



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

Fall/Winter 2013 / Vol 24. No. 1

“Don’t Be Afraid to Travel”

By Joan Swain



Linda Wheeler
Donahue

“Traveling not only provides fun and adventure, it also affords marvelous insights and enlightens our minds.” With this introduction, Linda Wheeler Donahue led a stimulating workshop that she said would “encourage you to leave your comfort zone and get out and travel,” at the Polio Network of New Jersey’s 23rd Annual Conference for Polio Survivors in April.

Helping Linda, who is President of the Polio Outreach of Connecticut and a frequent presenter at conferences, were Lottie Esteban and Joan Swain, board members of the Polio Network of New Jersey. Linda spoke about air travel, Lottie, about land travel, and I covered ocean cruising. Lottie’s and my portions of the Travel Workshop will appear in a later newsletter.

“What are the steps you need to take to assure a barrier-free flight?” Linda asked. Planning ahead was her number one suggestion, followed by:

- Try to locate a non-stop flight
- Call the airline
- Tell of your disability needs (these are called Special Service Requests (SSR) in airline terminology)
- Tell them you will need Meet and Assist service (a wheelchair and pusher)
- Tell them about your wheelchair/scooter
- Request an aisle seat (that will make it easier to get to the rest room)

At the Airport

Once at the airport, you and your equipment will undergo security screening. This can be done in your chair or scooter. You will board the plane before others (first on, last off). If you cannot ambulate to reach your seat, you can use a narrow wheelchair called an aisle chair. During the flight, Linda advises moving your legs every hour to avoid deep vein thrombosis. She suggests reminding the flight attendant to confirm with ground crew personnel that you require Meet and Assist service when the plane lands.

When you have landed, you will be the last to deplane. Meet and Assist will meet you at the plane door on the jetway and then take you to Baggage Claim, where you will reunite with your own chair and airline personnel to reassemble it. (Ed. Since I do not request Meet and Assist service, my experience is that my scooter is waiting at the plane door.)

So What Happens if Your Mobility Device is Damaged?

Linda explained how, in 2005, she experienced damage to her power wheelchair on a flight to speak at a conference. That’s the bad news. But the good news was that a Complaint Resolution Officer (CRO) at the airport worked with her to resolve the problem. “They gave me a loaner chair and arranged fairly prompt repair of my own chair,” she said. “And they delivered my repaired chair to me at the conference three days later.”

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PNNJ’s 2014 Conference to Highlight Two Physicians with “Polio Credentials”

PNNJ takes great pleasure in announcing the principal speakers for our 24th annual conference, set for Sunday, April 27th, 2014, at the Bridgewater Marriott Hotel, in Bridgewater, NJ. Further program details and registration information will be included with the Spring 2014 *Newsletter*.

Dr Glaser, Osteopath, to be Keynoter



Judith Glaser, MD

Judith Glaser, Doctor of Osteopathic Medicine (DO), of New Hyde Park, NY, will be the principal medical speaker for the one-day conference. In addition to being

among the rare physicians who care for people with post-polio syndrome, Dr Glaser has developed expertise in diagnosis and treatment of various pain conditions. She is Board Certified in physical medicine and rehabilitation and has presented nationally and internationally on post-polio issues. Dr Glaser also has specialized training and is certified in medical acupuncture for pain relief.

After graduating from New York College of Osteopathic Medicine in 2005, Dr Glaser completed her residency training at the renowned RUSK Institute of Rehabilitation Medicine in 2009. She

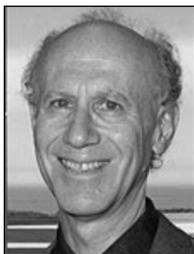
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2014 Conference

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was co-director of the Post-Polio Clinic and an attending physiatrist at the National Rehabilitation Hospital, Washington, DC, from 2009 to 2012, after which she returned home to Long Island to start her own practice. She holds hospital privileges at North Shore University Hospital-LI Jewish Medical Center. Website: www.drjudithglaser.com

Dr Salk to be Luncheon Speaker



Peter L Salk, MD

Peter L Salk, MD, president and director of the Jonas Salk Legacy Foundation, will be the luncheon speaker. Dr Salk, whose medical practice is located in La Jolla,

California, is the eldest son of Dr Jonas Salk. After graduation from Johns Hopkins University School of Medicine and staff training in internal medicine at the University Hospitals of Cleveland, he worked in his father's laboratory at the Salk Institute from 1972 to 1984, conducting research on immunotherapy for cancer and autoimmune diseases.

