



# Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

Fall 2010 / Vol 20. No. 1

## Polio Network Launches Public Relations Campaign

By Jean Csaposs

The Polio Network of New Jersey has embarked on a four-month professional public relations campaign to bring information to the many thousands of polio survivors still living in New Jersey and in nearby states, who may not be aware of the potential threat of post-polio syndrome. This will be accomplished through a significant publicity campaign and targeted presentations to medical professionals and public officials.

For its first major public relations initiative, PNNJ has engaged the MWW Group, a nationally known public relations firm based in East Rutherford, NJ. MWW is focusing its efforts in a broad-based program using various media and events in September and October. Then, after a winter hiatus, efforts will resume in the spring of 2011, in advance of PNNJ's annual conference scheduled for April 16th at the Bridgewater Marriott Hotel.

### World Polio Day

The campaign kick-off was an observance of World Polio Day (scheduled this year for October 24th). PNNJ members visited the New Jersey State House on Monday, October 18th, during a session of the state legislature. Senator Loretta Weinberg, chair of the State Senate's Health, Human Services, and Senior Citizens Committee, presented a Ceremonial Resolution honoring the Polio Network of New Jersey and World Polio Day. The purpose is three-fold:

- To acknowledge that polio remains a very serious health threat in certain areas of the world, most notably for children in developing countries;
- to acknowledge that many polio survivors, including thousands in the United States, still live with physical and emotional challenges associated with the often debilitating disease; and
- to acknowledge that many people in the United States are affected by "post-polio syndrome" (up to 30,000 in New Jersey alone), a new condition that affects survivors years after the onset of acute poliomyelitis.

### Bequest finances campaign

For all of its 20-year history, the Polio Network of New Jersey has had as its primary goal finding and assisting polio survivors in our area. A substantial bequest from the estate of Dorothy E DeRose has finally made it possible to look beyond the

*(continued on page 2)*

## Bekir Elected PNNJ President



Veliko "Lee" Bekir, of Hillsborough, was elected President of the Polio Network of New Jersey (PNNJ) at their quarterly Board meeting in July. He succeeds Arthur Siegfried, who recently resigned the position for medical reasons after leading the group for five years.

Lee, who describes himself as "technically inclined," built the current PNNJ website and acts as its webmaster. He has developed numerous exciting features for the website, including most recently the multimedia section, which incorporates audio tapes and photographs of our conference speakers along with copies of their PowerPoint slides and handouts. Lee has also served as chair of the annual PNNJ conference for several years. He is a member of the Raritan Valley Post-Polio Support Group.

For twenty years, Lee was employed by MetLife Insurance Company in Bridgewater, retiring as senior systems analyst. For several years afterwards, he ran Computer Doctors of Hillsborough, using the tag line, "Doctors that still make housecalls."

Lee and his wife, Anna, have a son, Idris; two married daughters, Marie and Lillian; and a 6-month-old grandson, Reed. About his goals for the organization, Lee says, "We want to reach out to as many people as we can. We're here to serve, and we want people to come to us. We're good listeners, too, so if anyone has ideas to share, we want to hear them."

SAVE THE DATE

*Dr. Stuart A. Hirsch*

WILL GIVE THE LEONARD BLUMBERG MEMORIAL LECTURE AT THE

*PNNJ 21st Annual Conference on Saturday, April 16*

BRIDGEWATER MARRIOTT HOTEL

## 20th Anniversary Luncheon

(continued from page 1)

range of our dedicated volunteers to attain our goal through a concerted professional effort. A portion of the DeRose bequest is being used to finance the public relations campaign, in the conviction that Mrs DeRose, whose young sister died many years ago after her initial attack of polio, intended her legacy to assist the many polio survivors in New Jersey who still may be unaware that they are experiencing post-polio syndrome.

### Medical and professional societies

Other avenues to be used as the campaign unfolds are public presentations, meetings, events, and media-related actions. In each case, MWW will conduct the necessary writing, outreach, and coordination and will utilize its contacts within state and county organizations to secure their commitment to learn more about post-polio syndrome, be it for an audience of physicians or other healthcare professionals, and/or presentations at larger annual events.

MWW will target the Medical Society of New Jersey, the New Jersey Chiropractic Association, and county medical societies. Similar meetings will be sought with nursing organizations, such as Health Professionals & Allied Employees (HPAE), the NJ State Nurses Association, NJ Nursing Students, Inc., and visiting nurse associations. Opportunities will also be explored to conduct presentations to legislative health committees.



*Celebrants attend the ADA's 20th Anniversary in Toms River.*

### Media relations

MWW will seek placement of Op-eds about post-polio syndrome in select daily and weekly newspapers and will issue press releases to targeted state and local media outlets about activities of PNNJ and its eight support groups. News releases will also be sent to appropriate Spanish language media. Media coverage of PNNJ's activities beyond press releases, such as interviews and features, will be explored, as will the use of public service announcements (PSAs).

