POLIO NETWORK NEWS

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U.S. Post-Polio Clinic Survey Results

Since 1985 International Polio Network has compiled a listing of self-identified polio clinics. In an effort to better inform our readers, IPN surveyed approximately 70 clinics listed in the ***Post-Polio Directory***. Sixty clinics responded to the questions which have been tallied in chart form on pages 3 through 8.

Post-polio clinics are typically headed by physiatrists or neurologists.

A ***physiatrist*** is a doctor of medicine (MD) or doctor of osteopathy (DO) who is a specialist in physical medicine and rehabilitation (PM&R). Physiatrists specialize in the diagnosis of certain conditions causing neck and back pain, weakness, and a variety of other nerve and muscle problems. Through their specialized knowledge of electromyography, physiatrists are able to diagnose conditions causing pain, numbness, tingling, and weakness.

Rehabilitation medicine involves specialized medical care and training of patients, both adults and children, who have loss of function; enabling patients to obtain their potential — physically, psychologically, socially, and vocationally. The physiatrist directs these rehabilitation programs for individuals by prescribing and supervising physical therapy, occupational therapy, speech therapy, rehabilitation nursing, and other allied health personnel contributing to the team. The physiatrist evaluates the patient, prescribes the medical management, and orders the physical restoration program.

There are two common models for post-polio clinics led by physiatrists — ***the triage model,*** and ***the multidisciplinary model.***

The Post-Polio Clinic at St. Mary's Medical Center (Clinic No. 4), San Francisco, CA, utilizes the ***rehab triage model.*** Patients are seen in the clinic initially by the physiatrist who formulates a working diagnostic impression and treatment plan based on the history and physical findings, as well as other available lab data provided by the referring physician. At that time the treatment plan may include additional diagnostic laboratory tests such as EMG or x-rays and may include additional consultation with other medical or surgical specialists to rule out other treatable diseases.

The polio survivor returns to the clinic for a second visit after having obtained the additional diagnostic tests and consultations, and a more definitive treatment plan is formulated and discussed with the polio survivor in order to meet his or her particular needs. It is at that time that orders are written and referral is made to a spectrum of treating therapists, including a physical therapist, occupational therapist, speech pathologist, rehab psychologist, and orthotist, depending on their particular needs. The patient then is scheduled to return to the outpatient rehabilitation center where he or she may be seen by one or more therapists for a customized treatment program for flexibility exercises, non-fatiguing general conditioning exercises, pacing, training in use of a new brace or orthosis, evaluation and measurement for a wheelchair, energy conservation in day-to-day activities, consideration for new adaptive equipment, psychological counseling, relaxation techniques, etc. Particularly difficult to manage functional problems may require a joint meeting between the attending physiatrist and the post-polio therapists.

Utilizing this model requires that a polio survivor return to the clinic on more than one occasion to take advantage of the full array of services. Utilizing this model allows for shorter diagnostic and treatment sessions which are not so tiring for polio survivors. Additionally, they are not bombarded with a lot of information from multiple individuals on one particular occasion, which polio survivors have sometimes felt overwhelming and confusing. It allows for more of a customized treatment program as opposed to a one or two visit consultation with multiple disciplines, some of which may or may not necessarily be relevant for that particular polio survivor.

The Post-Polio Clinic at St. John's Mercy Medical Center (Clinic No. 28), St. Louis, MO, was established in 1987 using ***the multidisciplinary model.***

The professionals are led by a physiatrist whose

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U.S. Survey Resullts *(continued from page 1)*

formal training is in physical medicine and rehabilitation.

The multidisciplinary treatment team also includes a physical therapist, occupational therapist, speech therapist, recreational therapist, rehabilitation psychologist, rehabilitation social worker, rehabilitation nurse, a dietitian, orthotist (brace fabricator), and a vocational counselor. There is access to specialists in pulmonary medicine, neurology, and orthopedic surgery.

The selected team members have developed special expertise to evaluate and treat individuals with post-polio syndrome. They are well versed in treatment techniques utilized in the past as well as newer protocols.

The individual completes a medical history infor-- mation sheet prior to the initial evaluation. The client is then seen by a physiatrist who will review the client's medical history and perform a thorough neurologic and musculoskeletal examination. When appropriate, further evaluations by the above-mentioned treatment team will be arranged that day.

