



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

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20th Anniversary Luncheon Celebrates PNNJ

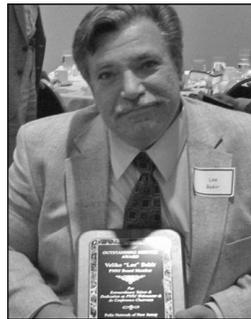
Close to 100 polio survivors, their families and friends joined to celebrate 20 years of service to the polio community by the Polio Network of New Jersey at a luncheon held at the Bridgewater Marriott Hotel, in Bridgewater, NJ, on May 15. The Network has continued to present annual conferences on post-polio syndrome (PPS) since the very first one in New Jersey in 1990, which featured eight recognized experts on PPS.



Dr Margaret Backman

At the luncheon, Margaret Backman, PhD, a clinical psychologist, was the featured speaker on “Maintaining Equilibrium in an Unsettling World.” She designed her presentation to incorporate questions provided by polio survivors attending the luncheon. A report on her presentation is included in this *Newsletter*. Additionally, an audiotape of Dr Backman’s talk, along with copies of her handouts, will appear on the multimedia page of our website: www.njpolio.org.

Veliko “Lee” Bekir, webmaster of the PNNJ website, was awarded the PNNJ Outstanding Service Award for “extraordinary talent and dedication as PNNJ webmaster and as conference chairman.” Lee designed the Network’s current website in 2004 and has continued to add features, most recently the multimedia page, that have made it a state-of-the-art information source for polio survivors. His service to the organization has also included two terms as conference chair.



Veliko “Lee” Bekir

Among the guests at the luncheon were Thomas Westerman, MD, who is leading the study on PPS and his associate, Smita Kargutkar, MD. Dr Westerman spoke briefly about the goals of the survey, which is aimed at informing physicians about post-polio syndrome and the issues surrounding it.

Recognition was given to the nine board members, who direct the organization, and to the eight support group leaders, who reach out to the estimated 30,000 polio survivors in New Jersey to offer camaraderie, valuable information about PPS, and a chance to talk with other polio survivors. The program featured “Polio Network of New Jersey Highlights 1990-2010,” which will appear on the PNNJ website.

“Maintaining Equilibrium in an Unsettling World”

By Jean Csaposs

When a professional friend of long standing pays a return visit to PNNJ, there is cause for rejoicing. When that friend is Margaret E Backman, PhD, that’s a reason to cheer. Polio survivors in outstanding numbers have been Dr Backman’s patients in her private practice of clinical psychology for well over 25 years. She is the author of “The Post-Polio Experience,” a book from which readers have gained much wisdom since it first appeared in 2005. Dr Backman returned to make the solo presentation at PNNJ’s 20th anniversary luncheon on May 15.

Times change. . .

And we change with the times. Dr Backman opened her remarks with a brief account of the evolving concerns of her post-polio patients. At first, people were worried about new weakness and disturbing memories of their early polio. As time went on, those concerns broadened to include difficulties in family relationships – particularly with spouses and children. Then came the need to care for aging parents when one was starting to experience problems of one’s own. Being forced to consider early retirement or cutting back from full to part-time work also entered the picture. For many, whole new challenges began to surface, such as the need for handicapped parking, for walkers, wheelchairs, and scooters. Add to that list the economy, terrorists, and health care: “If the problem of ‘maintaining equilibrium in an unsettling world’ could be solved,” said Dr Backman with

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PPS STUDY DEADLINE AUGUST 9

If you are interested in taking part in the Polio Network of New Jersey Post-Polio Study being conducted by S. Thomas Westerman, MD, be sure to get your survey in on time. All entries must be postmarked by August 9.

To obtain a copy of the Post-Polio Survey, phone Dr. Westerman at 732-460-0045. The aim of the study is to inform doctors about post-polio syndrome and the issues surrounding it.



Maintaining Equilibrium

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her characteristic good humor, “it would rate the Nobel prize!” She said she would not answer the questions provided by her listeners, but would address them.

