported with increasing frequency among people, occurring 30 to 40 years after the patients contracted wild poliovirus infection in childhood. The cause is unknown but probably is related to the aging or death of nerves and muscles that were compensating for the original damage. Patients experience muscle pain and exacerbation of existing muscle weakness. Risk factors for developing the post-polio syndrome include (a) increasing length of time since acute poliovirus infection, (b) presence of permanent residual impairment

after recovery from the acute illness, and (c) female sex.^{1,2,10,74,77}

Severe poliomyelitis can result in lower limb deformity such as flexion contracture of the knee or lateral rotation deformity of the tibia, leading to impaired mobility.^{82,83} Other complications of poliomyelitis may include impairment of respiration due to paralysis of the respiratory muscles, airway obstruction due to involvement of cranial nerve nuclei or lesions of the respiratory center. Myocarditis, gastrointestinal problems (hemorrhage, paralytic ileus, gastric dilatation), and urinary tract infections also have been reported.⁴

Management of poliomyelitis is supportive and symptomatic, since antiviral agents specific for the treatment of this illness are not available. Patients with abortive or mild nonparalytic poliomyelitis may require only bed rest for several days. Analgesics, antipyretics, or hot, moist packs applied to muscles may be helpful. During active myelitis, rest on a firm bed is advisable. Physical therapy is very important in the management of paralytic poliomyelitis during the convalescent period.⁴ ■

References

1. Advisory Committee on Immunization Practices. Poliomyelitis prevention in the United States: introduction of a sequential vaccination schedule of inactivated poliovirus vaccine followed by oral poliovirus vaccine. *MMWR Morb Mortal Wkly Rep* 1997; 46(RR-3): 1-25.
2. Grabenstein JD. Poliovirus: which vaccine when? *Hosp Pharm* 1997; 32(6): 866-80.
3. Ren R, Racaniello VR. Poliovirus spreads from muscle to the central nervous system by neural pathways. *J Infect Dis* 1992; 166(4): 747-52.
4. Modlin JF. Poliovirus. In: Mandell GL, Bennett JE, Dolin R, editors. *Principles and practice of infectious diseases*. New York: Churchill Livingstone Inc; 1995. P. 1613-20.
5. Sabin AB. Paralytic poliomyelitis: old dogmas and new perspectives. *Rev Infect Dis* 1981; 3: 543-64.
6. Sutter RW, Patriarca PA, Suleiman AJ. Attributable risk of DTP (diphtheria and tetanus toxoids and pertussis vaccine) injection in provoking paralytic poliomyelitis during a large outbreak in Oman. *J Infect Dis* 1992; 165(3): 444-9.
7. Wyatt HV. Mothers, injections and poliomyelitis. *Soc Sci Med* 1992; 35(6): 795-8.
8. Strebel PM, Ion-Nedelcu N, Baughman AL, et al. Intramuscular injections within 30 days of immunization with oral poliovirus vaccine: a risk factor for vaccine-associated paralytic poliomyelitis. *N Engl J Med* 1995; 332: 500-6.
9. Wright PF, Karson DT. Minimizing the risks associated with the prevention of poliomyelitis. *N Engl J Med* 1995; 332: 529-30.
10. Ramlow J, Alexander M, LaPorte R, et al. Epidemiology of the post-polio syndrome. *Am J Epidemiol* 1992; 136(7): 769-86.
74. Panel comment, 10/98.
77. Reviewers' consensus, 10/98.
79. Knolle H. Transmission of poliomyelitis by drinking water and the problem of prevention. *Gesundheitswesen* 1995; 57(6): 351-4.
80. Swartz TA. Basic conditions for the eradication of poliomyelitis: indications for a common prescription. *Public Health Rev* 1993/94; 21: 157-60.
81. Panel comment, 11/98.
82. Asirvatham R, Watts HG, Rooney RJ. Rotation osteotomy of the tibia after poliomyelitis: a review of 51 patients. *J Bone Joint Surg* 1990; 72(3): 409-11.
83. Parekh PK. Flexion contractures of the knee following poliomyelitis. *Int Orthop* 1983; 7(3): 165-72.
86. van der Avoort HG, Reimerink JH, Ras A, et al. Isolation of epidemic poliovirus from sewage during the 1992-3 type 3 outbreak in The Netherlands. *Epidemiol Infect* 1995; 114(3): 481-91.