After the polio survivor has been through the appropriate evaluation and treatment program, the clinic staff collaborates to ensure that all of the special needs of the client have been addressed. If not, the coordinated treatment program is modified.

In one to two months, the individual returns for a follow-up physician appointment to assess the success of the program and to make sure the client's perceived needs, and the needs perceived by the professional staff, have been met. If needed, further evaluation and treatment is prescribed.

Some post-polio clinics are also led by ***neurologists.***

A neurologist is a doctor of medicine (MD) or a doctor of osteopathy (DO) who specializes in diseases of the nervous system. Some neurologists subspecialize in neuromuscular diseases, which is a subspecialty of diseases of the peripheral nerves (nerves in the arms and legs), the neuromuscular junctions (the nerve muscle junction), and the muscles, which includes the problems of the post-polio patient. Through their specialized knowledge of neuromuscular diseases, electormyography (EMG), and neuro-rehabilitation, these neurologists are able to diagnose and treat conditions causing pain, weakness, numbness, and tingling.

Post-polio clinics directed by neurologists may also follow the triage or the multidisciplinary model. At the SUNY Health Science Center at Syracuse, NY (Clinic No. 32), patients with the post-polio problem are treated by a triage team of professionals, including a neurologist, a nurse practitioner, and a physical therapist.

The initial evaluation includes a complete medical and neurological history and examination, and a physical/occupational therapy evaluation if appropriate. Based upon the presumptive diagnosis, patients will be sent for diagnostic testing. These diagnostic tests include blood tests, electromyograms (EMG), pulmonary function tests, swallowing tests, and various imaging modalities (X-rays, MRI, CT) as needed. This detailed evaluation is necessary, not only for treatment of post-polio syndrome but also to exclude other diseases that cause similar problems which may be contributing to dysfunction. The post-polio patient returns to the clinic for a follow-up visit after completion of testing for discussion of the diagnosis and formulation of the treatment plan. Additional referrals for social work evaluations and speech therapy assessments as well as to a pulmonary specialist, an orthopedist, a neuropsychiatrist, or a nutritionist may be necessary. Appropriate exercise techniques (non-fatiguing, conditioning, flexibility) and energy saving techniques are taught, lifestyle modification counseling is provided, and when necessary, brace and other orthotic modifications are prescribed with referral to the orthotist. Patients are followed on a periodic basis to monitor strength and functional status, and to make treatment adjustments.

W. Clinton Maxwell, MD, Plano Rehab Hospital (Clinic No. 60) has available a videotape in which he describes his clinical approach to the treatment of polio survivors. To purchase this videotape (approximately $15.00), contact Dr. Maxwell at Plano Rehab Hospital, 2800 W. 15th St., Plano, TX 75075 (214/946-0666).

Lauro S. Halstead, MD, National Rehab Hospital (Clinic No. 8) described his approach in *Post-Polio Sequelae: Assessment and Differential Diagnosis for Post-Polio Syndrome,* ***Orthopedics,*** Vol. 14, No. 11, November, 1991.

Post-Polio Directory — 1992 was published March 1, 1992 and lists the names, addresses, and phone numbers of clinics, health professionals, and support groups. It is available with an appendix of additions and corrections to polio survivors for $3.00 and to other interested individuals for $6.00. Canadian and overseas surface add $1.00. Overseas air add $2.00.

U.S. Post-Polio Clinic Survey • 1992

International Polio Network
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What medical professionals are physically present to see patients at the time of their first evaluation as well as return visits? *(Circle appropriate ones.)*

1 Physiatrist
2 Neurologist
3 Orthopedist
4 Pulmonologist
5 Physical Therapist
6 Occupational Therapist
7 Recreational Therapist
8 Respiratory Therapist
9 Speech Therapist
10 Social Worker
11 Psychiatrist
12 Psychologist
13 Orthotist
14 Nutritionist
15 Other *(Please name)*

Do medical residents see patients in your clinic?

What laboratory testing is routinely ordered on all patients? *(Circle appropriate ones.)*

1 CBC
2 Blood Chemistry
3 Electromyogram *(Name type: single, macro, etc.)*
4 X-rays *(Name kind.)*
5 MRI
6 CT Scans
7 Others *(Please name.)*

Do you have a Cybex to evaluate and score muscle strength?

Is a brace mold made if required at time of visit or must patient return?

Approximate date your clinic opened?

U.S. clinics responding to survey are in alphabetical order by state. Clinics 56 through 60 are the most recent additions.

