



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

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Join Us to Hear Outstanding Speakers at PNNJ's 25th Anniversary Conference

by Jean Csaposs

With great pleasure, the Board of Directors of the Polio Network of New Jersey announces an outstanding program for our 25th anniversary conference, Sunday, April 26th, 2015, at the Bridgewater Marriott Hotel. The one-day event will get under way beginning at 9 a.m. with registration, continental breakfast, and the opportunity for several "early-bird" sessions for those who like to begin gathering useful information before our main events. As usual, exhibitors of goods and services useful to polio survivors will be in attendance.



Dr Jerald Zimmerman

Dr Zimmerman To Be Keynoter

Our principal medical speaker will be Dr Jerald Zimmerman, a specialist for 28 years in the field of physical medicine and rehabilitation. A longtime friend of our Network, Dr Zimmerman has many years of experience dealing with polio survivors, including a number of our members. His practice as a physiatrist ranges beyond post-polio treatment and rehabilitation; he works to increase or restore functional ability and quality of life in patients "with injured bones, muscles and tissues," including those suffering a wide range of physical disabilities and

deficiencies such as brain injury, stroke, multiple trauma and spinal cord disorders. A 1982 graduate of the University of Illinois College of Medicine at Chicago, Dr Zimmerman practices in Englewood, New Jersey. He has been honored by his peers twice in "Castle Connolly Top Doctors: New York Metro Area," for 2002-08 and 2010-14. His website is: www.jeraldzimmerman.md.com.

"Clinical Edutainer" to Make A Joyous Return as Luncheon Speaker

Rosemarie Poverman, among the most enjoyable of our conference speakers, and clearly the most entertaining, is paying a return visit "by popular demand," to be our luncheon speaker. A licensed clinical social worker, she prefers the title "Clinical Edutainer" because of her light-hearted approach to life's problems. Rosemarie customizes her humor-based programs to her audiences. She has expertise in personal and stress management, problem-solving and decision-making, and communication and relationship enrichment, but she takes a wonderfully useful and funny approach to it all, teaching HUMOR SKILLS as self-empowerment skills. Most importantly she leaves her audience with a renewed sense of the ability to be creative, stay energized and keep "the self" smiling, while having a good time learning and laughing.



Rosemarie Poverman

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New York First to Use New "In-Motion" Wheelchair Logo



A revamped version of the blue and white icon that's long symbolized accessibility everywhere from parking lots to restrooms will soon be commonplace in more communities.

New York will become the first state to require all new and replacement signage used to signify accessibility for people with disabilities to include a more active, in-motion image of a person using a wheelchair.

The state will also change the terminology on such signs, employing the word "accessible" instead of "handicapped."

The shift is about more than aesthetics, New York Gov. Andrew Cuomo said in signing the legislation. "This bill is an important step toward correcting society's understanding of accessibility and eliminating a stigma," Cuomo said.

New York City and a smattering of other localities, businesses, and schools have already agreed to adopt the revamped symbol, known as the "Accessible Icon." The updated symbol was the creation of designers in Massachusetts and started as a street art campaign that illegally put the updated image over existing signs. Now its creators have co-founded an advocacy

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Dr. Calmes Outlines Anesthesia Issues for Post-Polio Patients

Selma Calmes, MD, retired Clinical Professor of Anesthesiology, UCLA School of Medicine, spoke at the September 20, 2014 conference “We’re Still Here!” Living with the Late Effects of Polio,” presented by the California North Coast Post-Polio Group. Included in Dr Calmes’ talk was the following list of “Anesthesia Issues for Post-Polio Patients.”

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you’re using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
3. Succinylcholine often causes severe, generalized muscle pain postop. It’s useful if this can be avoided, if possible.
4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to “spill-over” of the inflammatory response. Spinal cord “wind-up” of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.
5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original

disease (the inflammation and scarring in the anterior horn “spills over” to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilator function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It’s useful to get at least a vital capacity (VC) preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs are those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilator support. Another ventilation risk is obstructive sleep apnea, often a problem in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

COMMENT: Postop respiratory failure in these patients can be difficult to manage. The patient’s pulmonary physician could help by doing a preop evaluation and being involved in postop ventilator management. This situation might call for the resources of an ICU in a major medical center.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients is useful.
8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.
9. NEW IDEAS/THOUGHTS:
Spinals: Recent studies demonstrating the presence of cytokines in the CNS of PPS patients lead me to be less

enthusiastic about using spinal/epidural anesthesia. There is no data on this situation, and there are so many benefits to this regional anesthesia, and it might be suitable in some situations. Lidocaine would not be a suitable drug choice for PPS patients. It has been shown to cause nerve damage when used for a spinal.