Focus on the future

“Be positive but not Pollyanna,” Dr Backman advised. “Early in my career, I worked in rehab and dealt with people with many different disabilities. I have been educated by my patients, many of whom continued to suffer from past trauma, some with fears they had repressed. But at 75 (the age of the questioner), instead of looking back, ask whether advancing age should be a problem or a challenge. The question should be ‘Am I going to make the best of the years that I have?’ Life is a process – we now live with chronic diseases much longer than we might have expected in the past.”

Self-concept – self-esteem

Are there any common themes for polio survivors? Yes. For example, “exercise, exercise, exercise,” we were told. But exercise didn’t always live up to its expectations, leading to some distrust of authority in the medical field – a somewhat different outcome from that of people with other diseases. Instead of optimism, people began to fear “the past coming back to revisit the future.”

Another common theme is how to accept oneself as a person with a disability. The age of polio onset is a factor: children often felt guilt, as if they had done something wrong to bring on the disease. Issues of how people have responded to you and you to others is a common thread. Society’s prejudices are also a strong factor, as is some people’s fear that they are being pitied. How can moderately affected survivors relate to those who were severely affected, and vice versa: how can we develop kinship with someone who had a totally divergent history? Many people were advised, “Don’t tell anybody you had polio – nobody will want to marry you.” Also, especially in the earlier stages, there was a sense that people really wanted to ask, “Are you contagious?”

Men and women

The genders have different coping styles. Men have a harder time than women accepting disability. Women find it easier than men to talk about their feelings, while men are supposed to be stoic, the “fixers.” Interestingly, men in VA hospitals are more likely to accept their situations, even with severe disabilities, because they are in a group setting where others are in the same boat. Contrary to popular belief, people in the service did get polio during the epidemic years, but unfortunately, the military records have been destroyed.

Words matter

In answer to a question about feeling “inadequate” to perform simple everyday tasks, like reaching across the table for the salt, Dr Backman addressed such negative terms as “failure,” “flaw,” and “weakness.” She said we must move away from “feelings” and look for “problem-solving.” When it comes to “reaching for the salt” and other formerly easy tasks, try rearranging your household. Move beyond your limitation and think outside the box, substituting behaviors for labels like “inadequate.” The value of adopting more positive words is also shown in our choice of “survivor” over “victim.”

When we talk about “acceptance of deteriorating ability,” think about the definition of the word acceptance:

For More About Dr Backman’s Presentation

- To listen to audiotape of Dr Backman’s luncheon talk and read/print copies of her handouts, log onto www.njpolio.org and click on Multimedia.
- For copies of Dr Backman’s Handouts: Call 201-845-6860 or write PNNJ Newsletter, PO Box 537, Martinsville, NJ 08836. Include your complete PO mailing address.
- *The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families*, by Margaret Backman, PhD, iUniverse, (Paperback) \$18.95.

“tolerating something without protesting”
Protesting is good! How about “recognition” rather than “acceptance”? Now you have to analyze your situation and do something about it.

Avoiding isolation and self-pity

Do you find yourself cutting back on activities you used to enjoy, finding it more comfortable just to stay home and watch TV? Perhaps questions need to be asked. What’s keeping you at home? Fatigue? Fear? It’s good to stop and think about it in some depth. Write it down. When you see on paper what some of these excuses are, you can start to do something about it. Be part of the dialogue with people you want to be with. If you have avoided using a mobility device – “I haven’t descended to that level!” – think again. People who resist the “wheelchair image” often find that “scooters are cute.” (Hint to wheelchair manufacturers from Dr Backman: re-design them to look more appealing.)

