



# Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

Spring 2008 / Vol 17. No. 3

## “New Knowledge, Innovative Remedies” is Conference Theme

“Post-Polio: New Knowledge, Innovative Remedies” is the theme around which five outstanding speakers will make presentations at the Polio Network of New Jersey’s 18th Annual Conference on the Late Effects of Polio.

The event will be held at the Bridgewater Marriott Hotel on Sunday, April 13. Beginning with a continental breakfast at 8:30 a.m., and including lunch, the conference will extend until 3:00 p.m. Continuing a popular program added last year, a special “first timers” session will be conducted by PNNJ President Arthur Siegfried during the breakfast period.

### See registration brochure

Those who wish to stay overnight at the Bridgewater Marriott are cordially invited to join other participants for dinner, where they will have an opportunity to meet some of our speakers and Board members. A registration brochure for the conference is included with this issue of the *Newsletter*. If you read this without a brochure in hand, information is available by calling 201-845-6860, e-mailing NJPN10@hotmail.com, or on the Network website, [www.njpolio.org](http://www.njpolio.org).

The conference cost per person is \$40, 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.

Marie Gagliardi, a certified teacher of Integral Yoga, which incorporates poses, breathing, deep relaxation, and meditation into its program, will present “Chasing Stress with Chair Yoga.” Whether you sit or can stand holding onto the back of a chair, you will be able to do yoga poses and stretches in this workshop.

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

### Admired speakers returning



*Frederick M Maynard, MD*

Frederick M Maynard, MD, an internationally recognized expert on post-polio syndrome, will present the keynote talk, “The Role of Exercise in Post-Polio Health.”

We are delighted that Dr Maynard, whose practice in Michigan encompasses physical medicine and rehabilitation, will be making a return visit to our conference. The topic of exercise continues to head the list of concerns of polio survivors.

Joan L Headley, MS, Executive Director of Post-Polio Health International (PHI), St. Louis, another highly regarded return visitor, will present “What’s New in Our Post-Polio World?” She will discuss the most recent information about polio and its late effects and will describe the many activities in which PHI is involved.



*Joan L Headley, MS*

### A variety of afternoon workshops



*S. Thomas Westerman, MD*

In the afternoon portion of the conference, attendees will be able to select one of three workshops. S. Thomas Westerman, MD, otolaryngology, will present “A Polio Survivor’s Guide to Balance and Swallowing.” This is the first time we have had an ear, nose, and throat specialist at our conference; and we know that many attendees will have questions for this internationally regarded physician. His practice in Shrewsbury, NJ, includes treatment for hearing, balance, nasal and sinus, allergy, taste and smell, and laryngeal and esophageal problems.

Jack Purvis, AIA, architect, is a returning favorite who has an architectural practice in Allenwood, NJ. His more than 20 years of experience will be reflected in his presentation of “Making Your Home Accessible.” In addition to showing how to overcome architectural barriers in the home, he will bring attendees up to date on the latest in the field of universal design.



*Jack Purvis AIA*



*Marie Gagliardi*

## Silver Leaves Spaulding, Joins Dana Farber

Last summer Dr Julie Silver notified her patients that she was leaving her clinical practice at the Spaulding Out-patient Center in Framingham, Mass., where she headed the International Rehabilitation Center for Polio providing comprehensive physiatry and rehabilitation services for post-polio patients.

As a leading post-polio syndrome expert, she authored numerous articles and books on the subject and was affiliated with the Harvard Medical School.

Dr Silver has since started a new position at Harvard Medical School specializing in oncology rehabilitation and has also joined the medical staff of the Dana Farber Cancer Institute. Her interest is in making survivorship a distinct phase of cancer treatment, creating new programs for the comprehensive treatment and support of cancer survivors.

SOURCE: *TRIUMPH*, NEWSLETTER OF GREATER BOSTON POST-POLIO ASSOCIATION, WINTER 2008

## What's on Our Web?

Have you ever taken a look at the PNNJ website? If not, or if not recently, you may be surprised to see how much information is included. Everything from our "What is Post-Polio" brochure and details about the Ruprecht Memorial Fund to assist polio survivors – to links to helpful websites and PNNJ support groups – to photos and more photos.

Check out the PNNJ website today at [NJPOLIO.org](http://NJPOLIO.org). And if you're thinking of attending our exciting 18th annual conference on the late effects of polio April 13, be sure to click on Pictures to see photos of previous conferences and other events. A quick look will tell you that we know how to have fun! So come, join us.

## Rare Photos Enrich Polio Voices

*Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts*, by Julie Silver and Daniel J Wilson, was released in early September 2007 by Praeger Publishers, Westport, Conn. The hardcover (ISBN 0-275-99492-9), 192-page book sells for \$39.95 and is available online. Incorporating many rare photographs – most never made public before – from the family albums of survivors who tell their stories, the book includes testimonies from people who worked in polio wards and those involved in the worldwide eradication efforts. The book also addresses the emergence of the disability rights movement, the challenges of post-polio syndrome, and state of developments today.