The complete monograph entitled "Information on Poliomyelitis and Poliovirus Vaccine Live Oral Systemic" was developed with the support of the United States Agency for International Development. The document is available in French, Portuguese, Russian, and Arabic, in addition to the original English. To receive a copy (please indicate which language), contact Nancy Blum, MPH, MA, US Pharmacopeia, 12601 Twinbrook Parkway, Rockville, MD (Maryland) 20852 (301-816-8385, nlb@USP.org).

Incidence Rates of Poliomyelitis in the USA

Source: Supplement to *Morbidity and Mortality Weekly Report (MMWR)*, Summary of Notifiable Diseases.

Data from the MMWR are dependent on many factors. Severe cases are more likely to be reported. The completeness of reporting can be affected by public awareness, resources and priorities of state and local officials, and the availability of diagnostic testing and diagnostic facilities.

From 1937-1950, the USA total cases included both paralytic and nonparalytic polio.

Year	Reported Cases
1937	9,514
1944	19,029
1938	1,705
1945	13,624
1939	7,343
1946	25,698
1940	9,804
1947	10,827
1941	9,086
1948	27,726
1942	4,167
1949	42,033
1943	12,450
1950	33,300
Total	226,306

From 1951 to present, the MMWR distinguished between paralytic cases and nonparalytic cases.

Year	Paralytic	Nonparalytic	Year	Paralytic	Nonparalytic
1951	10,037	18,349	1979	26	8
1952	21,269	36,610	1980	8	1
1953	15,648	19,944	1981	6	0
1954	18,308	20,168	1982	8	0
1955	13,850	15,135	1983	15	0
1956	7,911	7,229	1984	8	0
1957	2,499	2,986	1985	7	0
1958	3,697	2,090	1986	8	0
1959	6,289	2,136	1987	6	0
1960	2,525	665	1988	9	0
1961	988	324	1989	11	0
1962	792	148	1990	6	0
1963	396	53	1991	10	0
1964	106	16	1992	6	0
1965	61	11	1993	4	0
1966	106	7	1994	8	0
1967	40	1	1995	6	0
1968	53	0	1996	5	0
1969	18	2	1997	3	0
1970	31	2	1998	1 confirmed	
1971	17	4	1999	No cases	
1972	29	2			
1973	7	1	Total from 1937-1950		226,306
1974	7	0	Total from 1951-1997		230,782
1975	8	0	Total from 1937-1997		457,088
1976	12	2			(paralytic and nonparalytic)
1977	17	1			
1978	9	6			

*Numbers may not reflect changes based on retrospective case evaluation or late reports.

Another source of data for determining the number of survivors of polio in the United States is the information gathered as part of the National Health Interview Survey (NHIS) conducted by the National Center for Health Statistics, part of the Centers for Disease Control and Prevention.

The NHIS is a continuously conducted survey of a nationally representative sample of the civilian, non-institutionalized population. It covers a broad range of health-related topics through personal interviews in the home. Interviews are conducted by specially trained interviewers employed by the Bureau of the Census.

The NHIS uses two questionnaires each year. The first is a basic health and demographic questionnaire. The second is a special questionnaire on current health topics.

In 1987, a special questionnaire was designed to collect information

from polio survivors. Researchers were surprised to identify 821 polio survivors. *Based on the '87 sample size, the estimate of polio survivors in the United States was 1.6 million. The estimate of 640,000 paralytic polio survivors was much higher than previous national estimates.* Researchers expressed a lack of confidence in the number because the data are self-reported and nonparalytic polio was often not diagnosed or misdiagnosed.

To validate the number, the 1994-1995 NHIS disability survey screened 200,000 persons in Phase I, and then went back to about 40,000 people including people who were identified as polio survivors (Phase II). *The 1994-1995 survey identified 445 polio survivors and, based on this sample size, the estimate of polio survivors in the United States is 1,000,000 with 433,000 reporting as paralytic polio survivors.*

A comprehensive Polio Survivor Questionnaire was included in the Phase II survey. Survivors were asked questions about their acute poliomyelitis and the rehabilitation period, their period of physical best, and their present physical condition. Because the questions were both numerous and detailed and because the sample size is so small (445), the NHIS is concerned about the privacy of the individuals. A committee is reviewing the issue and will determine how and when the data will be made available to qualified researchers. ■

Representatives of polio-related groups in other countries are invited to send incidence rates of polio in their country and the source of the numbers to International Polio Network for later publication.

