



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

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“Aging Well With PPS” is Conference Theme



Mary Ann Keenan, MD



Beth Young, MS, RD



William Ditto, MSW, LSW

“Aging Well With PPS” is high on the priority list of all those experiencing the late effects of polio known as post-polio syndrome. This year’s conference recognizes that concern by focusing on ways to increase the chances of “aging well.”

The 19th annual conference of the Polio Network of New Jersey will be held at the Princeton DoubleTree Hotel on Sunday, October 25. The conference will begin with a continental breakfast at 8:30, and will extend until 3:00.

Mary Ann E Keenan, MD, Chief of the Neuro-Orthopaedics Service at the University of Pennsylvania in Philadelphia, will be the conference keynote speaker. Dr Keenan holds an appointment as Professor of Orthopaedic Surgery at the University of Pennsylvania School of Medicine.

A pioneer

Dr Keenan has been a pioneer in the field of Neuro-Orthopaedic Surgery, performing reconstructive musculoskeletal surgery for persons with neurologic disorders such as stroke, brain injury, and polio. She is renowned for her expertise in shoulder care, a subject of concern to many polio survivors.

Aging well also requires attention to diet. Beth Young, MS, RD, will discuss this topic with special emphasis on obtaining the proper nutrition to maximize health and well being. Ms Young, a registered dietitian, is president of Princeton Health Systems, Inc. She is a nutrition consultant to a number of organizations and conducts a series of nutrition lectures.

Independence promoted

William A. B. (Bill) Ditto, MSW, LSW, Director of the Division of Disability Services, New Jersey Department of Human Services, will be our luncheon speaker. Mr Ditto’s chief areas of interest and experience are long-term care, community-based services for people with disabilities, consumer directed services, and innovative projects in human services. We’re pleased to welcome back Bill Ditto to our annual conference.

Throughout the day there will be opportunities to visit vendors of disability-related products and services. There will also be time to learn about PNNJ support groups and how they can help you with your post-polio needs.

The conference cost per person is \$35, which includes continental breakfast, lunch, and all conference materials. If any polio survivors cannot afford the fee, some financial help is available. Please contact us by e-mail, or phone, or write to : Arthur Siegfried, President, PNNJ, Box 537, Martinsville, NJ 08836.

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Universal Design Gaining in Popularity

By Jean Csaposs

“Making Your Home Accessible” was the theme of an information-rich workshop given by Jack Purvis, AIA, architect of Allenwood, NJ, at PNNJ’s 2008 Conference. Mr Purvis gave generously of his time on this return visit to cover a host of practical and imaginative solutions to problems that people with disabilities encounter when modifying an existing home or planning a new one from scratch. His illuminating talk was accompanied by an easy-to-follow visual presentation. The entire session became a give-and-take with the audience; he welcomed their lively questions and accounts of problems and solutions they had come up with or were hoping to find.

Universal Design, a concept born in the mid-20th century, gained impetus when the needs of injured veterans of World War II, Korea, and Vietnam dictated a new approach to housing accessibility. Mr Purvis took us briefly through this evolution in home design, from the era when accessible homes were very costly and not very attractive, up to the present, when innovative architects, greater public awareness, and an increasingly sophisticated clientele are making barrier-free design more affordable and attractive to all, not only to people with disabilities.

Universal Design helps all

“There are a hundred definitions of Universal Design,” Mr Purvis said. He recommended the websites of the AARP and the University of North Carolina as rich sources of information on the subject. Universal Design standards include some basic residential

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Conference

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Make it a weekend

As in previous years, we welcome those who wish to arrive on Saturday for our popular reception and dinner, where speakers, Board members, and participants have an opportunity to socialize in a relaxed setting. Registration information is enclosed with this issue of the *Newsletter*; copies can also be obtained by e-mail: info@njpolio.org or by calling 201-845-6860. Registration can also be conducted on the PNNJ website, www.njpolio.org.

Chasing Stress with Chair Yoga

By Jean Csaposs

"There is no such thing as chasing away stress," said yoga instructor Marie Gagliardi to the audience at her popular 2008 Conference workshop. "We always have stress, but yoga teaches you how to control and overcome it." A certified practitioner of Integral Yoga, Ms Gagliardi led her audience through an actual chair yoga class, one which she has tailored to meet the needs of people with disabilities who may not be able to stand or move about conveniently.