Regional anesthesia: Should the peripheral nerves of PPS patients be exposed to local anesthetics, especially for long periods postop? There is no data, but many PPS patients have atrophied peripheral nerves. Perhaps smaller doses of local anesthetics and avoiding continuous postop infusions would be safer.

Above-the-clavicle blocks (supraclavicular and interscalene approaches): These have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

SUMMARY:

PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery, and hospital care. For an optimal outcome, ALL MUST BE AT HIGH LEVELS OF PERFORMANCE AND ACHIEVEMENT! You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state’s hospital licensing department, the state’s medical board, and other resources. You should also research the operation and its consequences to be sure you can deal with them. Don’t rush into anything until you’re satisfied you’ll get the best. You deserve it.



“We’re Still Here!” Living with the Late Effects of Polio Conference

We’re grateful to Larry Csaposs, son of PNNJ President Jean and Jim Csaposs, who attended the “We’re Still Here! Living with the Late Effects of Polio” Conference presented by the California North Coast Post-Polio Group on September 20, in Pleasant Hill, California, and sent Jean a folder full of helpful information. Larry is a senior physical therapist for Kaiser Permanente, in Vacaville, California.

In addition to Selma Calmes, MD, whose “Anesthesia Issues for Post-Polio Patients” appears in this issue, conference presenters included other specialists in the fields related to post-polio syndrome. We’ll be including information from them in future issues of the *Newsletter*.

Letter to the Anesthesia Department Prior to Elective Surgery

It is suggested you send a letter such as the following sample:

(Addressee)

Can you please see that the anesthesiologist assigned to my case gets these documents in time to read and digest the material? It is imperative that he knows my weaknesses so that he can plan accordingly.

My surgery is at 8 a.m. on (date) at (hospital name and location).

*Thank you,
(signed)*

SOURCE: INFORMATION PACKET
“WE’RE STILL HERE! LIVING
WITH THE LATE EFFECTS OF
POLIO”

Nancy Frick Remembered

by *Jean Fox Csaposs*



Nancy M. Frick

Nancy, in the driver’s seat (her wheelchair), gave me my first ride in a lift-equipped van in 1980. She offered to drop me off at home in New Jersey after we met and worked together on a disability project in her office in Manhattan’s Federal Building, where she served in the Office for Civil Rights. We met frequently after that, mostly in Maywood’s Supermarket, and exchanged the latest news. I soon learned how much Nancy was contributing, along with her husband, Dr Richard Bruno, to research on the causes and treatment of post-polio syndrome and on the psychological impact of PPS on polio survivors. A widely respected author and lecturer, Nancy presenter at our Polio Network conferences, and was interviewed by the national media. An expert on the ADA, she was a leading advocate for people with disabilities. “Nancy was driven, smart, open, caring and, in spite of all she experienced,” said Dr. Bruno, “including two surgeries to fuse her back and literally years in the hospital – she was consistently happy and optimistic.” Nancy’s death on November 12th following surgery was a loss to those who knew her and to untold numbers of polio survivors.

Universal Hand-Free Phoning

For those with limited arm movement who can’t use touchscreens, Tecla is a burgeoning technology that allows you to use your wheelchair’s auxiliary controls on your cell phone. So now you can use your phone as easily as your wheelchair. It’s Android, iPhone, and iPad compatible. Go to www.tecla.com.
SOURCE: NEW MOBILITY, SEPTEMBER 2014

New Weakness in an “Unaffected” Muscle Explained

New weakness is the cardinal symptom of PPS. The new weakness is located in muscles previously affected by polio as well as in muscles believed to be unaffected by the original illness. At first glance, the phenomenon of “unaffected” muscles becoming weak seems contradictory but, in fact, is well known. Usually, it means that the polio was so mild in those muscles at the time of the original illness that the individual, as well as health care professionals, was unaware of any polio involvement in those particular limbs. However, there was enough loss of motor neurons that after many years of overuse, new weakness developed.

