



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

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Balance and Swallowing: Conference Topic of Dr S Thomas Westerman

by Jean Csaposs

"A Polio Survivor's Guide to Balance and Swallowing" was the topic of an informative presentation by Dr S Thomas Westerman at PNNJ's 18th annual post-polio conference in April 2008. A specialist in otolaryngology, Dr Westerman has a practice in Shrewsbury, NJ, that includes treatment for hearing, balance, nasal and sinus, allergy, taste and smell, and laryngeal and esophageal problems. He is clinical professor of otolaryngology at Drexel University College of Medicine.

Balance Problems

"When a patient presents with unusual symptoms related to balance," Dr Westerman said, "we first examine the gait." Using slides, he demonstrated a normal gait: the knee extends, the heel touches ground, and the toes point towards the ceiling. The arms alternate swinging backward and forward. There are three sources of input into maintaining balance: the ears, the eyes, and the spinal reflexes. Alcohol, when consumed, immediately affects the inner ear; the eyes move in a certain way, and the individual walks more slowly, feet apart, to maintain balance and make up for the inner ear problem slowed down by the alcohol.

"The inner ear knows where we are in space because of its balancing function. In post-polio patients," he continued, "the imbalance is not an inner ear problem, but lack of sufficient muscular support." Foot-drop, a typical polio problem, is a major cause of imbalance, but there are many others.

After reviewing the principal characteristics of PPS, Dr Westerman said it is imperative to determine that our symptoms do not have other causes. Throughout his presentation, he compared PPS symptoms to such disorders as multiple sclerosis, Charcot-Marie-Tooth disease (CMT), Parkinson's, diabetes, hypertension, and stroke, insisting that polio survivors are just as susceptible to these diseases as is the general population. Some of these also exhibit balance problems. Cranial nerve paralysis can develop in polio survivors; eye, facial, and neck muscles may become weaker with age, thereby increasing problems with balance.

The Overuse-Underuse Dilemma

Dr Westerman showed a slide of the part of the brain that controls "central services" – breathing, heartbeat, and temperature. In polio that affected the spine and anterior horn cells, with age comes a gradual weakening and gradual disappearance of the cells. He referred to "post-polio unit dysfunction," caused by both overuse and disuse. "But there is a dilemma: if you overuse, you experience cramps, pain, muscular trauma, and thus additional damage. But with disuse or underuse," he said, "you risk atrophy, further deterioration, and weight gain."

Dr Westerman reviewed three major types of dizziness: syncope (lightheadedness), disequilibrium, and true vertigo (the "merry-go-round" sensation). There are tests for these and other balance problems, and the good news is, there are some treatments. But the patient must provide a detailed history of the symptoms.

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William Ditto to Speak at PNNJ Conference October 25th

William A B (Bill) Ditto, director of the State Division of Disability Services, will be a principal speaker at PNNJ's annual conference on Sunday, October 25th, at the Princeton DoubleTree Hotel. Mr Ditto's primary professional areas of expertise are disability and aging issues, personal care services, consumer-directed services, long-term-care policy, healthcare policy and financing, and family support. The Division he directs is deeply involved in exploring and promoting the most progressive public funding of these services.

Encouraging Independence

A branch of the NJ Department of Human Services, DDS "promotes and facilitates the maximum independence and participation of people with disabilities in all aspects of community life through active information exchange and the provision of community services."

A pioneer in the cause of self-directed care in the home for those who need attendant services, Mr Ditto holds the Master of Social Work (MSW) degree from Rutgers University, and a B A from Monmouth College, West Long Branch. He joined state government in 1985. We look forward to his second visit to a PNNJ conference.

Dr Keenan Keynoting

As already announced, Dr Mary Ann E Keenan, an orthopaedic surgeon renowned for her expertise in shoulder care, will be the keynote speaker at the conference. Full program details and registration information will be included in the Summer issue of the *Newsletter* scheduled to mail in early September.

