



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

Fall 2008 / Vol 18. No. 1

Joan Headley Describes What's New in Our Post-Polio World

by Jean Csaposs

The Polio Network of New Jersey could not have asked for a more knowledgeable spokesperson for "What's New in Our Post-Polio World" than Joan L Headley, Executive Director of Post Polio Health International. A longtime friend of PNNJ, Ms Headley paid a return visit to address this multi-faceted subject at our 18th annual conference on April 13, 2008. PHI, as the St. Louis-based organization is known, was established in 1958, and Ms Headley took over as its head in 1989. Her wide-ranging presentation had five major themes: the progress of polio eradication around the world, recent literature, innovations in treatment, the PHI research fund, and PHI's latest activities.

Eradication: As of April 8, the number of new cases of polio in 2008 throughout the world numbered 291. In 2007, a total of 1,308 cases were recorded. In 1987, when Ms Headley joined PHI (then known as GINI), 250,000 cases were reported around the world. The countries where new polio is still posing serious problem are Northern India, Nigeria, Pakistan, and Afghanistan, although in that country, seven million children were immunized this year. Progress is being made in Congo and Nepal. The immunization effort is the combined work of Rotary International, WHO, UNICEF, and the CDC. A new challenge for the eradication effort that has emerged in the last decade is a small number of polio cases that are caused by the live vaccine. Out of one billion recent inoculations worldwide, only nine new cases have been vaccine related. The USA switched from the live to the inactivated vaccine in 2000. In the USA, the percentage of early childhood inoculations has grown from 91.7 % to 92.9%. For more information, visit [www. polio.eradication.org](http://www.polio.eradication.org).

New Books and Articles: A new textbook for college-level students of virology, *Understanding Viruses*, by Teri Shors (U of Wisconsin-Oshkosh), contains chapters on polio viruses and PPS. *Love, War and Polio, the Life and Times of Young Bill*
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New Support Group



Some of the participants at the first meeting of the new Essex-Union Area Support group stayed on for a group picture. Back row (l to r): Edwina Jackson, group leader; Delores Wolfe, Barbara Simon, Letty Case, Sandy Rubin, and Thelma Van Liew, co-leader. Front row: Jean Csaposs, who represented the PNNJ Board of Directors, Diane Shapiro, and Saida Young. (See story page 3)

A Ruprecht Fund Grant May Meet Your Need

The Alan and Peggy Ruprecht Fund, created by PNNJ and named in memory of the founders of Drive-Master, Inc., of Fairfield, NJ, continues to provide grants to assist polio survivors in the state of New Jersey. During the past eight years, the Fund has provided over \$14,000 in 42 separate grants, entirely through the generosity of polio survivors, their friends, and supporters of our network, to provide direct assistance to individuals for products and services that may be difficult to finance for many of us, particularly those on fixed incomes. This year, the Community Foundation of New Jersey has augmented our funds through a \$2,000 grant, which will be applied to the Ruprecht Fund.

A unique fund

To our knowledge, no other similar fund exists exclusively for polio survivors from private contributions, without regard to membership in our organization. Many years ago, when the threat of polio seemed to have been eradicated, at least in the United States, the March of Dimes changed its focus from polio to birth defects. Much good has been done to correct, and even more significantly, to prevent birth defects in the last half century, so we can join with all Americans in applauding this effort. But in the absence of a source of financial assistance geared specifically to the needs of polio survivors, many people in the aging population find themselves hard pressed to pay for such new needs as medical evaluations, braces, canes, crutches, wheelchairs, scooters, and home modifications.

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Joan Headley

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Porteous, by Timothy James Bazzett (Reed City, Michigan), recounts stories of servicemen who fought in World War II, only to contract polio on their return, and some servicemen whose history of polio was challenged or ignored by the examining physicians when they entered the service.

A useful article is a report on the longitudinal study done by Mary G Klein, PhD, of the Moss Rehab Research Institute, Philadelphia. "Actual and Perceived Activity Levels in Polio Survivors and Older Controls" compares activities of polio survivors 20 years ago with recent activity, and concludes that deterioration of the weaker knee extensor, plus osteoporosis, and minimum strength reserves are significant factors in the decrease in activity of polio survivors. Ms Headley requested that we send to her at PHI pictures and written statements of "where we were" 20 years ago and where we are now. She suggested that even three stages of photos would be welcome, if the third set shows how therapy and/or the acquisition of remedial devices tells a somewhat different story from the second stage.

New Therapy: Bioelectric stimulation therapy, developed in Belgium, is also known as micro-current electrotherapy (BEST), and is designed "to enhance the body's physiological processes." The hand-held device that activates the process was approved for sale in Europe in 2007 and this year in the USA. The developers claim that it works differently from TENS, which works on the motor unit level, and that BEST works on the cellular level to increase ATP (which transports chemical energy within cells for metabolism). The treatment is used one hour a day, five days a week for eight weeks. PHI is seeking opinions from post-polio experienced physicians. (Ed note: Physicians now state that a double-blinded study is needed to judge the benefit of this therapy.)