Clinic No.	Clinic Name and City, State
1	Alta Bates-Herrick Rehab. Center, Berkeley, CA
2	Rancho Los Amigos Med. Center, Downey, CA
3	UCLA Med. Plaza, Los Angeles, CA
4	St. Mary's Med. Center, San Francisco, CA
5	Santa Clara Valley Med. Center, San Jose, CA
6	Mercy Med. Center, Denver, CO
7	Spalding Rehab. Hospital, Denver, CO
8	National Rehab. Hospital, Washington, DC
9	Upreach Pavilion Post-Polio Eval. Clinic, Gainesville, FL
10	Tampa Gen. Rehab. Center, Tampa, FL
11	Roosevelt Warm Springs Institute, Warm Springs, GA
12	Rehab. Hospital of the Pacific, Honolulu, HI
13	Idaho Elks Rehab. Hospital, Boise, ID
14	Rehab. Institute of Chicago, Chicago, IL
15	Univ. of Chicago Post-Polio Clinic, Chicago, IL
16	Rehab. Medicine Clinics, Wheaton, IL
17	Northeast Indiana Rehab. Institute, Fort Wayne, IN
18	Hook Rehab. Center, Indianapolis, IN
19	Younker Memorial Rehab. Center, Des Moines, IA
20	Rehab. Medicine Clinic, Kansas City, KS
21	Univ. of Kentucky, Lexington, KY
22	Children's Hospital & Center for Reconstructive Surgery, Baltimore, MD
23	Spaulding Rehab. Hospital, Boston, MA
24	Univ. of Michigan Med. Center, Ann Arbor, MI
25	Pain Rehab., Detroit, MI
26	Sister Kenny Institute, Minneapolis, MN
27	The Rehab. Institute, Kansas City, MO
28	St. John's Mercy Med. Center, St. Louis, MO
29	Thomas Rehab. Hospital, Asheville, NC
30	Kessler Institute, East Orange, NJ
31	Sunnyview Rehab. Hospital, Schenectady, NY
32	SUNY Health Science Center, Syracuse, NY
33	Charlotte Institute of Rehab., Charlotte, NC
34	Regional Rehab. Center, Greenville, NC
35	Cleveland Clinic, Cleveland, OH
36	O'Donoghue Rehab. Institute, Oklahoma City, OK
37	Good Shepherd Rehab. Hospital, Allentown, PA
38	Reading Rehab. Hospital, Reading, PA
39	Magee Rehab. Hospital, Philadelphia, PA
40	Piedmont Physical Med. & Rehab., PA, Greenville, SC
41	Patricia Neal Rehab. Center, Knoxville, TN
42	Tennessee Christian Med. Center, Madison, TN
43	Rehab. Hospital of Austin, Austin, TX
44	Dallas Rehab. Institute, Dallas, TX
45	Environmental Health Center, Dallas, TX
46	The Institute for Rehab. and Research, Houston, TX
47	Stewart Rehab. Center/McKay-Dee Hospital, Ogden, UT
48	Univ. Associates in Neurology, Burlington, VT
49	Rehab. Medicine Center of Northern VA, Falls Church, VA
50	Sheltering Arms Rehab. Hospital, Richmond, VA
51	Northwest Hospital, Post-Polio Clinic, Seattle, WA
52	Univ. of Washington, Post-Polio Clinic, Seattle, WA
53	St. Joseph Hospital, Tacoma, WA
54	Univ. of Wisconsin Hospital Rehab. Clinic, Madison, WI
55	Theda Clark Regional Med. Center, Neenah, WI
56	Univ. of California Davis, Sacramento, CA
57	Shepherd Spinal Center, Atlanta, GA
58	Emory University, Atlanta, GA
59	The Ohio State University, Columbus, OH
60	Plano Rehab. Hospital, Plano, TX

What medical professionals are physically present to see patients at the time of their first evaluation as well as return visits?