Post-Polio Syndrome Slide Kit

A slide kit (English only) appropriate for a comprehensive lecture on post-polio syndrome to health professionals was produced by the Post-Polio Task Force and funded by ICN Pharmaceuticals, the manufacturers of Mestion (pyridostigmine). The kit, containing 54 slides and a script, covers the epidemiology, natural history, definition, diagnosis, pathophysiology, evaluation, and management of post-polio syndrome.

A limited number of free copies of the Post-Polio Syndrome Slide Kit is available from International Polio Network (IPN). Readers who would like to assist IPN in distributing this informational resource to the training programs of health profes-

sionals (medical schools, physical therapy and occupational therapy programs, etc.) are asked to send a letter to International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA. Please include the name, title, and address of the individual to receive the kit, along with a brief explanation as to how the kit will be used.

The Post-Polio Syndrome Slide Kit is the last project of the Post-Polio Task Force. Because the results of the double-blinded multicentered trial of Mestion, as reported in the slide kit, showed "no significant improvement in health-related quality of life, fatigue, isometric strength, but trend to increased strength in very weak muscles," funding from ICN Pharmaceuticals was terminated.

The Post-Polio Task Force included Neil Cashman, MD (chair), Lauro Halstead, MD, Joan Headley, MS, Burk Jubelt, MD, Frederick Maynard, MD, Robert Miller, MD, Dorothy Woods Smith, RN, PhD, and Daria Trojan, MD, MSc. They all continue their individual work related to the problems of polio survivors. ■

Groups support The GINI Research Fund

The Post-Polio Support Group of Lehigh Valley, Bethlehem, Pennsylvania, donated \$500 to The GINI Research Fund and challenged other groups to contribute. GINI acknowledges donations from the following:

Birmingham Post-Polio Support Group
Leeds, Alabama

Delaware Valley Polio Survivors Association
Abington, Pennsylvania

Florida East Coast Post-Polio Support Group
Ormond Beach, Florida

Long Island Post-Polio Support Group Suffolk
Brentwood, New York

Lowcountry Polio Survivors Network
Charleston, South Carolina

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Ontario March of Dimes
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Whitby, Ontario, Canada

Polio Echo, Inc. of Arizona
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THE GINI RESEARCH FUND WAS ESTABLISHED in 1995 by the Board of Directors of Gazette International Networking Institute (GINI). A generous bequest from Thomas Wallace Rogers provided the impetus for this fund's creation. Thomas Wallace Rogers contracted polio at age 19 and was paralyzed from the neck down. With breathing assistance from a rocking bed, Rogers pursued an education and worked as a financial planner and investment advisor. His financial contribution acknowledged the importance of GINI's work and challenged GINI to promote research in addition to its exemplary educational endeavors.



THE GINI RESEARCH FUND SUPPORTS the work of researchers and clinicians investigating the late effects of poliomyelitis and/or neuromuscular respiratory disease through **one** of two grants:

The Thomas Wallace Rogers Memorial Respiratory Research Grant to study the cause and treatment of neuromuscular respiratory insufficiency and the effects of long-term mechanical ventilation;

The Post-Poliomyelitis Research Grant to study the cause(s), treatment, and management of the late effects of polio.

THE GINI RESEARCH FUND WILL AWARD ITS FIRST GRANT IN THE YEAR 2000.

The postmarked deadline for Phase 1 is March 1, 2000. Applicants will be notified by May 15, 2000. The postmarked deadline for Phase 2 is July 1, 2000. Applicants will be notified by October 15, 2000.

- ◆ One grant for a maximum of \$20,000 is available.
- ◆ A review panel of research experts, health care professionals, and persons with disabilities will select an award recipient.
- ◆ The GINI Board of Directors will approve the panel's recommendation.