The Jonas Salk Legacy Foundation has undertaken a collaborative program with Spencer Trask & Company called BeyondPolio as part the global effort to eradicate polio and maintain success once eradication is achieved. The Foundation will work with other organizations to plan events for the centenary year of Jonas Salk's birth in 2014.

Travel

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This successful resolution of the problem is a result of the Air Carrier Access Act (ACAA), which prohibits discrimination on the basis of disability in air travel and requires air carriers to accommodate the needs of passengers with disabilities. As a result, every domestic carrier that operates scheduled service must designate at least one Complaints Resolution Official at each airport it serves to resolve ACAA complaints. This CRO must be available 24 hours per day at a given airport.

Linda now does a number of things before leaving home:

- Laminate information about battery type, dimensions, and weight of her chair
- Make name and address labels and put on all parts of the wheelchair
- Make arrow signs for "This end UP" and "Do not lay on SIDE"
- Scooter Users: bring a photocopy of instructions of how to dismantle your scooter
- Be able to explain, if need be, how to disassemble and reassemble your scooter

She also brings bubble-wrap and a cardboard cone to the airport to protect the sensitive joy stick on the wheelchair. And she brings a large zippered bag to hold loose parts of the chair during flight.

Knowing that help is available in the unlikely event one's wheelchair or scooter is damaged on the flight is certainly reassuring. As Linda advised, "Provided that you are resourceful, assertive, and plan ahead, there is no reason why your trip should not be a

PHI's 11th International Conference

*"Promoting
Healthy Ideas"*

Saturday, May 31, 2014 –

Tuesday, June 3, 2014

St. Louis, Missouri

www.post-polio.org

complete barrier-free success." Remember, don't be afraid to travel!

Two additional articles from the travel workshop and an article on swallowing, both from the PNNJ April 2013 Conference, will appear in future newsletters.

Your Flu Shot Could Have a Good Side Effect

Sometimes our drugs have surprising *good* side effects! New research finds some common drugs can also help prevent cancer, improve heart health, even enhance creativity. One of those drugs is the common flu shot. Its potential perk is heart disease and stroke protection.

A new review of research finds that getting a flu shot could cut your risk of having a heart attack or stroke by 48 percent. Study coauthor Jacob A Udell, MD, of Women's College Hospital in Toronto, speculates that getting vaccinated "may block the inflammatory response our bodies mount to combat a flu infection, which protects arterial plaques from rupturing and causing a cardiac event." This is one more reason to line up for your flu shot if you have not done so already.

SOURCE AARP MAGAZINE 2013

Able Newspaper Now Online

Able Newspaper, the newspaper for, by, and about people with disabilities, has moved online. Get a free subscription by visiting www.ablenews.com to register. Just click the FREE ONLINE EDITIONS button at the top left of the home page.



Edwina Jackson, leader of the Essex-Union Area Post-Polio Group, (seated, left), Irvington Mayor Wayne Smith (first row center), and Rotary Walk organizer Kim Joseph (standing, row 2, first on left) with participants at the first annual Irvington Rotary Walk for Polio, held May 4, 2013.

Findings of Dr Westerman's PPS Study

We are happy to report the results of a study of Post-Polio Syndrome prepared by S. Thomas Westerman, MD. Two hundred surveys were mailed to members of the Polio Network of New Jersey. The people with confirmed diagnosis of PPS were asked to complete the survey and return it by mail. Eighty-four patients with a known diagnosis of Post-Polio Syndrome completed the survey and were enrolled in the study. According to Dr Westerman, his findings are compatible with the major findings of polio studies. The aim of his work was to have a publication that polio survivors could give to their medical providers to enlighten or refresh their memory about PPS. In the following document, Dr Westerman describes his findings.