Clinic I.D. #	Physia-trist	Neurol-ogist	Ortho-pedist	Pulmonol-ogist	Physical Therapist	Occupat. Therapist	Recreat. Therapist	Respira. Therapist	Speech Therapist	Social Worker	Psychia-trist	Psychol-ogist	Orthotist	Nutri-tionist	Other (Pls. name)
1	●														
2		C	●	C	●	●				●		C	●	C	
3		●	PRN	PRN	●	●		PRN	●	●		●	●	●	Sleep Disorders Technician Specialist, X-ray
4	●	C	C	C	F	F	PRN	PRN	PRN	F		PRN	F		Rehab. Nurse
5	●														
6	●	C	C	C	●	C		C	C			C	C		Family Physician
7	●				●	●		●				●	●	●	Lab/X-ray Techn.
8	●				●	●	PRN	PRN	PRN	●		PRN	●	PRN	
9	●				●	●			●			●			
10	●	C	C	C	●	●		●	●	●	C	●	●	●	
11	●	C	C	C	●	●	●	●	●	●		●	●	●	Seating Clinic
12	●				PRN	PRN			PRN	●			PRN	PRN	
13	●				●	●		●		●			F	●	
14		●											●		D.O.
15		●				●				●					
16	●				●								●		
17	●				●	●	PRN		PRN	PRN		PRN	PRN		Rehabilitation Counselor
18	●														
19	●				●	●				●					
20	●	C	C	C	●	C			C	C	C	C	●	C	
21		●													
22	●		●		●	●		●				●	●	●	
23	●	F		F	●	●		F	F	F	F	F	F	F	
24	●	C	C	C	F	F		F	F		C	F	F	C	Patient Education & Peer/Advocate Specialist
25	●	●			●	●					●		●		
26	●				●	●		●	●			●	●		Exercise Physiol.
27	●	C	C	C	●	●	●	C	●	●	C	C	C	●	
28	●	C	C	C	●	●	C	C	●	●	C	●	●	C	
29	●				●	●		C	C	C		C	C	C	
30	●	C	C	C	●	●			●		C	●	C		
31	●														
32		●	C	C	●	●		C	●	●	C		C	C	
33	●	●			●	●	●		●	●		●	●	●	
34	●	C	C	C	C	C		●	C	C	C	C	●	C	R.N.
35		●			F	F			F	F				F	
36	●		●		●	●		●		●		●	●		
37	●				●	●				●			PRN		

KEY: ● = Available at time of first visit F = Available at following visit C = Available by consult PRN = As needed

What medical professionals are physically present to see patients at the time of their first evaluation as well as return visits?

Clinic I.D. #	Physia-trist	Neurol-ogist	Ortho-pedist	Pulmonol-ogist	Physical Therapist	Occupat. Therapist	Recreat. Therapist	Respira. Therapist	Speech Therapist	Social Worker	Psychia-trist	Psychol-ogist	Orthotist	Nutri-tionist	Other (Pls. name)
38	●				●	●		●	●						
39	●				●	●	●	●	●	●	●	●		●	
40	●	C	C	C	PRN	PRN	PRN	PRN	PRN	PRN	PRN	C	C	C	Rheumatologist
41	●	PRN	PRN	PRN	PRN	PRN	PRN	PRN	PRN	PRN	PRN	PRN	PRN	PRN	
42	●				●	●		●					●		
43	●				●	●							●		P.A.C.
44	●				●	●		●	PRN	●			PRN	PRN	
45	●	●	●	●	●									●	Environ. Special.
46	●				●				●	●			●		
47	●				●	PRN	PRN		PRN	PRN		●	PRN		R.N.
48		●			●	●								●	
49	●				●										
50	●	●			●	●							●		R.N.
51	●	F			●	PRN		PRN	PRN			PRN	●	●	
52	●											●	●		R.N., Vocational
53	●	C	C	C	●	●			●	●	C	●	●	Request	
54	●	C, F	C, F	C, F	C, F	C, F	C, F	C, F	C, F	C, F	C, F	C, F	C, F	C, F	Rehab. Nurse
55	●	●	●	●	●	●	●	●	●	●	●	●	●	●	
56	●	C	C	C	C	C	C	C	C	C	C	C	C	C	
57	●	O	O	O	O	O	O	O	O	O	O	O	O	O	
58	●				●	●									
59	●				F	F			F	F		F			
60	●	C	C	C	C	C	C	C	C	C	C	C	C	C	