CRITERIA FOR APPLICANTS

- ◆ Applicants must be affiliated with an institution or organization. Citizens of all countries may apply. Applications must be in English. Proposals will not be accepted via e-mail or fax.
- ◆ The research must be both quantitative and qualitative and follow sound and appropriate research standards relevant to the subject matter.
- ◆ The research findings must relate to improving the quality of life for people with disabilities.
- ◆ Preference will be given to innovative or original research.
- ◆ All requested information must be included. Incomplete applications will be disqualified.

PHASE 1 (*Deadline March 1, 2000; notification May 15, 2000*)

To be considered, applicants should identify which grant they are seeking – The Thomas Wallace Rogers Memorial Respiratory Research Grant **or** The Post-Poliomyelitis Research Grant – request a specific dollar amount (not to exceed \$20,000), and submit a concise concept paper (not to exceed five double-spaced pages) describing the following:

- ◆ Title of research project and names of investigator(s) and institution/organization
- ◆ Background information
- ◆ Overall goal and specific objectives
- ◆ Rationale for specific objectives
- ◆ Methodology/Protocols/Strategies
- ◆ Relevance and significance to people with disabilities

Applicants also should send their Curriculum Vitæ and a letter of support from a high-ranking official of their institution/organization, e.g., department head, chief financial officer, president, etc..

A review panel will screen proposals and determine whom to invite to submit a full proposal.

PHASE 2 (*Deadline July 1, 2000; notification October 15, 2000*)

Applicants who are invited to submit a full proposal must submit the following detailed information:

- ◆ The mission and current focus of the sponsoring organization or institution.
- ◆ The qualifications of the project's key personnel.
- ◆ A detailed description of the experimental design and procedures.
- ◆ Studies involving humans must be approved by an institutional review board.
- ◆ An itemized project budget indicating specific costs the grant would fund. Furniture, construction, and renovation expenses are not eligible nor are general operating expenses unrelated to the grant. If the submitted grant budget does not completely fund the proposed research, briefly describe other funding sources.
- ◆ Two letters from recognized and reputable research experts in the applicant's area of specialty that endorse the project's goals, rationale, and design; two letters from people with disabilities who support the project's goals, rationale, and significance.
- ◆ Any other information requested by the review panel.

GAZETTE INTERNATIONAL NETWORKING INSTITUTE'S (GINI) mission is to enhance the lives and independence of polio survivors, ventilator users, and others living with disabilities.

GINI's founder, Gini Laurie, a 35-year advocate for people with disabilities, began her life mission in the '50s as a Red Cross volunteer at Toomey Pavilion, a polio respiratory ward in Cleveland, Ohio. Her unique journal, *Rehabilitation Gazette*, connected people with disabilities and provided accurate, practical information. *Rehabilitation Gazette* and Gini's penchant for writing letters filled with information to empower recipients earned her the title of "grandmother of the independent living movement." Today, *Rehabilitation Gazette*, edited by Joan L. Headley, is a biannual update on disability issues, publications, resources, equipment, conferences, GINI activities, and other information useful in living independently.

Gini recognized the significance of a 1979 letter from a polio survivor describing what is now known as the late effects of polio. In 1981, she instigated the first of many periodic international conferences on post-polio problems. In 1985, she established the International Polio Network. Recognizing also that the experiences of polio survivors living at home with a ventilator should be shared, Gini started the International Ventilator Users Network in 1987.

International Polio Network (IPN) disseminates information and organizes conferences about the late effects of polio, encourages research, and promotes networking among the post-polio community worldwide. IPN publishes the quarterly *Polio Network News*, edited by Joan L. Headley. IPN also annually publishes the *Post-Polio Directory* which lists self-identified clinics, health professionals, and support groups. IPN recently revised its popular and informative *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, edited by Frederick M. Maynard, MD, and Joan L. Headley, a 120-page book in dictionary format containing 90 entries, a compilation of the research and experience of more than 40 experts.

International Ventilator Users Network (IVUN) connects ventilator users and their families with each other and with health professionals committed to home mechanical ventilation. IVUN publishes the quarterly *IVUN News*, edited by Judith R. Fischer. IVUN also annually publishes the *IVUN Resource Directory* which lists health professionals, ventilator users, equipment and mask manufacturers, service and repair sites, and organizations.

Research Updates

International Polio Network recently surveyed 40-plus researchers and clinicians requesting a summary of their current research. Following are the positive responses received prior to the printing deadline.