At the opposite end of the spectrum are the so-called “Type A’s” who may be people who just love life, love doing things, and don’t want to retreat into passive old age. Fine, but don’t push beyond fatigue. Take that afternoon nap without protesting and conserve your energies. That brings us to: How to help people learn to “just say no.” Also, how to get others to recognize that things are changing. Ask people if they would mind doing routine tasks, not just once, or once in a while, but routinely, say, on Friday morning. But bear in mind that people tend to forget – you have to remind them, but not in an accusing way, as if they have deliberately set out to hurt or ignore you. Forgive! Don’t keep reminding people that they forgot and attribute negative motives to their forgetfulness. The language should be, not “You forget because you don’t care about me,” but instead, “When you forget, it makes me feel ... etc.”

Help! (or not)

When someone offers to open a door or give you a seat, before rejecting the offer, consider accepting it and thus rewarding the behavior. If you refuse, they may not offer help again to someone else. Even if you have good reason to refuse the offer, do so with a smile. That too is a reward.

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When asking for help, there is a balance between being demanding and self-abasing. Learn to strike that balance, knowing that many people are eager to help and don't focus lasting attention on you: they move on. There should be no embarrassment in asking for help. Occasional anger and frustration? Turn them into positive action. Have a sense of humor about the little annoying things related to what you used to be able to do.

Depression?

Studies that report many histories of depression may not be reliable if the reports have come from volunteers. They may be biased towards reporting about their depression, whereas random surveys may yield more balanced results. However, by simply gathering information from people we know about, there is evidence that suggests living alone may be a factor. Having nobody to talk to can lead to feelings of sadness and loss. Health issues may also impinge: one study suggests "prior hospitalization" as a factor in depression.

Nutrition, Weight Control, Drugs

Plan meals ahead. Eat at specific times. Give permission to others to take food away when tempted to eat second helpings. Treats? Be careful – "once in a while" doesn't work very well. The use of alcohol and/or drugs does not seem to be significantly higher in polio survivors.

When questioned about the use of drugs, Dr Backman noted the accepted finding that statins such as Lipitor do weaken muscles and advised, "Pay attention to your body." Some anti-depressants may make muscles feel better, and as for meditation, it's always "a good thing."

ADA Celebrating 20th Anniversary

Celebrations are being planned around the United States to commemorate the 20th anniversary of the Americans with Disabilities Act (ADA). The document, signed into law on July 26, 1990, is a wide-ranging civil rights law that prohibits discrimination

LegalEase...

by Arthur P Siegfried, Esq

A whole new area of law is building and developing in this electronic age. A recent case to be decided by the US Supreme Court involves the question of whether a police department violated constitutional privacy rights of an employee when the police department inspected personal text messages sent and received on a government pager.

"A new frontier in Fourth Amendment jurisprudence" was included in the appeals court decision from California. The fourth Amendment prohibits unreasonable searches. This case is unique but could have widespread effects in that it deals with an individual's rights and a government's intervention into them.

It is interesting that this was a government employee using the computer and the Internet for what apparently was personal communication. I feel it will be an interesting case to follow. The eventual decision, which will weigh the rights of the employer against those of the employee's use of the employer's equipment and whether the fact that this is a government agency involved, remains to be seen. Many times the Supreme Court will make a decision restricted or limited to the facts of the particular case, and other times they use a much broader brush in issuing an opinion. So let's hold tight and see what happens.

In this age of electronics, e-mail, and such other communication methods that were not known a decade ago, the case will probably illustrate the thought that law is always changing and must keep up with the times.

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based on disability. It has changed the face of accessibility in the country.

The White House celebration was kicked off by Valerie Jarrett, Senior Advisor to President Obama, on June 6 at the Kennedy Center for the Performing Arts. She highlighted some of the President's initiatives thus far related to people with disabilities and previewed that senior administration officials will be commemorating this historic anniversary in the weeks to come with new policies and events.

"The Spirit of ADA... Lead On!," sponsored by over twenty non-profit agencies including Easter Seals, the National Council on Independent Living, and United Spinal Association, will take place on July 20 at the Grand Hyatt Washington, in Washington, DC.