PHI Research Fund: Every two years a \$25,000 grant is awarded competitively. This year a team working at the University of Arkansas, headed by Rahnema Wahid, PhD, a young woman scientist from Bangladesh, studied a possible "bio-marker" for PPS, which revealed

that there may be a connection between the immune system and PPS. Work on this theory is also being done in Sweden, Norway, and Italy. The team looked at a small number of polio-free individuals, several with diagnosed PPS, and several stable polio survivors. The study, although very limited, showed that PPS people have higher levels of T cells (indicators for injury and inflammation). PHI is currently looking at eight proposals from researchers in four different countries who are vying for the 5th annual grant.

What's New at PHI: "The Board of Directors is constantly looking for ways to support our core constituency," said Ms Headley, "and the needs are getting greater. We are looking at ways to transfer what we know, not only to polio survivors but also to people with disabilities generally."

PHI is working with the John P Murtha Neuroscience and Pain Institute in Johnstown, Pa. in several ways: A registry of polio survivors has been established which each of us can join (anonymously, if desired); those interested should go to PHI's website, scroll down to Networking, and look for directions to the registry. Also, since 2004, monthly conference calls have been linking directors of post-polio clinics and rehabilitation centers, doctors, researchers, and advocates to discuss issues of mutual concern.

"WE'RE STILL HERE!" is a campaign meant to call the attention of the world at large to the continuing lives and contributions of polio survivors. Impetus for the campaign came when a group of polio survivors from seven countries, members of the European Polio Union, joined forces in Brussels to present their case to members of the European Union's Parliament. PHI's 2007 "We're Still Here" campaign brought responses from 19 states and seven countries, including Tasmania. This year, October 12-18 is the week highlighted for the 2008 "WE'RE STILL HERE!" campaign in the USA.

"Stand Proud," a program established in the Democratic Republic of Congo, operates six centers where younger polio patients are fit for braces and are taught to walk with their braces. Walking is essential in the Congo as the only route to a better life, since wheelchairs don't work where there are no concrete sidewalks or paved roads. The children

are also educated while in rehab, in the belief that education is the greatest leveler for people with disabilities.

What else is new? The 10th International PHI Conference, "Living with Polio in the 21st Century," April 23-25, 2009, at the Roosevelt Warm Springs Institute for Rehabilitation in Georgia. The organizers are still working on topics – Ms Headley urged people to submit ideas. A Wellness Retreat will precede the conference.

Membership in PHI: At the 2006 PHI Conference, the subject of Association Membership was introduced. A membership fee schedule was established at one dollar per support group member, with a maximum of \$250 per year. Association members receive the e-Newsletter, *Communiqué*.

The International Ventilator Users Network (IVUN) is a part of PHI that serves a smaller group of people who use portable ventilators on a daily basis. These, including those with SCI, MD, ALS, etc., have special needs, such as educating emergency room personnel about how they need to be treated. A grant from the Christopher and Dana Reeve Foundation enabled PHI to produce a four-part guide, "Take Charge, not Chances," devoted to the special concerns of IV users.

"What's new with you and your post-polio health?" Ms Headley asked. "Health is in the PHI title consciously because people sometimes equate disability with illness and we need to show that most of us are in basic good health. We need to connect 'mind, body, spirit.'" Are you doing less these days? If so, are you replacing it with something else? Don't suffer in silence. This is not a call to complain. Be positive, but speak up about your situation and your needs."

In conclusion, Ms Headley spoke of the need to recruit more physicians – older friends are retiring. There is interest among younger medical professionals, and "there are still people out there who are not able to have their needs met and not able to get to all the places they want to go."

All polio survivors are invited to learn how they can share information and experiences online by going to PHI's website, www.post-polio.org, and clicking on Support Groups and Support Group Leaders.



Lee Bekir, Conference Chair; Fred Maynard, MD; Joan L Headley, Executive Director, PHI; Jean Csaposs, and Joan Swain at the Polio Network of New Jersey's 18th annual conference April 13.

Network Goes to the Races

The Polio Network of New Jersey sponsored the sixth race at Monmouth Park Racetrack on August 6. The event was the brainstorm of Monmouth County Post-Polio Support Group President Toni Wilczewski and her husband, Tom, to highlight post-polio awareness. In addition to heading the sixth race in the official program, the network name was up in lights on the billboard:

"Monmouth Park Racetrack, sponsored by PNNJ."



(Rear l to r) Trainer Jason Servis, Gerard Wazater, Arthur Siegfried, President, Polio Network of New Jersey, and (front l to r) Toni Wilczewski, President Monmouth County Post-Polio Support Group; winning jockey Elis Trujillo, and Susan Payne Gato, Co-Chair, Ocean County Post-Polio Support Group, gather for a photo after My Kim won the Sixth Race.

LegalEase...

by Arthur P Siegfried, Esq

The United States Supreme Court considered a conflict of interest question concerning disability benefits earlier this year. Under the law prior to this decision, employees who felt they were improperly denied benefits had to prove that their plan administrator had acted in an arbitrary, capricious, or unprincipled way in providing benefits to employees.

