

Polio Perspective
December 2015

Millie Malone Lill Editor

Wilma J Hood Publisher

IN THIS ISSUE

FDR Probably Didn't Have Polio After All

by Keith Veronese

Good Doc Directory

compiled by the Post-Polio Coffee House on Facebook

The Polio Viruses Live On and On..

International Post-Polio Task Force

OPM

by Millie Malone Lill

WEB CORNER

A LITTLE BIT OF HUMOR

Franklin Delano Roosevelt probably didn't have polio after all

President Franklin Delano Roosevelt ended Prohibition, pulled the United States out of the Great Depression, and bolstered Allied Forces during World War II. He also suffered from paralysis, which was widely believed to have been caused by polio.

After his death, physicians argued that he actually suffered from Guillain-Barre Syndrome. It could be the most famous misdiagnosis in history.

The Accident

On an early August day in 1921, a 39 year-old Roosevelt summered with his immediate family at a retreat in Canada. Roosevelt dove (or fell, depending on the account) into the Bay of Fundy while

boating. Over the next two weeks, he experienced paralysis that began in his legs and extended to his chest, resulting in a lack of movement and bowel control.

This came at a pivotal point in his political career. Roosevelt would have been Vice President under James Cox if the Democrats won the 1920. But he'd retreated to private life after the Democratic ticket lost the election in a landslide.

Did FDR Have Polio?

Roosevelt visited a Boy Scout Camp two weeks before onset of his paralysis. Roosevelt's presence at this gathering played a major role in his diagnosis, because the gathering of youth provided a likely origin for the polio virus. The physician who diagnosed FDR, Robert Lovett, had an expertise in the field of polio, possibly lending additional bias to the diagnosis.

Physicians and scientists have struggled with the diagnosis of polio in the decades after Roosevelt's death, as Roosevelt's advanced age made him an unlikely candidate for the disease. Roosevelt also experienced paralysis in both legs, while polio usually affects only one side of the body. Polio does not often affect the intestinal tract, yet the events of August 9th left FDR without control of his bowels. The future president continued to experience pain and other sensations in his legs. Confounding the diagnosis, Roosevelt exhibited a fever, a key diagnostic criteria for polio.

There are notes of clinical cases of Guillain-Barre Syndrome from this time period, with two soldiers diagnosed with the disease in 1916 using samples of spinal fluid. Testing of spinal fluid for increased protein levels without a concomitant increase in white blood cell count continues to be a key factor in the diagnosis of Guillain-Barre Syndrome. Whether any of FDR's physicians knew of the then-obscure Guillain-Barre Syndrome is completely unknown.

A 2012 study published in the Journal of Medical Biography conducted a [probability analysis](#) based on Roosevelt's symptoms, with the outcome suggesting Roosevelt likely suffered from Guillain-Barre Syndrome instead of polio.

Treating Guillain-Barre Syndrome in FDR

If a physician did diagnose Roosevelt with Guillain-Barre Syndrome, his prognosis would have strayed little. Guillain-Barre Syndrome is a viral infection of the body without a specific cure. The disease causes cells to attack other cells, leading to an eventual wasting away of the myelin sheath that surrounds nerves.

Guillain-Barre is currently [treated](#) with doses of immunoglobulins in the hopes that the body's immune system will attack these foreign proteins instead of itself. Immunoglobulin therapy did not exist in Roosevelt's time, but if it did, it would have been prohibitively expensive.

Guillain-Barre is also treated through the difficult process of plasma exchange. Plasma exchange removes blood and sequesters white and red blood cells before re-introducing the cells to the body. For a short time, plasma exchange lowers the patient's blood plasma volume with the hope of removing antibodies that are causing the body to attack itself. If available, this treatment would have exposed FDR to infection at the site of blood withdrawal as well as complications involving blood clots and calcium deficiencies.

An FDR diagnosed with Guillain-Barre would have little to gain over one diagnosed with polio due to a deficit in possible treatments.

