

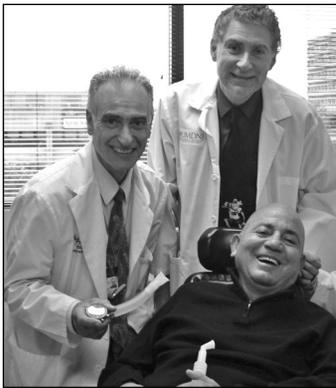


Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

Winter 2012 / Vol 22. No. 2

Dr John R Bach to Keynote 22nd Annual Conference on Post-Polio Syndrome



Dr Bach treats both the famous and the “infamous” for breathing problems at his office in Newark’s medical complex. He and respiratory therapist Lou Saporito (left) are pictured with the late Philip Carlo, best-selling biographer of notorious villains.

he has authored more than 250 publications including seven books on neuromuscular pulmonary rehabilitation, and noninvasive mechanical ventilation. He has lectured on these topics in over 30 countries and has written extensively about them.

Author to speak at lunch

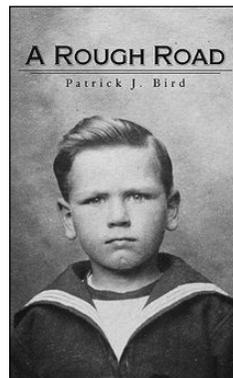
Patrick J Bird, author of *A Rough Road*, will be our luncheon speaker. Bird’s book tells the tale of a four-year-old boy from New York City who is sent to a “reconstruction home” to learn to walk after a bout with polio in 1940. The book is based on the author’s 19-month experience at what is now the Helen Hayes Hospital in West Haverstraw, NY. (The book was reviewed in the Fall issue of the *Newsletter*.)

Patrick Bird has held professorial and academic administrator positions at the Universities of Minnesota, Virginia, and Florida. Now retired from academia, he lives and writes in Gainesville, Florida. He will speak about his reasons for writing *A Rough Road*, and some of his experiences in reconnecting with that long-ago world.

The Polio Network of New Jersey has announced its 22nd Annual Conference on Post-Polio Syndrome, which will be held at the Bridgewater Marriott Hotel, in Bridgewater, on Sunday, April 22. Returning to speak with the group is John R Bach, MD, pulmonary specialist and longtime friend of the Polio Network of New Jersey. He will speak on respiratory issues, a major concern of all men and women in their senior years, not only polio survivors.

Since 1983, Dr Bach has been on the faculty of the UMDNJ-New Jersey Medical School, where he currently is Professor of Physical Medicine and Rehabilitation and Vice Chairman of the department. He is also Professor of Neurosciences in the Department of Neurosciences. At University Hospital, Newark, Dr Bach is Director of Research and Associate Chief of Service of the Department of Physical Medicine and Rehabilitation. He also serves as Medical Director of the Center for Ventilator Management Alternatives.

Rehabilitation of patients with neuromuscular disease, pulmonary disease, and home mechanical ventilation are the primary clinical focus of Dr Bach, and



A young, determined Paddy stares out from the cover of A Rough Road.

The End of Polio

An ambitious project was inaugurated in July 2011 in Australia by The Global Poverty Project, a public education and advocacy organization launched at the UN in 2008. The goal was to work toward The End of Polio, in support of efforts led by the Global Polio Eradication Initiative, Rotary International, UNICEF, the World Health Organization, and the Bill and Melinda Gates Foundation.

The End of Polio project is a grassroots organization of youthful men and women that, after starting in Australia, expanded to New Zealand, the United Kingdom, Canada, and the US. The campaign is based on four points:

- Asking individuals to demonstrate their support by signing The End of Polio petition;
- Meeting with key decision-makers to ask governments to give to the Global Polio Eradication Initiative and commit to realizing the end of polio;
- Sharing the remarkable stories of progress in fighting polio through the media and online;
- Holding events to demonstrate support for ending polio, which culminated in a huge concert on October 28 in Perth.

Polio survivors asked for their stories

Polio survivors around the world were asked to write their stories about polio. Two of the nine stories that appear on The End of Polio website (www.endofpolio.com) are by Jean Csaposs and Joan Swain of the Polio Network of New Jersey and are reprinted in this *Newsletter*. To read others, including one by Dr Lauro Halstead, go to the group’s website, click on Blog, then on We’re Still Here, and scroll down.

A positive international response

On October 29, at the Commonwealth Heads of Government Meeting, the governments of Australia, the United Kingdom, Canada, Nigeria, and

(continued on page 2, box)

You Can Help “Younger” Polio Survivors

**By Joan Headley,
Executive Director,
Post-Polio Health
International**

PHI's new additional website, "Polio Place," (www.polioplace.org), has been described as "superb," "terrific" and "comprehensive, well-written, informative." And we add to it daily! You can help. Consider submitting information for the "Artifacts" section. As you can see by reviewing what is already there, we are looking for photos, scans of letters, documents, etc, that tell part of the polio story, but also information that would be encouraging and useful to "younger" polio survivors.