LegalEase...

by Arthur P Siegfried, Esq

The United States Supreme Court recently rejected a drug company's claim that it cannot be sued for damages in State courts if the product and its label have been approved by the FDA. The drug company argued that the approval by the FDA and Federal regulatory rulings automatically preempted the states from enforcing any tougher standard on drugs. This raised several issues, one of which is the conflict between Federal courts and State courts.

The case before the United States Supreme Court involved a Vermont woman who developed gangrene after a botched injection of an anti-nausea drug, necessitating the amputation of her hand and lower arm. Vermont's courts awarded the woman \$6.7 million considering, apparently, that she was a musician. The woman injured lost her livelihood, and also claimed that the drug company failed to warn, emphatically enough in the label approved by the FDA, that the intravenous push technique used on her was highly risky.

The needle was supposed to be inserted in the vein, but if the needle enters an artery by mistake, it can cause serious and irreversible gangrene. There is another procedure that should have been used, and the fact that the physician's assistant who injected the drug caused catastrophic results speaks for itself. The article indicates that now the woman, her supervisor, and her clinic have settled out of court.

We now have a situation wherein the acceptance or approval by the FDA does not automatically provide a so-called standard of safety. As a result of this court case, State damage suits will be more readily available for redress for injuries. It should also cause manufacturers to exercise greater care in production and labeling of their products.

THIS LEGALEASE COLUMN IS INTENDED FOR PURPOSES OF INFORMATION ONLY AND IS NOT TO BE CONSIDERED LEGAL ADVICE.

Balance and Swallowing

(continued from page 1)

Swallowing

The mouth, the throat, and the "food pipe" (esophagus) are the three major parts of the swallowing system; many nerves are involved. The gap between the palate and the throat must be closed so that food is not forced into the nose or the "air pipe" (trachea). Aspiration is brought on by food going down the air pipe and into the lungs. Acid reflux, infection, throat polyps, and spasms are other major risks, particularly for those who had bulbar polio. Belching and heartburn, caused by acid reflux, may be more prevalent in polio survivors who gain weight. Acid can be forced up from the stomach, burning the back of the throat. If the acid goes down into the lungs, it can cause asthma.

Be Your Own Advocate

"Surgery can sometimes close off parts of the airway to help keep food from going into the nose or airway," Dr Westerman advised. Before a lively question and answer period, he closed his remarks with a strong plea: "You must be your own advocate! Don't be afraid to ask questions. Keeping a diary is a tremendous help in recording new or developing symptoms. Teamwork, involving the patient, the physician, and the allied healthcare giver, is the only way to go. Symptoms must be investigated – failure to do so can be life-endangering."

Ed. Note: In the months following his presentation at our conference, Dr Westerman decided to launch a study of how post-polio syndrome is recognized – or not – by physicians consulted by polio survivors. We invite readers who wish to join in this study to contact Dr Westerman, following the procedures on page 3. Ed.

Q&A's From Talk

Meniere's Disease

Prompted by a question from the audience, Dr Westerman discussed Meniere's Disease at some length. It is characterized either by an increase in

fluid production in the inner ear, or a decrease in fluid absorption in the inner ear. The symptoms are a feeling of "cotton" in the ear, spinning dizziness, loud noises, and hearing loss. Post-polio syndrome does not increase its likelihood, but polio survivors can be affected just as with any other disease. Meniere's can be treated with a low-sodium diet – less than 1,000 mg per day. The average age of onset is in the fourth decade, with a general decline after age 60. Right and left ears are affected with fairly equal frequency. There may be a genetic "weakness," as well as environmental factors, that affect the occurrence of Meniere's Disease.

Benign Positional Vertigo

Another question prompted a review by Dr Westerman of benign positional vertigo, caused when the calcium carbonate crystals in the inner ear, which normally work to ensure good balance, detach from the nerves and cause temporary dizziness. This can be alleviated, tests have shown, by moving the head slowly from the more affected side to the less affected, then gradually sitting up or righting the position of the head.