Clinical Features of Post-Polio Syndrome (PPS): An Under-Recognized but Common Syndrome in Polio Survivors

(DOCUMENT FOR PPS PATIENTS TO GIVE TO MEDICAL PROVIDER)

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Thank you to all the participating members in the study of Polio Network of New Jersey for your responses.

The objective of this study was to update healthcare providers' knowledge of Post-Polio Syndrome (PPS). With PPS, new onset of symptoms, such as progressive muscle weakness, pain,

muscle atrophy, unusual fatigue, cold intolerance, and swallowing and breathing difficulties, that occur many years after acute poliovirus infection is common. The weakness is usually in muscles that were previously affected by poliovirus.

PPS is rarely life-threatening; however, untreated respiratory muscle weakness can result in under-ventilation, weakness in swallowing muscles can result in aspiration pneumonia or food passage obstruction, and weakened muscles can result in falls.

Epidemiologic studies indicate that PPS affects a substantial proportion of the approximate 500,000 polio survivors in the United States, including approximately 30,000 polio survivors living in New Jersey. The exact prevalence of PPS is not known, but our study with the Polio Network of New Jersey revealed that the PPS prevalence was close to 100%. The post-polio problems usually begin 30 to 40 years after initial episode.

The cause of PPS is not fully understood, but a combination of distal degeneration of motor units caused by increased metabolic demands and the normal aging process, in addition to inflammatory mechanisms, are thought to be involved.

Comparison of symptoms between persons with PPS and those without PPS >65 years as per surveys:

Symptoms	People with PPS age 52-87yrs	General Population >65 years
Pain	100%	25-65%
Difficulty Swallowing	96%	30%
Dizziness and imbalance	99%	29-36%
Anxiety/ depression	95%	25%
Sleep disturbances	96%	50%

METHODS: Two hundred surveys were mailed to members of the Polio Network of New Jersey; the people with confirmed diagnosis of PPS were asked to complete the survey and return by mail. There were no patient identifiers on the surveys, and the envelopes were shredded after the survey was removed. All survey answers were entered into a database and abstracted to collate the results.

RESULTS: Eighty-four patients with a known diagnosis of PPS completed the survey and were enrolled in the study.

- 96% of patients reported that their physicians did not have any knowledge about PPS and ascribed their symptoms to age or psychological factors.
- 60% did not receive any specific treatment;
- 8% received anti-depressants or benzodiazepines
- 14% received what is considered the appropriate treatment of rest, balanced exercise, dietary modification, physical therapy, psychotherapy, and use of assistive devices
- 16% received treatment consisting of non-steroidal anti-inflammatory agents, exercise, multivitamins and dietary supplements.

Symptoms of Post-Polio Syndrome (PPS) usually appear earlier in patients who have very severe residual weakness; individuals who had early bulbar respiratory difficulty in the acute illness; and persons who were older when they contracted acute polio. The severity of residual weakness and disability after acute poliomyelitis tends to predict the development of PPS. PPS symptoms tend to occur first in the weaker muscles. In individuals without polio or PPS, the functional consequences of aging and loss of motor units may be unnoticeable until a very advanced age. In the individual with PPS, loss of strength may be more readily apparent sooner. Weakening of bulbar muscles causing dysphagia, weakness of voice, and vocal changes has been reported among PPS patients but bulbar symptoms are not among the most frequent features. The risk of respiratory insufficiency should be considered, because it could lead to serious complications including increased frequency of respiratory infections, hyperpnea, pulmonary arterial hypertension, and ultimately, cor pulmonale. For PPS patients, weakened respiratory muscles in addition to severe chest deformities, such as kyphoscoliosis, can cause respiratory insufficiency. Typical symptoms are daytime sleepiness, sleep apnea, morning headache, and dyspnea.

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The basic principle of management of PPS lies in physical activity, individually tailored training programs, and lifestyle modification. An afternoon short nap may alleviate fatigue and allow normal continued afternoon work. There is no definitive treatment for PPS but symptomatic improvement may be obtained with analgesics, local heat application to affected joints or muscles, and a low-impact, non-fatiguing exercise program to prevent the development of muscle atrophy. Patients may benefit from rest, increased sleep time, and other energy conservation methods to overcome fatigue.