PNNJ will appreciate feedback from *Newsletter* readers throughout the state about articles they may see in local newspapers; radio and TV announcements; and notices of meetings and events related to post-polio syndrome and the Polio Network of New Jersey.

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## New Advocacy Group Hosts ADA Celebration

*By Dorothy McDowell,  
ADAOCAN Chair*

A celebration honoring the 20th anniversary of the signing of the Americans with Disabilities Act (ADA) was hosted by ADAOCAN on July 26 at the American Legion Hall, in Toms River. More than 100 people arrived to meet and greet, learn about the ADA, enjoy a delightful luncheon, and have a good time.

ADAOCAN stands for "Americans with Disabilities Act Ocean County Action Network," formed in February of this year and comprised of representatives from four organizations, including Ocean County Post-Polio Support Group (OCPPSG). This event was their first joint venture.

Keynote speaker Bill Ditto, retiring director of the NJ Division of Disability Services, recounted the history of the ADA, emphasizing its positive impact on people with disabilities and the need to continue working to improve access. Other speakers included American Legion veterans, Ms. Wheelchair NJ, and OCPPSG board members Susan Gato, Jerry Bojko, and Ruth "Daisy" Stack.

The Ocean County Freeholders honored the group with a Proclamation and Senator Frank Lautenberg sent his wishes for a successful celebration. A big welcome was extended to members of the Mosaic Deaf Foundation, representatives from the Department of Developmental Disabilities, and several Ocean County agencies, organizations, and ADA coordinators, in addition to friends and families.

The program ended with merry inspirational tunes from the harmonica players and the uplifting sing-along voices from the audience. According to evaluation comments, people felt welcomed, learned more about the ADA, and had fun. Several people offered to work with ADAOCAN "to keep the ADA alive in Ocean County." The anniversary celebration was underwritten in part by a \$1,000 grant from the Polio Network of New Jersey's DeRose Fund.

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## Playground Plans Advancing

The "Universal Playground" planned for Hillsborough is one step closer to completion now that the Township Committee has approved the purchase of 27 ADA-accessible play components. An article about the playground, suggested by Dr. Stuart Hirsch, an orthopedic surgeon who treats many area people with post-polio syndrome, appeared in the Spring issue of the *Newsletter*. Municipal officials hope to begin construction of the playground shortly with the help of volunteers. Residents have volunteered in obtaining grants, running a July fundraiser, and gaining contributions for the playground that will be accessible for children with and without special needs.

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## Internet Notes

- Did You Know that you can go to your local library to use a computer? You'll find that the library staff is ready and willing to help you find a website, use e-mail, or accomplish many other useful tasks.
- Check [www.post-polio.org](http://www.post-polio.org), the website of Post-Polio Health International, every week for new information included in the feature "This week at PHI."

# Ruprecht Fund Continues To Meet Post-Polio Needs

By Jean Csaposs

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 living in New Jersey. During the past 10 years, the Fund has provided over \$17,000 in 52 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.

## Helps meet polio needs

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.

## Annual allowable

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. An individual can qualify for a grant of up to \$500 once annually. 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.

## Outside administrator

We invite NJ polio survivors 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. Phone: 201-996-9100; fax: 201-966-9422. We chose an outside administrator to preserve confidentiality and impartiality. Maria Valentin at hip will be glad to hear from interested persons. 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.

## Accessible Air Travel: A Guide for People With Disabilities

Review by Norma Markson

Published by the United Spinal Association, "Accessible Air Travel: A Guide for People with Disabilities," is a twenty-two page booklet with clear and concise information about what airlines may and may not require of disabled persons and what services disabled persons may expect from the airlines – as regulated by the Air Carrier Access Act (ACAA), 1986, amended in 2000.

Organized as a series of questions and answers, the topics covered start with "Making Reservations," breaking this down into Refusal of Service, Advance Notice Requirements, Seating Assignments, Airline Liability for Equipment (the airlines cannot make you sign waivers of liability for damage or loss of wheelchairs or other assistive devices), Security Screening, and Certification and Attendants.

The next topic is "Getting to the Airport," about airport accessibility. This is followed by "Boarding the Airplane," which is broken down into Boarding Assistance, Transfer and Lifting, Equipment and Storage, Aircraft Accessibility, and Service Accommodations.

"Handling Violations" is the final topic, a good one to be familiar with before you embark. The Complaint Procedures section takes up two full pages. You can start with the Complaints Resolution Officer at the airport, proceed through the process of filing written complaints with the air carrier, then the federal authorities, and finally, if necessary, going all the way to a civil lawsuit.