Each "Artifact" is coupled with a narrative from the author's point of view. We are particularly interested in hearing from people who can show and write about getting an education, the work world, about dating, marriage and having children, but the invitation is open. Think about what memorabilia or "moment" you can submit online.

We are interested in essays about having had polio. See examples in *Living with Polio, Relationships, Essays*. Also, we are looking for photos that demonstrate a solution, particularly low-tech, for living with polio. See *Living with Polio* and *Photographs*, the very last entry. Send your ideas to info@post-polio.org.

What's in a Name?

Recording for the Blind and Dyslexic has officially changed its name to *Learning Ally*. It carries the tagline "Making reading accessible for all." Among users of these recordings are polio survivors who have difficulty in handling a standard book. Keeping up to date with new technological advances, the organization provides books available on cassettes, CDs, computers, and most recently, on devices such as the iPhone, iPad, and iPod. For information call 866-732-3585. SOURCE: NEW JERSEY ABLE NEWSPAPER

End of Polio

(continued from page 1)

Pakistan pledged to see the end of polio. It was later announced that the Australian Government would put

\$50 million toward a worldwide initiative to stamp out the disease, and Bill Gates announced a \$40 million contribution. On The End of Polio website, 25,364 have signed the online petition.

ONLINE PETITION

Dear World Leaders,

We call for your support to help eradicate the second human disease in history.

We call on you to fully fund the critical work of the Global Polio Eradication Initiative, which will provide vaccines for hundreds of millions of the world's poorest children and support health workers to protect future generations from this debilitating disease.

25,364 HAVE SIGNED THE ONLINE PETITION

The World Has Suffered From Polio. Let's End It Now

By Jean Csaposs

Yes, I would like to live long enough to see the end of suffering from polio. Although I would not characterize myself as having lived as a "sufferer" or "victim," polio certainly brought its share of suffering to my family as well as myself. In 1931, how could a mother know that her 5-month-old baby hadn't caught the dreaded disease through the bite of the wandering mosquito she hadn't swatted in time? How could she get used to the reality of braces, crutches, and a wheelchair as her daughter's daily companions? Later on, how could she win her fight for educational equality for me, against overwhelming odds? Fortunately, she lived long enough to enjoy my successes, to see many barriers – physical and societal – removed at last, and to finally learn that polio is caused by a common virus and not through any fault of hers.

In those parts of the world where, either through ignorance or fear – or both – children are not being immunized against polio, the suffering continues, for them and for their families. Death itself is no stranger, and polio's crippling effects ruin lives. Poverty, primitive sanitary conditions, poor healthcare, and lack of education magnify the suffering. We can help to end that suffering so that, in time, none of the world's children will even know that polio ever existed.

My Polio Story

By Joan Swain

I was about to enter my senior year in high school when polio changed my plans in September of 1949. Instead, I spent the next five months in a rehab hospital strengthening muscles and learning how to live with crutches and braces. Life went on, albeit in a now-inaccessible world. The ADA (Americans with Disabilities Act) would not arrive for another 40 years! In that time, I graduated from high school, then college, then married and had two children. In the 1980's just as Post-Polio Syndrome was raising its threatening head, I realized that I was gradually losing my ability to physically do things. Stairs became difficult. My balance tottered. I developed painful joints.

By the mid-80s, I had found a nearby post-polio support group to join, and in 1990, we held a major conference on post-polio syndrome with international speakers knowledgeable about this frightening development facing polio survivors (that's what we called ourselves). The next year, we founded the Polio Network of New Jersey to reach out to and educate polio survivors in our state. And their healthcare professionals. We're still doing that. I wholeheartedly support the campaign to end polio globally. A vaccine exists to prevent this dreaded disease. Not one more child on the planet should have to experience it.

Pre-Existing Condition Reforms Take Effect

Although some provisions of the Affordable Care Act of 2010 will not kick in until 2014, one aspect of healthcare reform – coverage for people with pre-existing conditions – has already taken effect.

On May 31 the Department of Health and Human Services announced new eligibility standards and lower premiums for the federally administered Pre-Existing Condition Insurance Plan (PCIP). Starting July 1, premiums were to be dropped by up to 40 percent in 18 states, and eligibility standards

were to be lowered in 23 states and the District of Columbia.

The program covers a wide range of health care benefits and is designed for people with pre-existing conditions who cannot obtain private health insurance. After 2014, insurers will be barred from denying coverage or charging higher premiums to people with pre-existing conditions. The PCIP is designed as a “bridge” until that time.

Funds for the program have already been allocated and will not be affected by current budget negotiations between Congress and the White House, according to an HHS spokesperson.

To find out about eligibility, benefits, and rates, as well as how to apply, go to www.pcip.gov and click on “Find Your State.”

