



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

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Dr Mary Ann E Keenan to Keynote 19th Annual PNNJ Conference

Mary Ann E Keenan, MD, an orthopaedic surgeon renowned for her expertise in shoulder care, will be the keynote speaker at the 19th Annual Polio Network of NJ Conference on the late effects of polio, October 25, at the Doubletree Princeton Hotel.

Dr Keenan is Chief of Neuro-Orthopaedic Service, and Vice Chair of Graduate Medical Education, University of Pennsylvania Health System. She has had lengthy experience working with post-polio patients and understands the painful difficulties they face after using their arms for decades to compensate for other polio-related weakness. Additional speakers will be named in the Spring *Newsletter*.

New time, new place

In a departure from tradition, the conference is being held in October rather than in the Spring to avoid conflicting with the scheduled PHI Warm Springs Conference April 23-25. A new central location, Princeton, NJ, will be the setting for the conference. As previously, a reception and dinner will be held the evening before the conference for the speakers, those arriving early, and any others who wish to attend. Watch for more conference details in future issues of the *Newsletter* and on the PNNJ website.

PHI Sets Warm Springs Conference

Post-Polio Health International is holding its 10th International Conference, *Living with Polio in the 21st Century*, April 23-25, hosted by the Roosevelt Warm Springs Institute, Warm Springs, Ga. Details are available by phone: 314-534-0475; website: www.post-polio.org; or e-mail: info@post-polio.org. Warm Springs alumni, please contact Carolyn Raville at 352-489-1731.

A Post-Polio Wellness Retreat at Camp Dream, Ga, April 18-23, is modeled after popular retreats held at Bay Cliff Health Camp in Upper Michigan. It will be led by Frederick M Maynard, MD. Call Reenae White at 706-655-5715 for information.

PNNJ Receives a Generous Bequest

By Joan Swain

The Polio Network of New Jersey is the recipient of a generous bequest from the estate of Dorothy E DeRose, 71, who lived in Port St Lucie, Florida, at the time of her death on May 13, 2008. Born in Plainfield, NJ, she lived in Monmouth County for many years before retiring to Florida. The bequest is in memory of her sister, Shirley Mae Will.

Elizabeth A Nanna, sister of Dorothy DeRose, has contacted the Network to relate the story behind her sister's bequest. It is a story of love and a promise fulfilled.

Dorothy and Elizabeth Will had a sister named Shirley Mae, who contracted polio at the age of 15. Paralyzed from the neck down and in an iron lung, she spent time in Monmouth Memorial Hospital in Long Branch during the early 1950's.

Dorothy, who was in her teens, was devoted to Shirley and went to the hospital daily to comfort her. She promised Shirley that if she had enough money when she died she would leave something to the polio foundation in



Shirley Mae Will

her memory. In 1954, Shirley died – a month before her 19th birthday.

The story then jumps to 2003. When Dorothy made a trust that year, she wanted a gift to go to an organization in full support of polio. Searching the Internet, her lawyer found the PNNJ website, recognized a doctor whom he knew, and recommended the organization to Dorothy. Now, 54 years after Shirley Mae's death, Dorothy's promise is fulfilled.

The Network plans to use this bequest to offer assistance to the Network's support groups, to special projects related to polio, and to individuals through the Ruprecht Fund. The Network is extremely grateful for the opportunity provided by this bequest to further touch and improve the lives of polio survivors in New Jersey.

Warm Springs: Traces of a Childhood at FDR's Polio Haven

by Susan Richards Shreve

Paperback, \$13.95; Hard Cover, \$24
Houghton Mifflin Company

Review

by Gail Caldwell, *The Boston Globe* staff

Our cultural fascination with illness derives in part from the impact that disease has on the social order – the fears of contagion, the rush for a cure, or a vaccine, the almost predictable ostracism that befalls victims (a rough moral insurance that it could never happen to us). These tenets have held in the modern world from smallpox to AIDS, though the polio epidemics of the mid-20th century may have occupied a unique place in the collective consciousness. The worst casualties of polio are often children, whose immune systems are not yet strong enough to fight back, and the virus tends to maim rather than kill. So we were left with the photographs: of kids on crutches or in iron lungs, of March of Dimes poster children with broken bodies and strong hearts.

The visual metaphors were anguished but ongoing: If polio let you live, it left a permanent reminder of what it had taken.

Novelist Susan Richards Shreve contracted the disease as an infant in 1941; by the time she was 3, she was able to walk with braces on both legs – and with the help of a mother who is one of the competing female heroines of *Warm Springs*.

“We were odd,” writes Shreve about the Richards family more than halfway through this affecting memoir, though by now the reader has long since figured that out. Her father was a radio broadcaster in Washington, DC, who took in stray dogs and drunken journalists. Her mother, who dressed out of *French Vogue* and counseled her daughter to stand like a dancer, retired to her bedroom for a year when Shreve was 8; the family installed a Dutch door so that Mrs Richards could hear conversations from the rest of the house. Yet she had tirelessly worked with her daughter’s frail body until the girl was able to hobble forth into the world, imbuing her with a mobility of spirit that is as striking as anything in *Warm Springs*.