Ruprecht Fund Grants Available

The Ruprecht Fund, established by PNNJ to provide direct assistance to polio survivors who live in New Jersey, is now in its ninth year. We have been able to help a number of individuals meet pressing needs that could not have been addressed without our help. Grants of up to \$500 are available once annually. While income is a factor, it is not the sole criterion, since it is well known that it costs a lot to be disabled! Goods such as durable medical equipment and services that might include medical evaluations for PPS are among the fundable items. Applications can be obtained from the administrator of our fund, Heightened Independence and Progress (*hip*), 131 Main Street, #120, Hackensack, NJ 07601. Phone: 201-996-9100 (ask for Maria Valentin), or fax 201-996-9422, to Maria's attention. (We cannot reimburse for expenses already incurred or pay for renewable supplies.) All requests are completely confidential.

iBOT Discontinued

In January, Independence Technology, a Johnson & Johnson company, discontinued marketing and selling its revolutionary iBOT Mobility System. There was not sufficient demand nor was the company successful in obtaining reimbursement from Medicare or Medicaid. Technical support and service to iBOT owners will continue until 2013, when the company will close. Licensing will revert to iBOT designer Dean Kamen.

“Reasonable Modifications” Under Fair Housing Act

The Departments of Housing and Urban Development (HUD) and Justice (DOJ) have released new guidelines that reinforce the right of people with disabilities to modify buildings in which they live – including common areas – so that they can fully enjoy the premises. The guidance is designed to help housing providers and homeowners’ associations better understand their obligations, and help people with disabilities better understand their rights.

The Federal Fair Housing Act (FHA) prohibits discrimination in housing based on disability, race, color, religion, national origin, sex, and familial status. HUD and DOJ share responsibility for enforcing the law. HUD is the agency with primary responsibility for investigating individual complaints of discrimination.

One type of discrimination that is prohibited is the refusal by housing providers or homeowner associations to allow a structural alteration of existing premises, occupied or to be occupied by a person with a disability, when the modification is necessary to afford the person full enjoyment of the premises. Although the housing provider must allow the modification, the tenant (or prospective tenant) must pay the cost. Examples of reasonable modifications include widening doorways or installing a ramp.

The guidelines are available online at both www.usdoj.gov/fairhousing and www.hud.gov/offices/fheo/disabilities.

SOURCE: *THE COUNCIL*: NJCDD'S NEWSLETTER, SEPTEMBER 2008

Polio Network of New Jersey Post-Polio Study Under Way by Dr Westerman

Have you had trouble trying to make your doctor understand your post-polio issues?

When you inquire about his or her knowledge of PPS, do you get a blank stare?

Have you been told “It’s all in your mind!”?...

Dr S Thomas Westerman, who made a fine presentation at PNNJ’s April 2008 conference, plans to do a study of this important concern for polio survivors, with the help of several other knowledgeable physicians and their medical students. He hopes to have the results published in a medical journal for the benefit of physicians and other health care professionals. If you would like to participate, here is what you need to know:

The questions were prepared and the study will be performed in cooperation with Arthur P Siegfried, President, Polio Network of New Jersey, Network members, and Dr Westerman.

Study pending IRB (Institutional Review Board) approval.

Brief responses or check-off answers will be used.

Responsibility for the study will be in the hands of the physicians. PNNJ will be acting as a valuable conduit of information.

Dr Westerman is open to suggestions and comments. Do not hesitate to correspond. Email, fax, or US mail are the easiest means, but do phone if that is best for anyone.

All participants’ privacy will be strictly protected according to Federal law.

Participants will be assigned a number. The response form will have only that number. He and the other physicians have performed numerous studies and are VERY STRICT with privacy issues.

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\$635 Million Pledged to End Polio

The governments of Germany and the United Kingdom and charities including the Bill & Melinda Gates Foundation have pledged \$635 million toward eradicating polio.

The Gates Foundation pledged \$255 million, while the governments of Germany and the U.K. will together donate a total of \$28 million. Rotary International members will raise \$100 million over the next three years toward the effort. Rotary has been a longtime advocate for eradicating polio, raising funds, and deploying volunteers to help with inoculation efforts.