The Misdiagnosis that Saved Lives

Roosevelt did not hide his diagnosis, forming a polio rehabilitation center Georgia before running for president. He did downplay the affliction's role in his life, hiding the weakness of his legs behind sturdy

podiums, relying on an aide or his son to help him remain standing at public events, and ordering a swift secret service detail to cover any shots of him in a wheelchair.

As president, Roosevelt founded the National Foundation for Infantile Paralysis in 1937, a organization headed by polio victim and Roosevelt's former law partner, Basil O'Connor. In time the National Foundation for Infantile Paralysis would become known as the March of Dimes, with donations going to fund research grants at a number of universities searching for a cure and setting the table for Jonas Salk's successful development and implementation of a vaccine against the virus in 1952.

A final verdict on whether FDR suffered from Polio or Guillain-Barre Syndrome is impossible, and will continue to be. The only method to accurately diagnose the former president with Guillain-Barre Syndrome involves testing spinal fluid. No matter the degree of scientific curiosity, we are unlikely to exhume the body of one of our greatest presidents to test for proteins that have long since degraded.

While we will never truly know if Roosevelt suffered from polio, the attention Roosevelt brought to the illness ended the most rampant cause of death and paralysis in human history, a disease dating to Ancient Egypt. Not a bad outcome for a possible misdiagnosis.

Top image from dantegeek/Flickr. Additional images by Seva Mafin/Flickr and the U.S. Army.

GOOD DOC DIRECTORY as of November 24, 2015

Rehab docs, orthopedists (and even a neurologist or two) whom COFFEE HOUSE members have SEEN and say know something about PPS.

Also included are rare specialists (GYN, Internists) who can help polio survivors with other PPS issues (slow guts, fast or slow heart rate, etc.) and some decent DME dealers for wheelchairs, et al.

Hold "COMMAND – F" to SEARCH BY STATE INITIALS, e.g., NJ, CA, etc.

Dr. Clifford Baker

NovaSpine Inst.

14420 Meeker Ste 2, Sun City West, AZ 85375

(623) 777-4747

(Tell them Dr. Bruno referred you.)

Dr. Darren Rosenberg

Spaulding Rehabilitation Hospital

570 Worcester Road (Route 9), Framingham, MA 01702

(508) 872-2200

Dr. Hooman Sedighi

1420 W Mockingbird Lane, Suite 420, Dallas, TX 75247

(214) 267-0101

Dr. Gilbert J. Toffel, Neurologist

1919 East McKellips Rd # 102, Mesa AZ 85203

(480) 834-9575

Dr. William M. DeMayo

Summit Medical Rehab

360 Goucher St., Johnstown, PA 15905
[His Post Polio Clinic is closed, but he continues to see patients.]
(814) 288-4498

Dr. Gary Ward
Rehabilitation Medicine Associates
Good Samaritan Bldg. 2
1040 NW 22nd Ave. Suite 320, Portland, OR 97210
(503) 413-6294

Dr. Helen Horstmann
Children's Hospital of Philadelphia Buc Orthopedics Center
500 West Butler Avenue, Chalfont, PA 18914
(215) 997-5730

Dr. Sanjiv Jain
Rehabilitation at Carle
602 W. University Ave., Urbana, Il. 61801
(217) 383-3800

Dr. Victoria Johnson
Carle Spine Institute
610 N. Lincoln Ave., Urbana, Il. 61801
(217) 383-6555

Dr. Kenneth Aronson
Neurosciences at Carle
602 W. University Ave., Urbana, Il. 61801
(217) 383-3440

Dr. Angel Malavet
130 Centerway, Corning, NY
(607) 973-8000

Dr. Richard Schubin
1015 N 1st Ave, Arcadia, CA 91006
(626) 566-2866

Dr. Chun
Rancho Los Amigos
7601 E Imperial Hwy, Downey, CA. 90242
(562) 401-7111

Dr. Debra Walter
2560 E. Fort Lowell, Tucson, AZ 85716
(520) 795-6412

Dr. Tamara Schwartz
Maine Medical Neurology
49 Spring St., Scarborough, ME 04074
(207) 883-1414