The following suggestions are usually beneficial:

- Self-management is essential for treatment.
- Limit activities that cause pain or fatigue.
- Protect the lungs – avoid environmental pollutants and extremes in temperature.
- Stay warm, as cold increases muscle fatigue.
- Conserve energy by pacing activities.
- Healthy life style: No smoking, eat healthy foods, avoid stress.
- Support groups can help many persons with PPS deal with common problems.

CONCLUSION: Post-Polio Syndrome is an under-recognized but common syndrome in polio survivors and many Primary Care Physicians are not familiar with the diagnosis and treatment of PPS.

Post-Polio Syndrome is characterized by new weakening in muscles that were previously affected by the polio infection and in muscles that seemingly were unaffected. Symptoms may include tiredness, breathing and swallowing dysfunction, and balance problems which may have tragic consequences if not diagnosed and treated in a timely manner. Lack of awareness of PPS symptoms places the patients at risk of complications. Symptoms of problems with breathing, sleep apnea, falling, swallowing, muscle fatigue, and depression require specific attention and treatment in a person with PPS.

S. Thomas Westerman, MD
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Gov. Christie Proclaims Post-Polio Awareness Week

New Jersey Governor Chris Christie proclaimed October 20 to October 26, 2013, as Post-Polio Awareness Week in New Jersey. The Proclamation points out that "Post-Polio Syndrome (PPS) is a secondary illness that sometimes strikes polio survivors 15 to 40 years after the initial onset of the virus and is characterized by progressive muscle weakness, severe fatigue as well as pain in muscles and joints." It is estimated that the condition affects 25 to 40 percent of polio survivors.



Polio Network of New Jersey NEWSLETTER

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You Can Copy Us!

You are welcome to copy material from this newsletter. We ask that you credit the Polio Network of New Jersey Newsletter.

Tuning in on the Polio Network of NJ

ATLANTIC COUNTY AREA

Ye Olde Mill Street Pub
6033 Main St, Mays Landing
3rd Wednesday at 12 noon
Contact: Marge or Steve Disbrow
For directions and to confirm date
609-909-1518
kittystamp@comcast.net

BERGEN COUNTY

Maywood Senior Center
Duvier Place, Maywood
1st Saturday, 11:30 am-1:30 pm
Contact: Heather Broad 201-845-6317
hbroad@netzero.net

ESSEX-UNION AREA

East Orange General Hospital
300 Central Avenue, East Orange
2nd Saturday, 12 noon to 2 pm
March, June, September, December
Contact: Edwina Jackson 973-699-1564 or
Thelma Van Liew, 908-753-6514
nubianqueen8@aol.com

MONMOUTH COUNTY AREA

Seabrook Village
300 Essex Road, Tinton Falls
3rd Monday at 2 pm
Contact: Toni Wilczewski 732-229-9343
skywash01@aol.com

MORRIS COUNTY AREA

Denville Municipal Building
1 St. Mary's Place, Denville
3rd Saturday, 11 am
April, May, June, September,
October, November
Il Villaggio Restaurant
22 Gibraltar Drive, Parsippany
973-644-4888
Dinner meeting, 3rd Wednesday evening
March, July, December
Vince Avantagiato 973-769-0075
drvince@njpolio.org

OCEAN COUNTY AREA

Health South Rehabilitation Hospital
of Toms River
14 Hospital Drive, Toms River, NJ 08755
Four (4) times a year on Saturdays
April, June, September, and November
Contact and confirm date and time with:
Jerry Bojko 732-505-0151 or
Susan Payne Gato 732-864-0998
Website: www.tomsrivernjpolio.org

RARITAN VALLEY-

Somerset/Hunterdon Counties
Manville Library, Manville, 908-722-9722
1st Saturday, 10:30 am-12:30 pm
Oct, Nov, Dec, March, April
Contact: Ray Jajko 609-531-6595
flyguyray@verizon.net

SOUTHWEST JERSEY AREA

New Seasons at Voorhees
501 Laurel Oak Road, Voorhees
4th Saturday, 10:30 am-12 noon
Contact: Anna Nasuti 856-740-1106
amn46@comcast.net

As meeting locations, days, and times may change, it is advisable for those who are not in frequent touch with support groups to call the contact persons in advance of your planned attendance.