Clinic I.D. No.	Do you have a Cybex to evaluate muscle strength?	Is a brace mold made at time of visit or must patient return?	Approx. Date Clinic Opened
1	YES	Return	1985
2	YES	Return	1972
3	YES	If Necessary	1987
4	NO	Return	1981
5	NO	Return	1987
6	NO	Do Not Do	1974
7	YES, but not used	Return	1986
8	YES	Return	1986
9	YES, prefer manual	Referred	1988
10	YES	Prescription given	1986
11	YES, man. muscle test/PT	At time	30+ Years Ago
12	YES	Return or Orthotist	1989
13	YES, but not appropriate	Return	1987
14	YES, but don't use	Return	1990
15	NO, but available	Referred	1984
16	YES	Return	1990

Clinic I.D. No.	Do you have a Cybex to evaluate muscle strength?	Is a brace mold made at time of visit or must patient return?	Approx. Date Clinic Opened
17	Manually	Return	1991
18	NO	Return	1990
19	NO	Return	1989
20	YES	At Time	1986
21	NO	Return	1985
22	YES	If Necessary	—
23	YES	Return	1988
24	YES	Return	1983
25	NO	Return	1990
26	YES	YES	1982
27	NO	Return	1987
28	YES	Either	1987
29	If needed	Return	1992
30	YES	Return	1990
31	YES	Return	1987
32	NO	To Orthotist	1989
33	YES	Return	1991
34	NO	Return	1986
35	YES	Return	1983
36	NO	Return	1986
37	YES	Return	1988
38	YES	Return	1987
39	YES	Referred to Orthotist	1980
40	YES	Return	1985
41	YES	Return	1990
42	—	Return	—
43	If needed	Return	1992
44	YES	Return	—
45	NO	Do not do	1974
46	YES (Lido)	Usually at visit for out of town patients	1984
47	YES, but not used in polio	To Orthotist	1991
48	YES	Return	1983
49	YES	Return	1986
50	YES, but use manual	Return	1992
51	NO	Return	1987
52	YES, but rarely use	Frequently must return	1983
53	YES, but not good for polio	Return	1987
54	YES	At Time (try)	—
55	YES, but not used	Return	1983
56	NO	Return	—
57	NO	Return	1990
58	YES	Return	1989
59	YES, but not used	Return (but can be)	—
60	YES	Return	1985

Clinic I.D. #	Do medical residents see patients?	CBC	Blood Chem-istry	Electro-myo-gram	X-Rays	MRI	CT Scans	Others *(Please Name)*
1	NO							None routine
2	YES							●
3	Rarely	PRN	PRN	●	PRN	PRN	PRN	1&2, if not done last year
4	YES			PRN	PRN			See on referral/many already done
5	Occasionally							●
6	Occasionally							●
7	NO	●	●	●	●			Urinalysis Pulmonary Function
8	YES			●	PRN			●
9	NO	●	●	●	If indicated			
10	NO							●
11	NO	●	●	●	PRN	PRN	PRN	
12	NO							●
13	NO				PRN			●
14	NO							●
15	Frequently							None routine
16	YES							●
17	NO							Testing determined by Meds. patient is on
18	NO	●	●					
19	NO							None routine
20	Occasionally	●	●					
21	NO	●	●	●				
22	YES			●	PRN			
23	NO	●	●	Single	●			
24	YES							As indicated
25	NO				●			
26	NO							●
27	YES							None routine
28	NO							Testing individualized
38	YES							As indicated
29	NO	●						CPK, TSH, Sedrate
30	NO	●	●	PRN	PRN	PRN	PRN	Cortisol, ACTH, Thyroid

Clinic I.D. #	Do medical residents see patients?	CBC	Blood Chem-istry	Electro-myo-gram	X-Rays	MRI	CT Scans	Others *(Please Name)*
31	Occasionally	●	PRN	PRN	PRN	PRN	PRN	Thyroid profile/swallowing
32	YES	●	●	●	PRN	PRN	PRN	
33	YES	PRN	PRN	PRN	PRN	PRN	PRN	●
34	—	●		●	PRN	C	C	H/H, KT, CPK
35	YES	●	●	MOST	MOST	MOST		
36	YES							●
37	NO	PRN	PRN	PRN	PRN	PRN	PRN	
38	NO							None routine
39	YES	●	●	●	●			
40	NO	PRN	PRN	●	PRN	PRN	PRN	Testing individualized
41	NO							●
42	NO							None routine
43	NO							None routine
44	NO		Frequently	Frequently	Frequently	Some	Some	
45	—	●	●	PRN	PRN	PRN		
46	NO							As indicated
47	NO			PRN				
48	YES			●	PRN	PRN	PRN	CK, Immunoglobulins
49	NO	●	●	●	PRN	PRN	PRN	
50	NO			●				
51	YES	●	●	●				
52	YES							None routine
53	NO	PRN	PRN	PRN	●	PRN	PRN	All others by definition MMT & ROM
54	YES							
55	NO							None routine
56	YES			●				PFT
57	●							None routine
58	YES	●	●					
59	—							None routine
60	NO			Most				Rest, if indicated