Dr. James Sliwa
Rehabilitation Institute of Chicago
345 E Superior St, Chicago, IL 60611
(312) 238-1000

Dr. Todd Levine
Phoenix Neurological Associates, Ltd.
5090 N. 40th Street, Suite 250, Phoenix, AZ 85018
Phone: (602) 258-3354

Dr. John Aseff
Director, Post-Polio Clinic
MedStar National Rehabilitation Hospital
102 Irving Street, NW, Washington DC 20010
(202) 877-1916 (Just say **no** to unnecessary EMGs)

Dr. Kathleen Fink
NRH-McLean
6858 Old Dominion Drive, Suite 200, McLean VA 22101
(703) 288-8260 (Just say **no** to unnecessary EMGs)

Dr. Shawn Bird
Perelman Center for Advanced Medicine South Pavilion, 2nd Floor
3400 Civic Center Boulevard, Philadelphia, PA 19104
800-789-7366

Dr. Glenn A. Mackin
Lehigh Neurology
1250 South Cedar Crest Blvd, Allentown, Pa. 18103
610-402-8420

http://www.lvhn.org/find_a_doctor/profile-751

Dr. Richard Rosenstein
Abington Rehab Assoc.
He's right off the Pa. Turnpike (Willow Grove Exit)
(They have a 2nd office in Warminster, Pa.)
215-674-3337

http://www.abingtonhealth.org/find-aphysician/profile/?d=593361#.Vh_TUYeFND8

Dr. Thyagarajan Subramanian
Penn State Hershey, Dept. of Neurology
(Milton Hershey Medical Center)

30 Hope Drive, Bldg. B, Suite 1300, Hershey, Pa. 17033
717-531-3828
<http://www.penstatehershey.org/findaprovider/provider/1436>

Dr. Kevin J. Collins
Rehabilitation Medicine Consultants of Arkansas
3401 Springhill Drive Suite 460, North Little Rock, AK 72205
(501) 945-1888

Dr Melvin Karges
702 East 34th Street #100, Joplin, MO 64804
417-782-1700

Dr. Joseph Viroslav
Dr. Won Lee
Lungs & Sleep
5939 Harry Hines Blvd., Dallas, Texas 75390
214-645-5584
Appointments: 214-645-8300

Dr. Dale C. Strasser
Emory Clinic Rehabilitation Medicine
1365 Clifton Rd., NE Bldg. B, Suite B2200 Atlanta, GA 30322
Ph: 404-778-5770 Fax: 404-778-3279

MEDICAL SPECIALISTS

Dr. John Bach
University Hospital
Physical Medicine & Rehab
150 Bergen Street, Newark, NJ 07101
973-972-2802
(THE world's expert on breathing in polio survivors.)
<http://www.doctorbach.com>

Dr. Marta Spain, Gynecology
1701 W. Curtis Rd., Champaign, Il. 61822
(217) 365-6200

Dr. Kingsley Onymere, Endocrinology
1813 W. Kirby Ave., Champaign, Il. 61821
(217) 383-1850

Dr. Jeffrey Gold, Internal Medicine
468 Parish Drive, Suite 1
Wayne, NJ 07470
973-305-8300

DURABLE MEDICAL EQUIPMENT PROVIDERS

Millennium Respiratory
30 Troy Road, Whippany, NJ 07981
800-269-9436
Services NJ, NY, PA and parts of Florida

Day Elevator
50 Hempstead Gardens Drive, West Hempstead, NY 11552
516-486-5439
Sells and Installs Stair Lifts and Elevators

Pongratz Orthotics and Prosthetics: Arizona
Tucson, AZ: 520-322-4499
Phoenix, AZ: 602-222-3032

Fetterman Crutches and (The World's *Best*) Tornado Crutch Tips.
<http://www.fetterman-crutches.com>

Lightweight Crutches
<http://walkeasy.com>

THE POLIO VIRUSES LIVE ON AND ON . . .