SOURCE: *POST-POLIO HEALTH*, FALL 2007

## Only in America

Only in America do drugstores make the sick walk all the way to the back of the store to get their prescriptions while healthy people can buy cigarettes at the front.

SOURCE: *SECOND TIME AROUND*, BOCA RATON, REPRINTED FROM HAWAII POST POLIO NETWORK

## New Website Caters to Folks With Disabilities

A new website, [Disaboom.com](http://Disaboom.com), went live on October 1, and is signing up big-time advertisers to reach the estimated 50 million people in the United States that have some form of disability.

Polls have shown that people with mobility challenges are active consumers. A 2005 Harris Interactive study found that 69 percent of adults with disabilities – more than 21 million people – had traveled for either business or pleasure at least once in the preceding two years. More than half had stayed in hotels, while 31 percent had booked at least one flight and 20 percent had rented a car. More than 75 percent of people with disabilities dine out at least once a week.

Topics on [Disaboom.com](http://Disaboom.com) include Health, Living, Media Room, Community, Discussions, Reviews, and Career Center. The company acquired [lovebyrd.com](http://lovebyrd.com), a dating website for people with disabilities, in the fall.

Andrew J Imparato, president of the American Association of People With Disabilities, said [Disaboom](http://Disaboom.com) could serve as an important clearinghouse for people with disabilities, organizing them to make their voice resound more clearly with business and government.

SOURCE: *THE NEW YORK TIMES*, TUESDAY, OCTOBER 30, 2007

## Get to Know Our Conference Speakers by Visiting Their Websites

Frederick M Maynard, MD:

[www.mgh.org/directry/docmgh/maynarf1.html](http://www.mgh.org/directry/docmgh/maynarf1.html)

S. Thomas Westerman, MD: [www.westermanmd.com](http://www.westermanmd.com)

Jack Purvis, AIA, architect: [www.purvis-architect.com](http://www.purvis-architect.com)

Joan L Headley, MS: [www.post-polio.org/about/editstaff.html](http://www.post-polio.org/about/editstaff.html)

## Abilities EXPO March 28-30

New Jersey Convention Center  
Edison, NJ

For more information visit:  
[abilitiesexpo.com](http://abilitiesexpo.com)

or call  
800-388-8146

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## Thanks From Arthur

Time and energy do not permit me to thank each and every one of you personally for your punctual payment of dues and generous donations. They are what keep our polio Network going.

I hope to see all of you at our upcoming conference; and as always, should you have any questions, please do not hesitate to contact me at any of the PNNJ numbers, sites, or addresses listed in this *Newsletter*.

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## “My Polio Life” Available on Internet

A 16-page “patient questionnaire providing baseline information and comparison charts on the life of a polio survivor” has been developed by the Lincolnshire Post-Polio Network (UK). The questionnaire is to help polio survivors provide pertinent information to health professionals. It can be downloaded from [www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf](http://www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf). The survey is for your personal use, but you can also send a photocopy to Lincolnshire Post-Polio Network, PO Box 954, Lincoln, Lincolnshire, LN5 5ER UK, so it can be compiled with the responses of others. SOURCE: *POST-POLIO HEALTH*, FALL 2007

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## Beans for the Brain

Now, another reason to eat your spinach – and black beans and broccoli and whole grains. These foods are rich in folic acid, which may boost your brainpower, new research suggests, and possibly protect against Alzheimer’s disease.

Scientists at Wageningen University in the Netherlands studied 800 healthy men and women ages 50 to 70, giving half of them 800 micrograms of folic acid supplements (twice the US daily recommendation). In tests three years later, that group had “significantly improved” in memory and in information-processing speed, while those taking placebos showed little or no

## LegalEase...

by Arthur P Siegfried, Esq

The United States Supreme Court has again agreed to hear cases concerning job discrimination. These are, or may be, significant to us because of the direct or indirect effect upon disability issues.

One case deals with protection for employees against retaliation for reporting discriminatory actions of a supervisor. While the technical issue of “upon whom does the burden of proof rest” is apparently the main issue, these cases often have other points useful to our disability issues.

The second case concerns whether employees are protected against retaliation for allegations of discrimination or harassment that they made during an internal investigation. This case in part deals with “what is harassment.” It apparently deals with an uninvolved employee who made remarks during a company investigation.

I will follow these cases and keep you posted.

Meanwhile I suggest that recordkeeping in detail of any incident, be it related to employment or other activities, certainly is important in any claim or action brought. Obviously, we tend to forget details over time and with aging, so notes made in the course of our activities can be used to refresh our recollection and substantiate statements made by us.

That advice holds true for virtually anything we do where recordkeeping, or recollection of an event, may be important in the future. The notations should be dated, signed or initialed by the maker, and have enough information to recall everything that was said or done – and even why one made the notes.

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

improvement, according to a report in the *Lancet* January 20 (2007).

Another study, at the Columbia University Medical Center in New York, found that participants with the highest intake of folic acid had the lowest risk of developing Alzheimer’s. The researchers, who tracked the diets of 965 people 65 and older for six years, noted in January’s *Archives of Neurology* that clinical trials are needed to confirm the findings.