The case was brought by a plaintiff who suffers from heart disease and took a leave of absence in 2000, providing extensive documentation from doctors that she could not return to work. The employer had offered long-term-disability insurance as a benefit, but the plan administrator (that is, the insurance company) claimed the employee did not qualify.

The Supreme Court noted a conflict of interest between the insurance company's role and the employee's benefit and noted that the insurance company was hired by the employer who pays for the benefits. This is where the conflict of interest issue arose: the employer wants to keep the cost down, and in its guidance of the insurance company would be providing fewer benefits or more stringent requirements than a more liberal view and more liberal benefits for the employee. The majority opinion of the court now requires a trial judge to "bear in mind" the administrator's conflict of interest and consider it in its thinking.

This seems to leave us with the opinion that the issue is to be decided on a case-by-case basis. What does this mean to you and me? 1) Get a good lawyer, well experienced in the field. 2) Make sure you have records of everything pertaining to your illness or disability. And 3) Keep records on a day-to-day or week-by-week basis of all your activities and be sure to have documentation for everything that you say or include in your notes.

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

Good News! New Support Group Formed To Serve Essex-Union Area

The new Essex-Union Polio Support Group held its first meeting on September 13th at the East Pavilion of East Orange General Hospital. Edwina Jackson of East Orange, the group's founder, enlisted Thelma Van Liew of Plainfield as co-chair. Both are longtime members and supporters of the Polio Network of New Jersey. The first meeting brought polio survivors and family members from the surrounding area, each of whom told a personal story of polio onset, their life experiences, and the often traumatic arrival of post-polio syndrome. The mood was upbeat, energized by the enthusiasm and positive outlook of Edwina and Thelma. They have many plans for the future of the group and hope to reach out to help even more individuals deal with issues that are important to them.

The next meeting is scheduled for November 8th from noon to 2 p.m.

Light refreshments will be served. The convenient location, a former Kessler rehabilitation facility, overlooks Exit #145 of the Garden State Parkway. For further details and specific directions, call Edwina Jackson at 973-673-0380, e-mail her at nubianqueen8@aol.com, or call Thelma Van Liew at 908-753-6514. To reach the group's website, go to www.agreatertown.com. Click on Enter a Greater Town, go to Search (it's on the far right of the screen) and type in Polio Support.

Disability Services Directory Available

The 2008 edition of the Resources directory compiled by the NJ Division of Disability Services is now available. It made its public debut at the Abilities Expo, and the department is now mailing out copies upon request, according to William Ditto, Director. To request a copy, call toll free 888-285-3036, option 2. A web version is available at www.state.nj.us/humanservices/dds/. Click on the picture of the directory.

Ruprecht Fund

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The Polio Network of New Jersey created the Ruprecht Fund as an experimental program to help polio survivors pay for just such needs, in whole or in part. We allocate \$5,000 for each fiscal year. An individual can qualify for a grant once annually of up to \$500. Payment is always made to the provider of the product or service. Each grant has met a need that could not have been fulfilled by any other source without voluminous paperwork and lengthy waiting periods, and perhaps not even then.

Need help?

We invite others to consider whether they can benefit by applying for a grant. The fund is administered by Heightened Independence and Progress (*hip*), a highly respected Center for Independent Living in northern New Jersey. The address is: 131 Main Street, Suite 120, Hackensack, NJ 07601. We chose an outside administrator to preserve confidentiality and impartiality. Maria Valentin at *hip* will be glad to hear from interested persons. Phone: 201-996-9100; fax: 201-966-9422. While family income is a factor, it is not the sole criterion for eligibility. We all know it costs a lot to be disabled – many families well above the poverty line incur extraordinary expenses because of disability. So if you, or someone you know, has had polio and is in need of limited financial assistance, don't hesitate to apply.

“Snow Removal Act” Refresher

Snow may seem a long way off, but by the time our winter issue is delivered, we may have plowed more than one storm. So here is a refresher on an important topic.

The Snow Removal Act (Chapter 182, Public Laws 1999) was signed into law by the governor on August 16, 1999. It was enacted to correct the problem encountered by people with disabilities who found that snow plows frequently deposited snow in the designated handicapped parking spaces at shopping centers, restaurants, stores, malls, theaters, and apartment complexes.

Specifically, the law states that “a person who owns or controls a parking

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

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

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 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.



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area that is open to the public or to which the public is invited and which contains special parking spaces... shall be responsible for assuring that access to these special parking spaces and to curb cuts... is not obstructed.”

The law provides that the snow or ice causing the obstruction is to be removed within 48 hours after the weather condition ceases. So the owner or manager of the parking area basically has a day in which to address the problem after the storm has ended. Many people seem to be under the impression that the snow or ice removal must be immediate.

Violators can be fined anywhere between \$200 and \$500. The enforcement of this law rests with the municipal police department. If you have questions about this law or how to register a complaint, you can call the NJ Division of Disability Services, 888-285-3036, option two.

SOURCE: EXCERPTED FROM *NEW JERSEY ABLE* NEWSPAPER, “DIRECTOR’S DESK,” BY WILLIAM DITTO.