Several essential components of Integral Yoga, as taught by Ms Gagliardi, are "poses" or postures (asana), breathing (pranayama), deep relaxation, and meditation. Her approach was strongly influenced by Dr A. Mala Cunningham, founder and director of Cardiac Medical Yoga, and Dr Dean Ornish, noted cardiologist, whose philosophy emphasizes proper diet and exercise.

Experiencing chair yoga

"Sit as comfortably as you can," Ms Gagliardi began, "and mentally repeat everything I say to yourself. You will remember it." She was careful to suggest that if this first basic chair yoga class became too tiring, it was perfectly acceptable for anyone just to relax and observe. With their feet flat on the floor, or on their wheelchair or scooter platforms, the audience gave

themselves over to a deeply engrossing interaction with their own bodies, as Ms Gagliardi's voice and movements guided them, starting with the eyes, and gradually involving every movable part of the body. During the breathing instruction, she said, "We have a natural drugstore in our body. Through yoga, we learn ways to balance these drugs, to release toxins and achieve greater health." The climax of the class was an introduction to meditation, the most important aspect of yoga.

For info check Internet

The yoga workshop gave a new meaning to the term, "hands on," so writing about it in detail would not do it justice. Instead of taking readers step-by-step through the entire class, we urge those interested to go to the Internet. Calling up "Integral Yoga" will reveal a wealth of references. One source, Swami Satchidananda, describes Integral Yoga as "...a flexible combination of specific methods to develop every aspect of the individual: physical, intellectual, and spiritual. It is a scientific system which integrates the various branches of Yoga in order to bring about a complete and harmonious development of the individual."

A certified cardiac yoga instructor, Marie Gagliardi conducts a weekly chair yoga class for seniors in her hometown, Maywood, NJ. As participants emerged from the workshop, their many expressions of satisfaction and eagerness to learn more clearly showed that Ms Gagliardi is a worthy exponent of this ancient system for achieving health, happiness, and above all, inner peace.

PNNJ Website Translates Into 42 Languages

Did you realize that the PNNJ Website can be immediately translated into any one of 42 languages? Go to the bottom of any page on the website, www.njpolio.org, and Select Language. Click on the desired language, and a translated page will come up on your screen. The service is provided by Google.



Universal Design

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requirements: complete livability on one floor, with a living room, kitchen, bathroom, and a room that can be a bedroom when needed. Access from the outside must be without steps from a clear pathway from curb to house.

Ramps, stairways, elevators – these devices all came under discussion, followed by a complete "walk-through" of good design ideas for interiors, with emphasis on kitchens and bathrooms. Who knew that, at the kitchen sink, a faucet hose should be "long enough to fill a cooking pot"? It's a safety measure, especially for the wheelchair chef. In the bathroom, how about a "swing-out" shower curtain for the roll-in shower, and controls outside the shower stall as well as within? (These come with an anti-scalding device.) A toilet can be rotated for easier access in an inconvenient space by a wheelchair user. But the owner must bring this input to the discussion early on, says Mr Purvis. Many design improvements are not costly: lever handles, extra shelving, grab bars – even painting conveniently-positioned light switches a different color from the wall for greater visibility – all can be life-enhancing features.

Take a Web tour

The accessibility needs of persons with hearing and vision loss were not forgotten in the presentation. Audible, visual, and tactile signals and conveniences are elements of barrier-free design that make life easier for sensory-impaired individuals. Mr Purvis completed his talk with a pictorial "visit" to the Bove residence in Allenwood, a home completely redesigned for an owner after an automobile accident left her with paraplegia. Readers can tour this and other homes designed or redesigned by Purvis Architect by visiting their elegant website: www.purvis-architect.com.

NJ Resources 2009 Available

The 2009 edition of the New Jersey Resources Directory is available from the NJ Division of Disability Services. Call 1-888-3036 to request a copy. It is also available in PDF format at www.state.nj.us/humanservices/dds/home. SOURCE: *THE SECOND WAVE*, SUMMER 2009

PNNJ Spreading Word About PPS With PSAs

Keep your ears open. You may hear a public service announcement (PSA) about post-polio syndrome on your local NJ radio station. The 30-second messages, and there are four different ones, describe PPS and indicate that the Polio Network of New Jersey can help you. Our website and phone number are included. The goal is to spread the word about PPS and get important information to polio survivors.