Folic acid, one of the B vitamins, is found in green leafy vegetables, citrus fruit, beans, and fortified breads and cereals.

SOURCE: *SECOND TIME AROUND*, BOCA AREA PPSG, REPRINTED FROM *AARP BULLETIN*, MARCH 2007

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## Four Removable Ramps

Are you looking for a manufactured ramp that will allow you to enter your home more easily? If so, you may find the following four types of ramps worth considering.

The first one is built by Alpha One. It is a modular, removable ramp that allows renters, or those considering

moving, the ability to take it with them wherever they move.

The ramp was developed with support from the Department of Economic and Community Development and the HUD program. Youth Build in Lewiston, Maine, built the ramps and Ameri-Corp volunteers installed the ramps for customers in Maine. For further information, contact your nearest Alpha One office or call 800-640-7200.

Another ramp comes pre-packaged from Prairie View Industries. Made of aluminum with handrails, these ramps are advertised as being easily assembled and may be moved or reconfigured. For more information, call 800-554-7267 or e-mail: [info@pviramps.com](mailto:info@pviramps.com).

Ramp kits from Guldmann, Inc. are designed for threshold and small step areas. All ramps are 30” wide, made of polyethylene, and can tolerate household cleaning solutions. Call 800-664-8834 or e-mail: [info@guldmann.net](mailto:info@guldmann.net).

Starr Industries, Inc. manufactures the fourth portable entry system ramps. They are made of aluminum and can be reconfigured. Call 800-677-8377 for more details.

SOURCE: *POST-POLIO GROUP, CALIF. N. COAST*, SPRING 2007, REPRINTED FROM *OPTIONS*, THE POLIO SOCIETY NEWSLETTER

# Sinus Infections and PPS

By Joyce Insley

*"The following article has appeared in several newsletters (Echo News, Polio Connection of America, and The Seagull). I'm not sure where it originated, but thought it provided information that would be of interest to readers," Carol Prellberg, PNNJ member.*

I used to stay on antibiotics for sinus infections. I even had sinus surgery. As soon as I was off the antibiotics from the surgery, I got another sinus infection. I went through all the tests twice with four different specialists.

It wasn't until the late Dr Anne C Gawne diagnosed me with PPS that I finally found out what was causing the sinus infections. Dr Gawne let me watch a video and then she explained what was causing the infections. I was told that we have four very tiny gland pockets at the top of our throats. Food goes into the tiny pockets when we eat. It is a normal process for humans.

The problem for PPS-ers is that our throat muscles [may be] weakened by PPS. If so, when we eat, the food is not squeezed from those tiny glands and swallowed. Food stays in them, thus letting bacteria grow, causing infection to back up into your sinus cavities. I was taught how to eat and swallow my food so the tiny glands would not retain food. I was told to take small (not tiny) bites followed by several swallows of water. Tuck your chin down to your chest or turn your head to one side when you swallow. This will clear the food from the tiny glands.

Do not chew meat too much, as it tends to get larger the more you chew. I was told to stay away from potato chips, corn bread, and rice. These foods tend to stick in the glands more than most foods.

It is important that you get used to tucking the chin or turning your head sideways and drinking plenty of fluids with your food. I was taught this method of eating in October 2001 and I have only had one sinus infection since I started using this method to eat.

## 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, 10:30 am-12:30 pm  
Contact: Heather Broad 201-845-6317

### 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 Library  
Diamond Spring Road  
3rd Monday at 1 pm  
Contact: Marion Rosenstein 201-585-8125  
or 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 or  
Kevin Marie Moore 732-240-4272

### 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

### 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.

## Watercolorist Wilczewski to Have Exhibit

Tom Wilczewski, Long Branch watercolorist and a member of the Monmouth County group, will have a one-person exhibit of his watercolors at the Little Silver Borough Hall during April, May, and June.

Among the many paintings that will be on display are local scenes and those of upstate New York, the Hudson River, the Adirondacks, and Central Park as well as seascapes and florals.

Wilczewski is an award-winning artist whose paintings have been used for greeting cards and calendars by Very Special Arts of New Jersey, the Christopher Reeve Foundation, and the Polio Network of New Jersey among others. In 2002, the Easter Seals printed Wilczewski's painting of a lily on their stamps.

Wilczewski is an elected member of the New York and New Jersey American Artists Professional League,

an exhibiting member of the Guild of Creative Arts, an associate member of the New Jersey Watercolor Society and the Garden State Watercolor Society, and an officer of the Art Society of Monmouth County.

### 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

PO Box 537  
Martinsville, NJ 08836  
201-845-6860

WEBSITE:  
[www.njpolio.org](http://www.njpolio.org)

E-MAIL:  
[NJPN10@hotmail.com](mailto:NJPN10@hotmail.com)

Joan Swain  
*Editor*

NEWSLETTER DESIGN BY  
Barbara Conklin, Ridgewood, NJ