You can send for your copy of this booklet at:

United Spinal Association  
75-20 Astoria Boulevard  
Jackson Heights, New York 11370  
Phone: Publication Hotline:  
800-444-0120  
Email: publications@  
unitedspinal.org

SOURCE: TRIUMPH, GREATER BOSTON POST-POLIO ASSOCIATION. SPRING 2009

## End Senior Moments

There are lots of ways of looking at the Internet, and one of them is as a font of knowledge, some of it true.

"My iPhone is like a new brain for me," says Eliza Bell, 68, of New York City. "I use my Google app all the time when I can't come up with a name or fact in conversation." She likes other search engines, too. "I use both Google and Bing because I get different answers," she says. "A site nobody seems to know about is refdesk.com. It's one-stop shopping for a huge amount of information."

SOURCE: AARP.ORG/MAGAZINE

## ABLEDATA Informed Consumer Guide

A comprehensive website that lists a broad range of potential state-specific sources of funding and funding information for assistive technology and provides lists of specific organizations and programs from which funding and funding information are available. [www.abledata.com/abledata\\_docs/funding.htm](http://www.abledata.com/abledata_docs/funding.htm).

SOURCE: POST-POLIO HEALTH, SUMMER 2010

## Could a Camera Mouse Help You?

The Camera Mouse was developed by researchers at Boston College and Boston University to help people with disabilities use the computer. The program is offered as a free download. The main audience for this program are those who do not have reliable hand control but who can move their heads. Camera Mouse is a mouse replacement system for Windows computers. Requirements are Windows 7, Vista, or XP and a standard USB webcam. For additional information, go to [www.cameramouse.org](http://www.cameramouse.org).

## Look Good No Matter Where You Roll

Fashionable wheelchair-using women have more options than ever before, thanks to the increasing number of adapted clothing lines. Heels with Wheels is one such site, selling female-specific designs, like the easy-to-put-on (yet sexy) Lounging & Cover-Up line or the handy Happy Hour line. Heels with Wheels features outfits that go from day to night, and you don't have to change a single thread – [www.heelswithwheels.com](http://www.heelswithwheels.com). SOURCE: NEW MOBILITY, JUNE 2010

## Hotel-Booking Websites Offer Helpful Features to PWD\*

For disabled travelers, hotel-booking websites can be a huge source of frustration. Finding cheap lodgings on short notice is not that difficult, but how do you know if they are accessible?

On Feb. 16, one of the largest such sites, Hotels.com, announced new features enabling users to search for rooms based on specific needs, such as wheelchair access and roll-in showers. When an accessible room is reserved, Hotels.com will contact the

user to confirm the reservation or, if a room is unavailable, find a similar room at the same rate at another hotel.

Candy Harrington, editor of the *Emerging Horizons* travel newsletter and an expert on accessible travel, is cautiously optimistic. "I think it has great potential," she says. "But keep in mind, it may be a moot point, as the Department of Justice is currently thinking about requiring all properties and third party reservation services to do this."

Update: According to the *New Jersey Able* Newspaper, June edition, Expedia.com now offers a similar service.

\*People with Disabilities  
SOURCE: NEW MOBILITY, 2010, AND NEW JERSEY ABLE NEWSPAPER, JUNE 2010

**SAVE THE DATE**

**ABILITIES  
E X P O**

**MAY 20 – 22, 2011**

**NEW JERSEY CONVENTION  
& EXPO CENTER**

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### 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:

[info@njpolio.org](mailto:info@njpolio.org)

**Joan Swain**  
*Editor*

NEWSLETTER DESIGN BY  
Barbara Conklin, Hackensack, 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](mailto: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](mailto:hbroad@netzero.net)

### ESSEX-UNION AREA

East Pavilion of East Orange General Hospital  
240 Central Avenue, East Orange  
2nd Saturday, 12 noon to 2 pm  
March, June, September, December  
Contact: Edwina Jackson 973-673-0380 or  
Thelma Van Liew, 908-753-6514  
[nubianqueen8@aol.com](mailto: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](mailto: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 Gilbaltar Drive, Parsippany  
973-644-4888  
Dinner meeting, 3rd Wednesday evening  
March, July, December  
Vince Avantagiato 973-769-0075  
[drvince@njpolio.org](mailto:drvince@njpolio.org)

### OCEAN COUNTY AREA

Health South Rehabilitation Hospital  
of Toms River  
14 Hospital Drive, Toms River, NJ 08755  
Four (4) times a year on Saturdays  
April, June, September, and November  
Contact and confirm date and time with:  
Jerry Bojko 732-505-0151 or  
Susan Payne Gato 732-864-0998  
Website: [www.tomsrivernjpolio.org](http://www.tomsrivernjpolio.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  
[apecs@verizon.net](mailto: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](mailto: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.