"We are involved in two projects, the first of which is being conducted by Dr. S.A. Arshad, a specialist in rehabilitation medicine at the University of Leeds. The aims of this research are to improve service provision for individuals experiencing the late effects of polio/post-polio syndrome by identifying where there is a need for increased knowledge and better services in primary and secondary care.

"The British Polio Fellowship is one of eight organisations taking part in the Living with Long Term Illness (LILL) action research project, which addresses the needs of people living with long-term conditions, including new problems associated with polio. Each organisation is committed to running two self-management groups, one in 1999 and the other in Spring 2000. Coventry University will be researching the results and the effects on the participants, who will have covered topics such as relaxation, gentle exercise, nutrition, and problem-solving."

Andrew Kemp, Chief Executive
The British Polio Fellowship
Middlesex, England

"We have for the last decade conducted neurophysiological and muscle morphological studies in patients with post-polio with mainly neuromuscular dysfunction. We have been looking at adaptive and compensatory phenomena taking place in the remaining motor units. Patients with chronic overuse have been of special interest. The overuse resulted in muscle fibre hypertrophy and a muscle fibre transition from fast-twitch to slow-twitch. In the hypertrophic muscle fibres there was a decreased number of capillar-

ies per area unit, indicating a longer diffusion distance. Furthermore, a low level of oxidative and glycolytic enzymes was found. The firing pattern of the remaining motor units was an intermediate one, favouring strength before endurance. Thus, changes secondary to chronic overuse may play a role for the decreased muscle strength, muscle pain, and muscle fatigue seen in patients with post-polio."

Kristian Borg, MD, PhD
Department of Clinical Neuroscience
Karolinska Hospital
Stockholm, Sweden

"Since 1994, we have been collecting clinical data into the serum carnitine levels of polio survivors as patients present with concerns. We find there are varying degrees of deterioration of serum levels and varying degrees of supplementation requirements to normalize levels. We have found that restoration of carnitine levels by supplementation relieves some of the symptoms of muscle pain and fatigue. We are also collecting data on other amino acids and vitamin/mineral requirements such as glutamine, vitamin B₆, magnesium, boron, and potassium."

Tessa Jupp, RN
Post-Polio Clinic Western Australia
Subiaco, West Australia

"A followup analysis of our 100 patients with a childhood history of the paretic form of poliomyelitis showed a gradual worsening of mobility after 30-40 years in nearly 90% of the group. Other symptoms reported were excessive fatigue and muscular weakness (85-90%), increase of paretic symptoms and atrophies (45%), fasciculations or spasms (50%), pain (40-50%), and respiratory impairment, mainly at night (10-15%).

"We also are collecting data by using muscle spectroscopy to determine the degree of muscular atrophy. The group was checked for increased titres of antibodies against polioviruses 1-3 and the results

(35%) make us suspect an autoimmune problem in these individuals."

Miluse Havlová, Q. Navsimal,
and D. Kurková
Department of Neurology
Charles University
Czech Republic

"With funding from the National Institute on Disability and Rehabilitation Research, we are conducting a longitudinal study of people with post-polio whom we saw approximately eight to ten years ago. We, like others, found high rates of post-polio changes including pain, fatigue, and new weakness in over 50% of the individuals we studied. We found some fairly high levels of thyroid disease and high levels of cholesterol in many of our individuals. We also determined that approximately 24% of the sample had some form of depressive disorder, especially if they had post-polio changes as well. The presence of a supportive family environment helped to buffer the effects of depression to keep the functional consequences to a minimum. One of the larger socio-environmental problems people faced was changes in their work ability because of post-polio changes. People needed to retire earlier, often in their middle or late '50s. Many others needed to delimit the amount of work they could do or to ask for job accommodations.

"Our current research follows up on these people ten years later and tries to determine what aspects from the first data gathering predict further changes in their functioning and what is happening to the problems they experienced in the earlier investigation. We are also implementing a couple of research interventions. One is a treatment program for depression, which is showing very good results. The second is concerned with providing people with assistive technology and assistive devices to aid them functionally. We will be concluding this

CONTINUED ON PAGE 10

research in approximately two years."