“Speak first, my mother had always told me,” writes Shreve, “knowing that a bony child on crutches with the dark demeanor of a war survivor might not be well received. ‘Say ‘I’m Susan Richards’ and smile and reach out your hand.’” It was advice that the finest etiquette schools might have envied, and probably as essential as any treatment Shreve endured.

Warm Springs refers to the rehabilitation hospital in Warm Springs, Ga., where Shreve spent two years of her life: undergoing muscle transplants and physical therapy, behaving like a rascal or a saint, daydreaming from within her confines to hone the skills of the writer she would become. Felled by polio in 1921, Franklin Roosevelt had gone to the inn at Warm Springs for the mineral waters; he had found a milieu of such therapeutic hope that he bought the place, transforming it into a model of public health. With its boarding-school-like setting, Warm Springs sought to rebuild not just the atrophied muscles but the very psyches of its “polios,” as the disease’s victims were called. In other words, speak first.

Shreve has consciously set out to write her story as a shadow of the greater one: of the impact of polio on an America poised between the Allied victory and the civil rights movement, of a society with enough sophistication to found Warm Springs but still in the dark ages about health and morality. (When Shreve contracted rheumatic fever in the 1940s, “the treatment was ten Hail Marys, kale sandwiches on brown bread, and cod liver oil.”) But the real drama of *Warm Springs* lies within its more personal story, of a girl who spent her nights trying to outlast fear and her days bluffing her way through the obstacle course polio had wrought. Away from her family for months at a time, she became both resident clown and pious acolyte at Warm Springs, tending to bedpans and the infants on the ward, trying her damndest to convert to Catholicism (she failed). She challenged a boy to a wheelchair race, a disastrous affair that forms the narrative crucible of her memoir; there

is also a hilarious episode involving what used to be called a sanitary belt. She roused the other girls on the wing into laughter and games beyond the ordinary anguish that defined the place. About the post-surgery screams of one roommate, she writes, “But we were used to that in one another and could sleep through noises of pain and sadness, or talk through them, about movies and boyfriends and sex and God, back and forth across the beds. Never pain and sadness.”

Wrenching but entirely lacking in self-pity, *Warm Springs* is both funny and revelatory, its narrator emerging as a thoroughly endearing girl poised on adolescence who had grown up long before. As a primary resource (I had polio as an infant, a case milder than Shreve’s), I can testify that her description of the commonly called “polio personality” is spot on: stubborn to a fault, determined against all odds, capable of the “splendid deception” that FDR mastered to deny the effects of the disease. A great deal of this memoir is about waiting: the empty hours of not walking, the pause in time while you waited for the surgery or braces to work or for real life to begin. And so the child filled the hours with stories greater than her own – fantasies that involved other characters and more far-flung dramas. “I was always somewhere else and the narrative took over,” writes Shreve. “I had the illusion of living a life in full.” Most of us would agree that it was no illusion at all.

Gail Caldwell is chief book critic of The Boston Globe. She can be reached at caldwell@globe.com.

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SAVE THE DATE!

Abilities Expo
April 17-19

New Jersey
Convention Center
Edison, NJ

PNNJ Historian Wanted

Do you enjoy history? Do you get satisfaction from organizing things? Do you like scrapbooking? Then maybe you're just the person to fill the newly created position of Historian for the Polio Network of New Jersey.

We have loads of press clippings, photos, memorabilia, etc., and we believe it's important to assemble this interesting and valuable information in one place. This project is part of our recognition of the PNNJ's 20th Anniversary Celebration in 2010.

If you are interested in becoming our Historian, please contact Jean Csaposs at 201-845-6860 or at jjcsaposs@msn.com

Two Hot New Links on njpolio.com

Reji Mathew, PhD, a psychotherapist and clinical instructor at New York University, writes a monthly column for *Advance for Occupational Therapy Practitioners*, exploring the psychological dynamics of recovery and rehabilitation. Her column is now linked on our website. Dr Mathew is a polio survivor and member of PNNJ.

A second addition to our Resource/Links web page is the S.W.I.M. (Specialized Water Interest Movement) organization. At eight New Jersey pool locations, they provide free recreational water therapy for adults with a muscular impairment.

New DOT Rules

The US Department of Transportation (DOT) is extending the Air Carriers Act to apply to foreign airlines that fly to the United States. The department will be able to take action against any foreign carrier, along with domestic carriers, who discriminate against any passenger with a disability. The rule will go into effect in May 2009 to give airlines time to meet the guidelines.

SOURCE: *THE RECORD*, MAY 26, 2008

LegalEase...

by Arthur P Siegfried, Esq

I have previously written about a case involving Lilly M Ledbetter, who lost her sex-based pay discrimination case before the United States Supreme Court in 2007. She had claimed sex-based pay discrimination, and the Court in their ruling held that she should have filed her claim within 180 days of the "alleged unlawful employment practice."