Coalition Update

International Polio Network is still collecting information from individuals who are interested in receiving updated information about the National Polio Research Coalition's (NPRC) efforts to encourage post-polio research at the National Institutes of Health. If you have not already done so, please send your name to NPRC, 5100 Oakland Ave., #206, St. Louis, MO 63110.

Lauro S. Halstead, MD, testified before the House Appropriations Committee on April 30, 1992. His comments are printed below. He also testified before the Senate Appropriations Committee on July 23, 1992. The key congressional individuals in the Senate are listed ??? If your senator is listed, please consider a personal contact either by mail or by phone in support of funds for post-polio research.

Statement of LAURO HALSTEAD, MD, before House Appropriations Subcommittee for the Departments of Labor-HHS-Education, April 30, 1992.

Good morning Mr. Chairman. My name is Lauro Halstead. I am a physician and Director of the Post-Polio Program at the National Rehabilitation Hospital here in Washington, DC. I also serve on the Board of Directors of the Washington based Polio Society, and am a polio survivor myself.

I want to thank you and the rest of the subcommittee for including language last year in your report and the Conference Report urging the National Institute of Neurological Disorders and Stroke (NINDS) to enhance its research efforts of Post Polio Syndrome (PPS). I am sorry to report, however, that little, if anything, has been done to research the cause or treatments of post-polio syndrome since last year. We are aware that NINDS has reported to you that they have spent $884,000 on Post-Polio Syndrome research and that a program announcement was made in February 1992. From what we know the research funded by NINDS while important, was not entirely related to Post-Polio Syndrome and it predated the requests by Congress to increase funding for Post-Polio Syndrome. The program announcement earlier this year by NINDS was the least it could do to react to the Congressional mandate to address the need for research. Specific requests for applications (RFAs) with specific funding attached are desperately needed to get research underway.

This is my third opportunity to testify before you. What has happened over the past two years? Not nearly enough. We are seeing more cases in our clinics. There is greater uncertainty. Persons who had paralytic polio in the past, even those with mild cases, are now wondering what will happen to them over the next few years. Will they suffer new weakness — will they have to go back to using braces, crutches or a wheelchair — how will it effect their ability to work — should they restrict their activity even though they have no symptoms? We don't have the answers because we haven't done the research.

Polio has usually been considered a stable, chronic disease. Once a person recovered from the acute phase, the condition stabilized, or so it was thought. According to a 1987 survey by the National Center for Health Statistics, there are estimated to be 640,000 persons in the United States who contracted paralytic polio and are still alive. As many as two thirds of these persons have begun to experience new health problems which seem to be related to polio — a disease they thought had stabilized many years before.

The new health problems are called the late effects of polio, or Post-Polio Syndrome (PPS). There are many symptoms and their exact relationship to the original disease is not fully understood. But the evidence is unmistakable. Persons who had polio during the 1940s and 1950s are now experiencing new problems such as intense fatigue, muscle weakness, muscle atrophy, loss of function, joint and muscle pain, and respiratory problems at a much higher rate than the rest of the population. Many of these persons have been so seriously affected they have been forced to start using braces or wheelchairs; others have had to take early retirement, and others have died from complications.

RESEARCH NEEDS

There are basically two areas of research needs:

1) Investigation of the causes of Post-Polio Syndrome; and

2) Investigation of the most effective treatments of Post-Polio Syndrome.

Causes: The cause(s) of PPS is unknown. A number of hypotheses have been proposed. Both intramural and extramural NIH funded research should be directed through the new National Center for Medical Rehabilitation Research (NCMRR). Research should be directed at the most likely causes of PPS which include the following:

1) neuromuscular overuse;

2) neuromuscular transmission defects;

3) muscle cell breakdown;

4) normal and/or premature aging;

5) an immune response;

6) a reactivation or re-exposure to the polio virus; and

7) a hormonal imbalance or deficit.

Treatments: The only available treatments to date are supportive. There is no cure.