Bryan Kemp, PhD, RRTC on Aging
Rancho Los Amigos National
Rehabilitation Center
Downey, California

"A recent focus has been on quantifying muscle weakness and determining the effect of weakness on walking ability. In particular, the effect of late onset weakness in persons with prior polio has been investigated through the RRTC on Aging.

"After thirty or more years of functional stability following their episode of acute poliomyelitis, many patients now are seeking medical attention because of new weakness, pain, and fatigue which has reduced their ability to walk. Unless their acute polio left major muscular deficits, many of these people appear 'normal' and gait deviations are often subtle. In addition, manual muscle testing (the current clinical standard) can be insensitive to detecting slight changes in muscle strength. The purpose of our most recent investigation was to determine the patterns of lower extremity muscle weakness in patients with post-polio syndrome (PPS) and to determine the effects of their muscle weakness on walking ability.

"Forty subjects with PPS were compared with age-matched, sedentary control subjects. Strength of the subjects with PPS averaged approximately 50% of control subjects. The pattern of lower extremity muscle weakness was random. Walking speed averaged 72% of control subjects or just 62% of normal 30-year-olds. Hence, to walk with friends without impairment, either the friend would have to slow to a stroll or the person with post-polio would have to attempt to walk faster than their customary pace.

"This investigation identified the difficulty in diagnosing post-polio syndrome in the clinical setting. The primary substitution for muscle weakness was to reduce walking speed. Normal sensation and con-

rol allowed persons with post-polio to substitute for muscle weakness in subtle ways. In addition, new muscle weakness can be undetected owing to the limitations of manual muscle testing (MMT). Suggested guidelines for clinical practice include quantitative muscle testing for muscles registering 4/5 or 5/5 strength by MMT; recognition that 4/5 strength indicates a significant loss of strength; and test all major muscle groups of both legs as the pattern of weakness is random."

Jacquelin Perry, MD, DSc (Hon)
Pathokinesiology Laboratory
Rancho Los Amigos National
Rehabilitation Center
Downey, California

"We run a regional ambulatory clinic with an active research program. Our focus has been on establishing principles for prescribing treatments; describing the energy expenditure patterns of people with a history of polio and the effect of aberrant body mechanics; investigating the role of exercise and its prescriptive parameters that provide the greatest benefit and the least risk of exacerbating problems; understanding the relationship between activity/exercise and fatigue; investigating fatigue patterns, thresholds, and the prescription of physical activity and rest to minimize fatigue and hasten fatigue recovery; and understanding the elements of rest that are essential for optimal recovery in order to prescribe rest as judiciously as exercise.

"Our work has had implications for the early management of polio. My colleague and I have received Asia Pacific University Scholars' Awards to visit the Department of Pediatrics, University of Karachi in Pakistan. We continue our liaison with that department and continue to refine approaches to the early management of the disease."

Elizabeth Dean, PhD, PT
Professor, School of
Rehabilitation Sciences
University of British Columbia
Vancouver, British Columbia, Canada

"We sent self-assessment questionnaires to the members of the Bundesverband Poliomyelitis e.V. These included the following instruments: The Short Form Health Survey (SF-36, German version) for HRLQ (health-related quality of life), Frenchay Activity Index for activities of daily living, and the Wimbledon Self Report Scale for the emotional state. We added questions specific for the physical health of post-polio syndrome subjects. In total, 155 questionnaires were returned (2% were incomplete). We are in the process of data analysis."

Bettina Beck, MD
Asklepios Klinik Schauffling
Schauffling, Germany

"We are continuing our longitudinal studies of the late effects of polio. I have been joined in my research efforts by Dr. Eric J. Sorenson, a neurologist who trained in neuromuscular disease at Mayo and the University of Michigan. He is presently initiating a 12-year follow-up for the cohort of patients that we initially studied in 1987 and 1992. Fifty patients were identified from a cohort of 300 patients who had paralytic poliomyelitis and lived in Olmsted County, Minnesota. Fifty representative patients were chosen and studied with detailed functional, electrophysiological, and neurological tests. They were then re-tested after a five-year interval. The work was impressive because it showed no deterioration in function in this group of patients. During the period of study, they had aged from an average of 50 to 55 years. This cohort is now aged 62 on average. Doctor Sorenson has identified an appropriate group of control patients so we will be able to compare change of neuromuscular function between subjects who had paralytic polio and those who did not have polio."