SOURCE: DR. ELIZABETH SANDEL,
PHYSIATRIST, MEDICAL DIRECTOR OF
KAISER FOUNDATION REHABILITATION
CENTER, VALLEJO, CALIFORNIA

Health Briefs

Brain Food. Fish is brain food. Researchers who looked at brain scans of healthy older adults enrolled in a 10-year study found that those who regularly ate any kind of baked or broiled fish – but not fried – once a week had more gray matter in brain regions responsible for memory and cognition.

D for Dementia. One of the largest studies of its kind finds that low levels of vitamin D may double the risk of developing Alzheimer’s and dementia. Researchers who followed nearly 1,700 adults over age 65 for six years found that those with low vitamin D had a 53 percent increased risk of developing dementia and a nearly 70 percent higher risk of Alzheimer’s.

*Abilities
Expo*

May 1-3, 2015
NJ Conference &
Expo Center
www.AbilitiesExpo.com

Weather Observer Jim McKay Receives Thomas Jefferson Award

James S McKay, of Estell Manor, NJ, a member of the Atlantic County Area Post-Polio Group, received the National Weather Service (NWS) Thomas Jefferson Award at a ceremony in September. For almost 50 years, Jim has been an active and dedicated cooperative weather observer for the NWS, taking daily temperature and precipitation measurements since a teenager.

Jim worked for the NWS as a meteorologist for 15 years, and since then, has continued to provide thorough and accurate reports on a daily basis. He has encountered numerous extreme weather conditions over the years, including Superstorm Sandy, in order to maintain continuous weather reports. This 50-year feat is even more exceptional considering Jim deals with the effects of polio and uses crutches and a golf cart to obtain his daily observations.

The weather records collected by Jim have been used by the local shore community, including the Estell Manor Volunteer Fire Department and by organizing officials for Atlantic City Race Week. CONGRATULATIONS, Jim!
SOURCE: NATIONAL WEATHER SERVICE, PHILADELPHIA/MOUNT HOLLY, PA/NJ WEATHER FORECAST OFFICE

ADA Legacy Tour Kicks Off

The Americans with Disabilities Act Legacy Tour kicked off on July 25 at the NRG Center in Houston, Texas. Organizers say they chose Houston because it is the home of former President George H. W. Bush, who signed the ADA into law.

The yearlong bus tour will crisscross the nation, generating awareness for the landmark civil rights bill. At each stop a large display will educate visitors on disability history and milestones. There will also be workshops and giveaways to help celebrate the civil rights law.

For the latest information on the tour visit www.adalegacy.org.

SOURCE: NEW MOBILITY, SEPTEMBER 2014

25th Anniversary

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Rosemarie tells us that her life experiences allow her to connect with a broad spectrum of people. She has been a flotilla commander in the Coast Guard Auxiliary, has worked as a licensed flag-person in the Sports Car Club of America, raised three children, stayed married to her college sweetheart, and is a published photographer. She does not, however, take housework seriously and laughs whenever possible at the absurdities of life that get in the way of lusty living. Her website is: www.rosemarieoverman.com.

The PNNJ 25th Anniversary Conference also coincides with the 25th Anniversary of the passage of the Americans with Disabilities Act (ADA). That milestone gives us additional cause for celebration on April 26th. Registration information for the Conference will be supplied in the spring *Newsletter*, scheduled for early March 2015 – but be sure to save the date *now* for an unforgettable experience!!

“In Motion” Logo

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organization that is pushing to have the symbol accepted around the world.

The city has been using the new icon on car placards since last December, and hopes to have all DOT parking spots updated by the end of the year. The Social Security Administration has also started using the new logo.

SOURCE: DISABILITYSCOOP, 11/28/14, AND PBS NEWSHOUR, 10/11/14

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
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
Lunch meeting, 3rd Wednesday at 1 p.m.
March, July, December
Vince Avantagiato 973-769-0075
Vincent_wfgmail@verizon.net

OCEAN COUNTY AREA

Health South Rehabilitation Hospital
14 Hospital Drive, Toms River, NJ 08755
Four (4) times a year on Saturdays
April, June, September, and November
Contact: 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, May
Contact: Lee Bekir 908-359-6736
leebekir@njpolio.org

SOUTHWEST JERSEY AREA

Voorhees Senior Center, 3rd floor
501 Laurel Oak Road, Voorhees
4th Saturday, 11:00 am-12:30 pm
Contact: Anna Nasuti 856-740-1106
amn46@comcast.net

DELAWARE LIAISON

John Nanni
609-605-4007 or jntenor@yahoo.com

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.