On July 26, The Committee on Disability Power & Pride is hosting a 20th Anniversary ADA Gala Celebration, also in Washington, DC. A large Disability Pride Parade is scheduled in Chicago on July 24.

Locally, the Ocean County Post-Polio Support Group will be joining other advocacy groups in the ADA Ocean County Action Network at an event on July 26 in Toms River to promote greater compliance with the ADA in their area. PNNJ supported this endeavor with a \$1,000 grant from the DeRose Fund.

Anesthesia Warning Card Still Available from NJ Health Dept.

The New Jersey Department of Health and Senior Services has received a deluge of messages from polio survivors throughout the country thanking the Department for the wallet-size anesthesia warning card developed by the Ocean County Post-Polio Support Group, issued by the Department, and included in the mailing with the Spring PNNJ *Newsletter*. In response to several inquiries about the source of the information, the listing of PPS symptoms highlights those established through research or observed by clinicians; and the warning language regarding anesthesia and surgery issues was supplied by Richard Bruno, PhD. The card can be obtained from the NJ Health Department by calling Bernadette Marx (609-292-4043) or by e-mail to Bernadette.Marx@doh.state.nj.us. Post-polio information and clinics in New Jersey can be accessed at www.nj.gov/health/cd/postpolio, or by visiting the PNNJ website, www.njpolio.org.

National Park Service Offers Free "Access Pass" to People with Disabilities

The Access Pass – a free, lifetime pass to National Parks and recreation centers, such as New Jersey's Sandy Hook National Seashore, and the Delaware Water Gap's National Recreation Area – is now available to United States citizens or permanent residents with disabilities. Caregivers may also enter Federal Recreation sites for free when accompanying a child. The Access Pass also provides the pass owner a discount on some expanded amenity fees.

Proof of disability, such as a statement by a licensed physician or a document issued by a state or federal agency, is required to obtain the pass.

The Forest Service, the National Park Service, Fish and Wildlife Service, Bureau of Land Management, and Bureau of Reclamation all honor the Access Pass.

Individuals may apply in person at any park or recreation center, or visit the National Park Service website at <http://www.nps.gov>

SOURCE: THE NJCDD COUNCIL, MAY 2010

Drive-Master Offers Accessible Van Rentals

Drive-Master Co., Inc, a company familiar to many for their auto and van conversions, offers wheelchair-accessible van rentals at their Fairfield, NJ, location. They cover New York and New Jersey, including the airports.

Van rentals may be arranged for the day, week, or month. Delivery and pick-up services are available within an hour and a half radius of their Fairfield location. For price quotes, availability, and additional conditions, contact Drive-Master at their toll-free number, 877-282-8267, or online at www.drive-master.com.

Hit the Road!

Guides for Travelers with Disabilities

Thinking about taking a vacation? Afraid to take the leap because you use a wheelchair? The latest edition of a popular resource guide may be just the thing to get you moving.

The third edition of *Barrier-Free Travels: A Nuts and Bolts Guide for Wheelers and Slow Walkers*, contains detailed information about the logistics of planning accessible travel – whether by plane, train, bus, or ship.

"Planning an accessible vacation can be daunting if you don't even know where to start, but this book gives you the resources to do it," said the author, disability travel writer Candy Harrington (www.candyharrington.com). "And it will save you some time, money, and frustration in the process."

The book includes important details about accessible air travel, traveling with oxygen, accessible ground transportation, choosing a travel agent, online booking, accessible recreation, and budget travel. This and two other travel books, *101 Accessible Vacations* and *There Is Room at the Inn*, may be ordered online at www.candyharrington.com/book/books/php or in bookstores.

SOURCE: NEW MOBILITY, AUGUST 2009

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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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, 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

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, Denville
3rd Saturday, 11 am
April, May, June, September,
October, November
Il Villaggio Restaurant
22 Gilbraltar Drive, Parsippany
973-644-4888
Dinner meeting, 3rd Wednesday evening
March, July, December
Vince Avantagiato 973-769-0075
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

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

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.