The money will ultimately be used by the World Health Organization and Unicef, adding to funds from other countries and philanthropies. The money will be focused on the four countries where polio remains endemic: Nigeria, Afghanistan, India, and Pakistan

The grants add to the roughly \$6 billion spent on polio eradication since 1988, when the WHO and partners launched an effort to wipe out the crippling disease

SOURCE: WALL STREET JOURNAL, JANUARY 22, 2009

A Browbeating For Charity

A 72-year-old man with eyebrows so long he brushed them each morning raised \$1,600 for charity from people who paid to take turns trimming his out-of-control brows. Some of the wiry hairs shorn from Si Burgher's shaggy eyebrows measured more than three inches long because the former jeweler's brows had never been trimmed.

Burgher's brows were so long that he'd brush them before leaving the house. He agreed to have them tamed by Bloomfield Rotary Club members to raise money for a polio eradication campaign. Burgher barely winced as his wife, Amy, got the first whack at the overgrown hairs. "I don't care if they ever grow back," he said. "My wife says I look 20 years younger."

Lawyers, bankers and others put up \$100 each for their turn to snip away at Burgher's brows, with the money going to Rotary International's Polio Plus,

Tuning in on the Polio Network of NJ

ATLANTIC COUNTY AREA

May's Landing Library
Farragut Avenue, May's Landing
3rd Saturday, 10 am-12 noon
Contact: Marge or Steve Disbrow
For directions and to confirm date
609-909-1518

BERGEN COUNTY

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

ESSEX-UNION AREA

East Pavilion of
East Orange General Hospital
240 Central Avenue, East Orange
Quarterly. In 2009: June 13, Sept 12, and
Nov 14, 12 noon-2 pm
Contact: Edwina Jackson 973-673-0380 or
Thelma Van Liew, 908-753-6514

MONMOUTH COUNTY AREA

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

MORRIS COUNTY AREA

March, July, Aug, & Dec
Zeris Inn, Route 46 East, Mountain Lakes
3rd Wednesday at 7 pm
All other months
Denville Municipal Building
1 St. Mary's Place
3rd Saturday at 11 am
Contact: Marion Rosenstein 201-585-8125
or Vince Avantiato 973-769-0075

OCEAN COUNTY AREA

Health South Rehabilitation Hospital
of Toms River
14 Hospital Drive, Toms River
3rd Saturday, 10 am-1 pm or 11 am-2 pm
April, September, and November
Contact and confirm date and time with:
Susan Payne Gato 732-864-0998

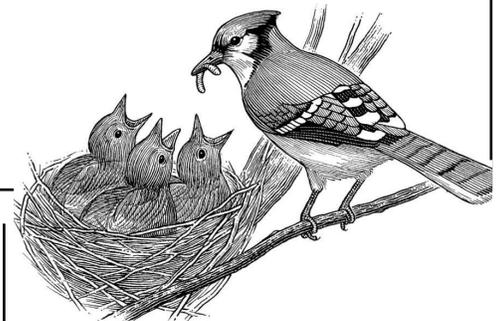
RARITAN VALLEY—

Somerset/Hunterdon Counties
Manville Library, Manville, 908-722-9722
1st Saturday, 10 am-12 noon
Oct, Nov, Dec, March, April
Contact: Arthur Siegfried 908-722-7212

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

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.



which has raised \$500 million for polio eradication in the developing world since 1985. Burgher's wife said she likes his new look. "Beneath the eyebrows is a really handsome man," she said.
SOURCE: THE RECORD, JANUARY 22, 2009

A Sad Warning

Last year a woman who had spent nearly 60 years in an iron lung died after a power failure shut down the machine that kept her breathing. Family members were unable to get an emergency generator working.

To the PNNJ member who sent him a newspaper article reporting this sad event, President Arthur Siegfried wrote: "I use a CPAP (continuous positive airway pressure) at night. I am on the Priority Electric Restore list with the electric company, and have a generator that I start and run periodically."

If you use assistive devices requiring electricity, be sure that you are prepared in the event of an emergency.

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Polio Network of New Jersey NEWSLETTER

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