INTERNATIONAL POST-POLIO TASK FORCE International Centre for Post-Polio Education and Research PostPolioInfo.com

I thought I'd repeat this 2009 release about a US man with a WEAKENED IMMUNE SYSTEM who died when he was infected by an unknown person who had been shedding the ORAL vaccine strain of poliovirus for at least nine years.

**POLIO KILLS IN THE U.S. - Minnesota Death Gives "Nipp It Year" New Emphasis
TUESDAY APRIL 14, 2009: THE ASSOCIATED PRESS TODAY REPORTED THE DEATH OF
A PERSON INFECTED WITH THE LIVE POLIOVIRUS USED IN THE ORAL VACCINE
THAT WAS DISCONTINUED IN THE U.S. NINE YEARS AGO.**

The health department says the patient died with polio symptoms, but it's not known to what extent polio contributed to the death. The patient also had a WEAKENED IMMUNE SYSTEM and multiple health problems. THE MINNESOTA DEPARTMENT OF HEALTH SAYS THE PATIENT MOST LIKELY BECAME INFECTED FROM SOMEONE WHO HAD RECEIVED THE LIVE-VIRUS VACCINE BEFORE ITS USE WAS STOPPED IN 2000.

"For reasons we don't understand, the live poliovirus remained inside this person for fifteen years, mutated and became virulent, then contributed to the person's death," said Dr. Richard Bruno, chairperson of the International Post-Polio Task Force. "This death is the latest sad reminder that polio may be forgotten in the U.S., but that it is far from gone."

ALARMING DROPS IN POLIO VACCINATION IN US BORDER STATES AND PORTS OF ENTRY

Unfortunately, rates of polio vaccination have decreased in the US in spite of six other U.S. polio cases since 2005 -- five of them in Minnesota, where a woman with a weakened immune system harbored the

poliovirus for years and infected her own children -- and in spite of polio breaking free of vaccination efforts last month in Africa, with Kenya and Uganda reporting their first polio cases and deaths in twenty years.

“The latest Centers for Disease Control data show drops in polio vaccination in twenty states and in ten large U.S. cities,” said Dr. Bruno, who is also director of the International Centre for Polio Education. The CDC estimates that more than one million U.S. toddlers are unvaccinated. “Even Minnesota has had a decrease in polio vaccination, which is obviously disturbing,” said Dr. Bruno. “It is frightening that states with the largest drops lie next to Mexico and Canada, across whose borders the poliovirus is believed to have been imported into the U.S. since 1997.” Seventy percent of the states that border Canada had drops in polio vaccination as did Arizona, Texas and New Mexico.

CITY CHILDREN HAVE LOWEST POLIO VACCINATION RATES

Dr. Bruno is also concerned about cities that are major points of entry into the U.S. -- New York, Philadelphia, Houston and Seattle -- where drops in polio vaccination were also reported.

“Toddlers living in poverty have the lowest polio vaccination rates -- below 87% in Boston, Indianapolis, Memphis and Phoenix, and below 85% in Detroit, Houston and Seattle -- rates lower than in Western Pacific countries that include Cambodia, Mongolia and Vietnam,” said Dr. Bruno. “I’m worried that those who recently had polio in the US are canaries in the mine shaft.”

"NIPP IT YEAR" UNDERScoreD BY MINNESOTA DEATH

The International Post-Polio Task Force proclaimed 2008-2009 “National Immunization for Polio Prevention in Infants and Toddlers -- or ‘NIPP IT’ -- YEAR,” to prompt parents, healthcare professionals and state health officials to ensure that all American children receive four doses of the injectable, inactivated polio vaccine by age two.

“‘NIPP IT YEAR’ is intended to raise awareness of the need for polio vaccination, to stop state legislatures from allowing parents to refuse vaccinations for their children because of a ‘philosophically objection’ to vaccines, and hopefully ‘nip’ America’s next polio epidemic in the bud,” said Dr. Bruno. “The polio vaccine has been a victim of its own success. Young parents do not vaccinate because they have not experienced the devastation, death and disability caused by diseases vaccines eliminated.” Nor are people unaware that polio remains a scourge transportable from Africa, Pakistan and Afghanistan.