Research funded through NCMRR should include:

1) intervention trials of nonsteroidal drugs;

2) trials of various exercise regimens;

3) evaluation of the effect of lifestyle modifications including the use of orthotics and new assistive device technologies;

4) prospective studies on asymptomatic polio survivors at risk for developing PPS to identify the most effective strategies to avoid or minimize the onset of PPS;

5) studies of symptomatic and asymptomatic polio survivors to learn more about the effects of aging with a chronic neuromuscular disability and how to minimize those effects; and

6) new outcome measures to be used in the ambulatory setting need to be developed, tested, and validated which are appropriate for the type and degree of functional changes experienced by persons with PPS and other chronic neuromuscular disorders.

CONCLUSION

PPS has been a neglected area of research and it has not been listed as a priority by NIH. Investigators will not submit competitive proposals until funding agencies specifically solicit this type of research. This is the same problem with any new area of research. We commend the NCMRR for the interest they have already shown in Post-Polio Syndrome. We request you include language with the appropriations that require National Center for Medical Rehabilitation Research to initiate Requests for Applications (RFAs) for the cause(s) of PPS and to fund research for the treatment of PPS in the amount of $3 million. We also support the request of other disability related organizations to fund NCMRR at $20 million for FY 1993.

We thank the National Institute of Neurological Disorders and Stroke for their program announcement and encourage them to continue and expand their efforts on Post-Polio Syndrome. Specifically, we ask that this subcommittee require NINDS to issue RFAs for $2 million. Our recommendation to fund additional research at the NCMRR is predicated on the Center receiving a substantial increase in funding.

The post-polio problem offers a unique scientific opportunity to study the effects of aging on the nervous system. Lessons learned from studying polio may be important in understanding other neurological diseases, and there is a moral obligation to the 640,000 polio survivors who have led the fight for disability rights and the Americans with Disabilities Act (ADA), and struggled hard to overcome adversity in their own lives.

I thank you for your support in the past and this opportunity to speak to you again today.

Key Congressional Committees for Post-Polio Issues

U.S. Senate

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

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

Arlen Specter (R-PA) Ranking Minority Member staff: Douglas Loon
Mark Hatfield (R-OR) staff: Betty Lou Taylor
Ted Stevens (R-AK) staff: Jane Rosenquist
Warren Rudman (R-NH) staff: Christine Ciccone
Thad Cochran (R-MS) staff: Forest Thigpen
Phil Gramm (R-TX) staff: John Cerisano

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

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

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

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

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In the Spring 1992, ***Polio Network News*** (Vol 8., No 2) we incorrectly printed a P.O. Box number for Nancy Baldwin Carter's book of 50 essays entitled ***Of Myths and Chicken Feet: A Polio Survivor Looks at Survival.*** It is available from Nebraska Polio Survivors Association, P.O. Box 37139, Omaha, NE 68137 USA for $6.95 plus $2.00 shipping and handling.

Co-sponsors of National Polio Awareness Week

The following legislators co-sponsored HJ Res. 404 — National Polio Awareness Week for 1992.

CALIFORNIA Frank Riggs, Bob Dornan , Barbara Boxer, Carlos Moorhead, Jerry Lewis, Julian Dixon, Glenn Anderson, William Thomas, David Dreier

FLORIDA William Lehman, Charles Bennett

ILLINOIS William Lipinski, Harris Fawell

INDIANA Andy Jacobs

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TEXAS Bill Sarapalius, Martin Frost, Ralph Hall, Charles Wilson

VIRGINIA Jim Moran

WASHINGTON John Miller, Rod Chandler

WEST VIRGINIA Bob Wise

WISCONSIN Jim Moody, Gerald Kleczka

DISTRICT OF COLUMBIA Eleanor Holmes-Norton

The number fell short of the 218 sponsors needed. **International Polio Network** would like to thank the leaders and individuals in the above states for their cooperation. We would like to invite leaders/individuals from the states not listed to join us in our future efforts.

Thanks to John T. Doolittle, CA and his staff for introducing the resolution and for their cooperation in bringing post-polio issues to the attention of the Department of Health and Human Services.

Poliomyelitis and Scoliosis by Serena S. Hu, MD, will appear in the Fall 1992 (Vol. 8, No. 4) issue of ***Polio Network News.***

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

Ms. Joan Headley, Executive Director
International Polio Network
5100 Oakland Ave., #206
St. Louis, Missouri 63110

Dear Ms. Headley:

I am pleased to recognize this week of June 1 through June 7, 1992 as "National Polio Awareness Week" to increase our understanding of polio and its late effects.