This interpretation of the statute of limitations has been used by many courts to reject claims under such laws as age discrimination, sex discrimination, fair housing, and similar items, including the Americans with Disabilities Act.

The New York Times reported on January 5 that legislation may be passed that in effect could overturn the 2007 decision, thus allowing more claims to be filed.

The most sensitive case from our point of view involved a wheelchair user who alleged that his apartment violated federal standards because it was not readily accessible. The court interpreting the law said that the two-year period representing a statute of limitations ran out after the building had been completed. The fact that the suit was not filed within two years of renting the apartment, but after ten years after it was built, barred any relief.

Let's see where this new proposed legislation goes.

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Study: Surfing Web Can Aid Older Brains

Time spent Googling the latest news or searching for choice eBay buys may help stimulate and improve the minds of middle-aged and older Americans, suggests a new study by scientists with the University of California at Los Angeles.

Research reported in the *American Journal of Geriatric Psychiatry* is the first to assess how performing Internet searches affects brain activity in older Americans, says study author Gary Small, professor at the Semel Institute for Neuroscience and Human Behavior at UCLA.

The research included 24 healthy volunteers ages 55 to 76. Half had Internet-searching experience, while the others had none. All were asked to perform web searches and book-reading tasks while undergoing functional magnetic resonance imaging scans, which recorded brain-circuitry changes.

All of the volunteers showed significant brain activity during the reading task, which stimulated brain regions that control language, reading, memory, and visual abilities. But during Internet searches, only those who had previous web-search experience registered extensive activity in the decision-making and complex-reasoning portions of the brain.

Small said that over time, he'd expect the inexperienced Internet searchers to benefit brainwise as well.

Harvard neuroscientist Randy Buckner says the study is interesting, but he wonders whether it's the activity of web searching that causes a leap in brain bustle, or if any novel activity can do so.

SOURCE: *COURIER NEWS*, OCT. 15, 2008

New Tax in 2009

As of January, sales taxes will be charged on purchases of mobility-enhancing equipment such as walkers and wheelchairs unless the buyer has a prescription. Be sure to request an Rx from your doctor before purchasing such equipment.

SOURCE: *COURIER NEWS*, JAN. 2, 2009



*Thank
You*

PNNJ Thanks. . .
Garden State Scooters/
Monmouth Vans of
Farmingdale, NJ,
AND
Mobility Elevator and Lift,
of West Caldwell, NJ,
for generous contributions in
2008 in support of our
annual conference.

Certain Antibiotics Can Cause Tendon Ruptures

The Food and Drug Administration (FDA) announced in July that it will require a "black box" warning on fluoroquinolone antibiotics, as well as an FDA-approved medication guide to be dispensed when prescriptions are filled, according to *Public Citizen's* October 8, 2008, issue of *Worst Pills, Best Pills News*. Brand names of the antibiotics involved are Cipro®, Ciloxan®, Penetrex®, Tequin®, Factive®, Levaquin®, Maxaquin®, Avelox®, Noroxin®, Chibroxin®, Floxin®, Ocuflor®, and Zagam®.

Public Citizen, which petitioned FDA on this issue in 2006, says that FDA is "currently silent on our request that it also send a warning letter to physicians clearly describing possible adverse reactions, such as tendon pain, so that patients with such pain can immediately notify their informed physicians and be switched to alternative treatments before tendons rupture."

This is not a new subject. Ruth Wyler Plaut, a medical writer who frequently contributes to the PNNJ *Newsletter*, wrote an article warning of side effects of the fluoroquinolone class of antibiotics that appeared in the Fall 1996 issue.

At that time, she wrote "These drugs can cause weakness, inflammation of the tendon (tendinitis) and, if patients continue taking them after the tendon

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, 11:30 am-1:30 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

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.



becomes sore, the tendon can rupture (tear) requiring surgery to fix. Polio survivors developing sore joints or muscles when taking such drugs should check with their physician immediately."

Handicapped License Plates Easier To Seek

It's now easier to apply for handicapped license plates and placards.

The application process used to be handled through the Motor Vehicle Commission's Trenton headquarters but now can be pursued through any of the 45 agencies around the state.

Previously, applicants for handicapped plates or placards had to mail an application to Trenton, where the request was reviewed and processed. Now, customers can download the application on the web at www.njmvc.gov, and visit any agency to obtain the plates or a placard instantly.

Customers may also obtain plates/placard applications by calling the general information line at 888-486-3339.
SOURCE: *COURIER NEWS*, JUNE 26, 2008

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Polio Network of New Jersey NEWSLETTER

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

WEBSITE:
www.njpolio.org

E-MAIL:
info@njpolio.org

Joan Swain
Editor

NEWSLETTER DESIGN BY
Barbara Conklin, Mahwah, NJ