SOURCE: NEW MOBILITY

Universal Playground Opened June 11

A unique playground opened in Hillsborough, NJ, in June – one that can be used by children with and without disabilities. Known as a universal playground, it was suggested and supported by local orthopedic surgeon Stuart A Hirsch, MD, of Bridgewater, who was the keynote speaker at the annual Polio Network of New Jersey’s conference in April. He was inspired by a program initiated by the American Academy of Orthopedic Surgeons that has resulted in the building of universal playgrounds in 10 other cities. In addition to providing exercise, these playgrounds enable children with disabilities to play on the same equipment as children without.



PNNJ President Lee Bekir and his grandson, Reed, meet with Hillsborough Mayor Gloria McCauley.



Reed plays with wheels and gears on the universal playground structure.



Children explore the ramp at the universal playground in Hillsborough on opening day.



Polio Network of NJ is listed on the plaque recognizing donations.

PNNJ Board Holds Leadership Meeting

The Board of Directors of the PNNJ met with Barbara White, of the New Jersey Self-Help Group Clearinghouse to discuss “The Art of Effective Self-Help Support Groups.” The discussion ranged from starting a support group to examining why support groups diminish in attendance over time. The Self-Help Group Clearinghouse provides help to a wide variety of groups throughout the state on a voluntary basis. They also provide a rich supply of handouts to guide groups through a full range of organizational issues. The PNNJ currently has eight support groups in the state. Anyone interested in starting a new post-polio support group is invited to contact Lee Bekir at LeeBekir@PNNJ.org or at 908-698-2769. The meeting was organized by Susan Payne Gato, leader of the Ocean County Post-Polio Support Group and Secretary and member of the PNNJ Board.

PNNJ’s Ruprecht Fund May Meet Your Need

Polio survivors living in New Jersey may apply for limited funding for polio-related needs. Call Maria Valentin at 201-996-9100, or e-mail mvalentin.ber@hipcil.org. You may qualify! See more information on www.pnnj.org

Did you miss Stuart Hirsch, MD, and children of polio survivors who spoke at the PNNJ 2011 Conference? You can catch them online at our website, www.pnnj.org, or purchase the DVD – or both!

To buy, send \$10 (check payable to PNNJ) to:
 Lee Bekir
 PNNJ-DVD
 4 Coronet Way
 Hillsborough, NJ 08844-4802

What's An ADRC?

You may have seen a new acronym lately: ADRC. So what is it, what does it do, and why should you care? ADRC stands for Aging and Disability Resource Center. Each national region is supposed to have one. They're all funded by the federal government, and they're the newest twist on the old one-stop-shop idea. If you need any type of personal assistance service, you ought to be connected to whatever is in your area by contacting an ADRC first. From there, being plugged into whatever you're eligible for ought to be seamless and easy. No more being sent on wild goose chases, theoretically. Find the one closest to you at www.adrc-tae.org.

Editor's note: In New Jersey, the lead agency is the state Department of Health and Human Services.

SOURCE: NEW MOBILITY

Some Specifics on New ADA Final Rule Regulations

- **Service Animal** means any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability. Other species of animals, whether wild or domestic, trained or untrained, are not service animals for the purpose of this definition.
- **Power Mobility Devices/ Wheelchairs.** The Department of Justice has finally come up with a definition of a wheelchair: "A manually operated or power-driven device designed primarily for use by an individual with a mobility disability for the main purpose of indoor or of both indoor and outdoor locomotion."

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.

People who use wheelchairs can use any area open to pedestrians.

- Other power-driven mobility devices include Segways, golf carts, or other electronic personal assistance mobility devices. Public accommodations must also allow people to use these devices unless the facility can show a danger or interruption of services
- In other words, a facility must be very careful in developing policies concerning these vehicles and their use.
- An individual may not ask a person with a wheelchair or other power-driven mobility device about the nature or extent of the individual's disability.
- A tank chair is designed to go off-road through streams, mud, snow, sand, and gravel or anywhere outdoors. A tank chair is designed to be used outdoors but it is marketed as an indoor chair as well.

SOURCE: LEONA MATHER, ADA COORDINATOR, GLOUCESTER COUNTY, NJ

ABILITIES EXPO MAY 4 - 6

New Jersey Convention and Expo Center
Edison, New Jersey
Friday and Saturday 11am-5pm
Sunday 11am-4pm

Polio Network of New Jersey NEWSLETTER

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201-845-6860

WEBSITE ADDRESS:
www.pnnj.org

E-MAIL:
info@njpolio.org

Joan Swain
Editor

NEWSLETTER DESIGN BY
Barbara Conklin, Hackensack, NJ

Tuning in on the Polio Network of NJ

ATLANTIC COUNTY AREA

Ye Olde Mill Street Pub
6033 Main St, Mays Landing
3rd Wednesday at 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

80 South Munn Avenue, East Orange
2nd Saturday, 12 noon to 2 pm
March, June, September, December
Contact: Edwina Jackson 973-699-1564 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 Gibraltar 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: Ray Jajko 609-531-6595
flyguyray@comcast.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.