Anthony J. Windebank, MD
Professor of Neurology
Dean, Mayo Medical School
Director, Molecular
Neuroscience PhD Program
Rochester, Minnesota

"A team of investigators is currently conducting several clinical studies on post-polio syndrome. The multi-centered, randomized, double-blinded, placebo-controlled trial of pyridostigmine in post-polio syndrome has been completed (*Polio Network News*, Vol. 14, No. 1). The placebo-controlled phase of the trial has been analyzed, and the results have been published in *Neurology* (See Post-Polio Bibliography). The open label phase of the study (which consisted of an evaluation six months after the completion of the placebo-controlled phase of the trial) is currently being analyzed. We are also performing other analyses of the data collected during this clinical trial. The goals of these analyses are to determine if serum insulin-like growth factor-I (IGF-I) is associated with various clinical parameters in post-polio syndrome such as isometric strength, fatigue, and quality of life; to determine the clinical parameters which have the most important impact on quality of life in post-polio syndrome patients; and to determine the predictive factors and correlates for muscle and joint pain in post-polio syndrome patients.

"Other clinical studies which are in progress include another smaller placebo-controlled, discontinuation trial of pyridostigmine in patients who are regularly taking the medication, studies on the electrophysiology and electrodiagnosis of post-polio syndrome, and Magnetic Resonance Spectroscopy (MRS) studies of the brain in post-polio syndrome patients (to determine whether or not there is nerve cell loss in certain areas of the brain)."

Daria A. Trojan, MD, MSc
Assistant Professor
Montreal Neurological Institute,
McGill University
Montreal, Quebec, Canada

"We are conducting a randomized trial with pyridostigmine at the academic hospital Vrije Universiteit Amsterdam in collaboration with researchers from several other

institutions. When we started our work, we were unaware of the study done by Daria Trojan, MD, and her colleagues (*Polio Network News*, Vol. 14, No. 1). After consultation with her, we discovered our study design was quite different. Our study is a randomised, double-blinded, placebo-controlled trial for a period of 14 weeks on 64 patients with post-polio syndrome and demonstrated neuromuscular transmission defects in the symptomatic quadriceps. The patients take 60 mg of pyridostigmine orally four

times a day or placebo. The outcome measures include a fatigue questionnaire, walking performance (distance and speed), neuromuscular transmission defects (single fibre electromyography), and the patient's opinion of the effect of the medication. The study is being conducted between September 1998 and September 2000."

Frans Nollet, MD
Rehabilitation Medicine
Vrije Universiteit Amsterdam
The Netherlands

Post-Polio Bibliography

- Jubelt, B., & Drucker, J. (1999). Poliomyelitis and the post-polio syndrome. In D.S. Younger (Ed.), *Motor Disorders* (pp. 381-394). Philadelphia, PA: Lippincott, Williams, & Wilkins.
- Jönsson, A.-L., Möller, A., & Grimby, G. (1999). Managing occupations in everyday life to achieve adaptation. *The American Journal of Occupational Therapy*, 53(4), 353-362.
- This qualitative study yielded 18 concepts describing adaptive strategies for persons with the late effects of polio. The 18 concepts were arranged in 6 general groups: utilizing physical capability, influencing emotions, altering pattern of occupations, promoting concrete problem-solving, influencing relations, and facilitating future activities.
- Nollet, F., Beelen, A., Prins, M., de Visser, M., Sargeant, A.J., Lankhorst, G.J., & de Jong, B.A. (1999). Disability and functional assessment in former polio patients with and without postpolio syndrome. *Archives of Physical Medicine & Rehabilitation*, 80(2), 136-143.
- Post-polio syndrome subjects are more prone to fatigue and have more physical mobility problems than non-post-polio subjects. In former polio patients, measurements of perceived health problems and performance tests are the most appropriate instruments for functional evaluation.
- Schanke, A.-K., Lobben, B., & Øyhaugen, S. (1999). The Norwegian polio study 1994 part II: Early experiences of polio and later psychosocial well-being. *Spinal Cord*, 37, 515-521.
- Twenty-seven percent of a nationwide sample of 2392 polio survivors reported on a mailed questionnaire that they had been psychologically harmed by treatment they received dur-

ing the original illness. This group was significantly younger at onset, was hospitalized for a longer period of time, and had fewer parental visits and less support. This subgroup of polio survivors today uses more medication, and reports more pain, general fatigue, sleep disturbances and concentration problems, more psychosocial distress, less satisfaction with life, and less social support than persons not reporting being psychologically being harmed (79%).