As a physician, I am well aware that the effects of polio can be devastating. While new and effective vaccines have dramatically decreased the number of Americans with the disease, the polio epidemics of the past have exacted an enormous emotional and physical toll on thousands of our citizens, thus preventing them from living full, productive lives. Long after their recovery from the initial illness, some of the 650,000 polio survivors in the United States now suffer from new muscular weakness and atrophy, fatigue, respiratory problems, anxiety, and pain. Together, these symptoms are known as post-polio syndrome. While modest exercise, weight maintenance, and physical and drug therapy can all help patients, a cure for this complex and mysterious disorder remains elusive.

For more than 100 years, physicians have recognized that some patients experience later-life problems related to polio. Until recently, however, little was known about the phenomenon. As the number of polio survivors with new symptoms continues to increase, the biomedical research community has begun to develop a better understanding of post-polio syndrome. Leading America in the effort to unlock the secrets behind post-polio syndrome is the Federal Government's National Institute of Neurological Disorders and Stroke (NINDS). Thanks to research supported by the NINDS, scientists now find that the new muscle weakness in patients can be related to overuse of polio-damaged nerve cells in the spinal cord. Investigators are also learning more about what happens to cause other symptoms of post-polio syndrome, such as swallowing abnormalities, that might be life-threatening. Such findings may pave the way to new treatments for the disorder.

I congratulate the International Polio Network and other volunteer organizations who share the common goal of improving the health and well-being of people with post-polio syndrome. In addition to educating the public, your efforts to promote research on post-polio syndrome, along with those of the NINDS, are our Nation's best hope for new methods of treatment within this, the Decade of the Brain. The Federal Government will continue to fight along with you to find better treatments, and ultimately a cure and method to prevent polio, thus erasing this disease once and for all.

You have my very best wishes for success in all your programs.

Sincerely,
Louis W. Sullivan, M.D.

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CALENDAR

How to Be a True Polio Survivor and Like It, Northeastern Ohio Universities, College of Medicine, Meshel Conference Center, **Rootstown,** OH, August 15, 1992. Contact: Betty Sugarman, Ohio Easter Seal Society, (1/800-451-8695).

Managing Post-Polio Problems II, Delta Pacific Resort Hotel, **Richmond,** British Columbia, Canada, October 15-18, 1992. Contact: PPASS, P.O. Box 6579, Dept. #1, Victoria, British Columbia V8P 5N7 (604/477-8244).

Polio Partnership, Australasia (Australia and New Zealand) Conference on Post-Polio, the Paris Hotel, North Terrace, **Adelaide,** November 15-16, 1992. Contact: Heather Trenorden, Neurological Resource Centre of S.A., Inc., 37 Woodville Road, Woodville, South Australia, 5011 (08/268-6222).

Second Annual Seminar, North Central Florida Post-Polio Support Group, Holiday Inn West, **Ocala,** FL, November 14, 1992. Contact Carolyn Raville, 7180 SW 182nd Court, Dunellon, FL 32630 USA (904/489-1731).

Second International Medical Congress of the Stiftung Pfennigparade Rehabilitation Centre, Congress Centre, Arabella-Hotel, **Munich,** November 19-21, 1992. Contact: Dr. Angelika Bockelbrink, Stiftung Pfennigparade, Barlachstr. 38, 8000 Munich 40 (tel: 49.89. 30 61 62 01).

Post-Polio Syndrome: Symptoms, Treatments, and Networking, Long Beach Airport Marriott, **Long Beach,** CA, November 21-22, 1992. Contact: Southern California Post-Polio Network, 9041 Imperial Highway, Suite L, Downey, CA 90242 (310/862-7674).

Second Conference on Polio Eradication and Post-Polio Physical Rehabilitation in the Indian Region, Home for Handicapped (Polio) Children, LMS Compound, Trivandrum 795033, **Kerala, India,** January 27-30, 1993. Contact: S. Jones, Honorary Director and Convener at the above address.

International Polio Network

5100 Oakland Ave., #206
St. Louis, MO 63110 U.S.A.
314/534-0475

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

ISSUED QUARTERLY

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Special Thanks:
Joseph B. Leone

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Joan Headley, *Executive Director*

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