The project was developed by the Board of Directors of PNNJ. Jean Csaposs wrote the messages, and they were recorded by Carla Foxx, a professional who is a friend of a Board member. Joe Gummere, Carla's producer, added background music. All volunteered their services, for which the Network is most grateful.

Radio stations are required to dedicate a certain amount of time to broadcasting public service announcements at no charge to the non-profit agency. We'd appreciate it if you would let us know if you hear one of the PSAs and indicate where and on what station you heard it. You can call our number, write an e-mail, or mail the information to our address. All are listed on the masthead in this newsletter.



Website Offers 1-Stop Help and Information

Disabilityinfo.gov is a comprehensive website designed to offer people with disabilities access to important information. The site is organized into subject areas, including benefits, civil rights, community life, education, employment, health, housing, technology, and transportation. There is also information on social security, Medicare, and Medicaid.



Polio Network of New Jersey Post-Polio Study Under Way by Our Organization and S. Thomas Westerman, MD

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!"?...

S. Thomas Westerman, MD, Clinical Professor of Otolaryngology at Drexel University College of Medicine, who made a fine presentation at PNNJ's April 2008 conference, in cooperation with our organization plans to do a study of this important concern for polio survivors. He hopes to have the results published in a medical journal for the benefit of physicians and other health care professionals as well as in this *Newsletter*.

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 of our Polio Network of New Jersey, Network members, and Dr Westerman.
- Dr Westerman will collect, correlate, and is responsible for preparing the information for publication. No other person will have access to the information. If you have any questions for Dr Westerman, he can be reached at 732-460-0045.
- Brief responses or check-off answers will be used in the survey.
- All surveys are to be filled out anonymously. No names are permitted on the surveys. No return addresses are permitted on the envelope. You must return the information in the envelope that will be provided to you marked CONFIDENTIAL.

If you are interested in participating in the study, please contact:

Polio Network of New Jersey
PO Box 537
Martinsville, NJ 08836
S. Thomas Westerman
732-460-0045



In Memoriam

We mourn the loss of two women who contributed significantly to the Polio Network of New Jersey and to their communities.



Dr. Ellen M Brockmann served as a member of the Board of Directors of the Polio Network for many years. A math teacher by profession, she played an active role in statewide teachers' organizations. She also advocated to improve transportation for people with disabilities.



Jean Brogdon was one of the founders of the Polio Network and served as its first President. She was also an early member of the Raritan Valley Post-Polio Support Group. She moved to Georgia, where she was active in her new community.

Vitamin D and Falls

"Roughly a third of all women over age 65 fall each year, and 20 to 30% of them suffer a serious injury like a hip fracture. Now researchers have more evidence that vitamin D could curb some falls.

Australian scientists gave vitamin D (1,000 IU a day) or a placebo to some 300 women aged 70 to 90. All had low blood levels of vitamin D (less than 24 monograms per milliliter) and a history of having fallen the previous year. Both groups also got calcium (1,000 mg a day).

Among the women who fell only once during the one-year study, 36 percent of the placebo takers – but only 2 percent of the vitamin D takers – fell during the winter or spring. There were no differences in falls during the summer or autumn. That's not surprising, because people make less vitamin D from the sun's ultraviolet rays in the winter, and stores of vitamin D in the blood are still low in the spring, but not in the summer or autumn. Vitamin D had no impact on women who fell two or more times, possibly because they had more serious disabilities.

What to do: If you're middle-aged or older, take a daily supplement with 1,000 IU of vitamin D. A supplement is inexpensive and the risk of consuming too much vitamin D is low. Other studies suggest that vitamin D may also reduce the risk of osteoporosis, cancer, and other illnesses.

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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*.

Polio Network of New Jersey *NEWSLETTER*

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Joan Swain
Editor

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Barbara Conklin, Mahwah, NJ

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
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 Pavilion of East Orange General Hospital
240 Central Avenue, East Orange
2nd Saturday, noon to 2 pm
Contact: Edwina Jackson 973-673-0380 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
3rd Saturday at 11 am
September, October, November
Contact: Vince Avantagiato 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
info@tomsvrjnpolio.org

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
Fax: 908-429-1045
apecs@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.