Weinberg, J., Borg, J., Bevegard, S., & Sinderby, C. (1999). Respiratory response to exercise in postpolio patients with severe inspiratory muscle dysfunction. *Archives of Physical Medicine & Rehabilitation*, 80(9), 1095-1100.

Five post-polio patients with associated scoliosis and with respiratory muscle dysfunction were studied at rest and during exercise. Ventilatory dysfunction was not evident in blood gas values at rest, but it was revealed by blood gas values during the exercise test. Diaphragm fatigue seems to be avoided at the cost of impaired blood gases.

Trojan, D.A., Collet, J.-P., Shapiro, S., Jubelt, B., Miller, R.G., Agre, J.C., Munsat, T.L., Hollander, D., Tandan, R., Granger, C., Robinson, A., Finch, L., Ducruet, T., & Cashman, N.R. (1999). A multicenter, randomized, double-blinded trial of pyridostigmine in postpolio syndrome. *Neurology*, 53, 1225.

This study showed no significant difference between pyridostigmine and placebo-treated post-polio syndrome patients on measures of quality of life, isometric strength, fatigue, and serum IGF-I.

The same issue of *Neurology* (p. 1166) features Why drugs fail in post-polio syndrome: Lessons from another clinical trial by Marinos C. Dalakas, Neuromuscular Disease Section, National Institute of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, Maryland. ■

Identifying Best Practices

The Office of International Programs of the March of Dimes Birth Defects Foundation has convened an expert committee to plan a symposium entitled "International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Clinical Management" to be held May 19-20, 2000, in collaboration with the Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia. Attendance is open to health professionals by invitation only.

The purpose of the meeting is to review and critique the current information on post-polio syndrome and to identify the best practices in diagnosis and management. The members of the committee include John Bach, MD; Neil Cashman, MD; Marinos Dalakas, MD; Lauro Halstead, MD; Joan Headley; Susan Perlman, MD; Daria Trojan, MD; and William Wendling, polio survivor. The Chair is Lewis P. Rowland, MD, Professor of Neurology, Columbia University. The lead representative from the March of Dimes is Christopher P. Howson, PhD, Director of International Programs.

The planning committee met October 8-9, 1999 and included time for polio survivors and health professionals to cite relevant data, make suggestions, and voice concerns. The committee heard from 17 individuals. Additional comments may be sent to Joan Roe, March of Dimes, 1273 Mamaroneck Avenue, White Plains, New York 10605 (jroe@modimes.org). Materials must be received by December 31, 1999 to be considered. ■

GINI periodically sends messages to its e-mail list. To be included, send an e-mail message to gini_intl@msn.com.

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EIGHTH INTERNATIONAL Post-Polio ^{AND} Independent Living Conference

SAINT LOUIS, MISSOURI

WHO: Polio survivors, ventilator users, health professionals, families, & friends.

WHEN: June 8-10, 2000
(Opening luncheon begins June 8 at 11:30 am;
Closing session concludes June 10 at 4:30 pm.)

WHERE: Saint Louis Marriott Pavilion Downtown
(800-831-4004; specify "GINI Post-Polio Meeting")

WHY: To educate the disability and health care communities about the issues of polio survivors and ventilator users.

The Eighth International Post-Polio & Independent Living Conference will feature several tracks offering its attendees numerous breakout sessions addressing:

- ◆ latest findings and management approaches
- ◆ cardiopulmonary issues
- ◆ training for health professionals*
- ◆ personal experiences and development, and
- ◆ independent living/advocacy issues

*A special seminar for physical therapists and occupational therapists, and physical therapist assistants and occupational therapist assistants, will be offered all day Friday and one-half day Saturday.

Program and registration details will be published in the Winter (January 2000) *Rehabilitation Gazette*, which will be sent complimentary to subscribers of *Polio Network News* and *IVUN News*.

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