"With the ease of air travel, what will happen when a polio-infected individual lands in one of America's potential polio pockets, like New York City, and passes poliovirus to the estimated 24,000 infants and toddlers in that city who are not immunized?" asked Dr. Bruno "We must do more to vaccinate America's children against this deadly and disabling disease. America's next polio epidemic could be just a car or plane ride away."

(Rev. 9/2015)

OPM

by Millie Malone Lill

Are you sounding out the title? If you are, I want to explain that even though it sounds like OPIUM, that is not what it stands for. Nope, it stands for Oh Poor Me. One of my friends mentioned that she has OPM days, days when she just wallows in self pity. I think it's a great idea and probably pretty therapeutic, too. Especially if we recognize it as such and limit it to one day or just a bit more. We

need to recognize the fact that we are disabled and that there are days that just plain stink. We don't, however, want to spend all our time in self pity.

I read about a family of sisters who, when one of them had a bad day or broke up with a boyfriend or was just having an OPM day, would all gather around the Inflicted One in a group hug while chanting "Poor Baby" and patting her back. It was very comforting, apparently.

I only have one sister left and while I'm sure she would be happy to give me a hug, pat my back and murmur Poor Baby to me, it has never occurred to me to ask her. This probably isn't the best solution for guys in our group as they would feel silly doing this. Even guys, though, have access to the comfort of a virtual hug, a cyber hug, if you will. That would be the job of the online support group.

I belong to several Face Book pages dedicated to polio survivors. The ones I post to are Closed and one is even Secret. That means that what I put on there cannot be seen by anyone but members of that group. The Secret one is by invitation only. They are safe places to vent, to openly admit you are having an OPM day. Someone, usually several someones, will commiserate with you. I highly recommend it.

It feels good to just get it off your chest. Even if you get no response. It is like lancing a boil, pretty ugly in the doing perhaps, but it feels so much better once it is done. As polio survivor, many of us were taught never to complain. We weren't to make people feel bad by mentioning that we were in pain, felt isolated, were depressed or whatever other sadnesses we were feeling.

"Be a brave little soldier." "You'll get used to that minor discomfort" That one was my favorite as I struggled with braces that didn't fit and which made huge blisters. Minor discomfort, apparently, is like beauty and depends on the eye of the beholder, or the leg/foot/knee of the beholder. We all know how to suck it up, put on a brave face and stuff that pain to the back of our mental closet. Sometimes it is a huge relief to be able to let it all out.

We all have OPM days. Even, I daresay, non polio survivors. We can take pills for the pain, or we can use heat or ice to alleviate physical discomfort. Sometimes, though, things pile up. You are in pain, you just dropped your favorite coffee mug. Full of coffee. On your keyboard. Your family has had a party to which you were not invited because "you couldn't have gotten in there with your chair anyhow" and you feel like screaming. That, my friend, is an OPM day. I hope you can find a sympathetic friend who will pat your back and murmur Poor Baby to you while patting your back. If you can't, just call me. I'd be happy to empathize with you.

WEB CORNER

Bruno Bytes

<http://www.papolionetwork.org/bruno-bytes.html>

Polio Outbreak in Ukraine

http://www.aol.com/article/2015/12/01/un-polio-outbreak-in-ukraine-is-a-state-of-emergency/21275839/?icid=maing-grid7/htmlws-main-bb|dl5|sec1_lnk3&pLid=-1421221481

Don't Blame Post Polio for Everything

<http://www.oyetimes.com/lifestyle/daily-life/85251-don-t-blame-post-polio-syndrome-for-everything>

Think you don't need the 'flu vaccine:

<http://www.npr.org/sections/health-shots/2015/11/27/456202280/many-americans-believe-they-dont-need-the-flu-vaccine?>

Post Polio It Takes a Team Approach

http://lermagazine.com/article/post-polio-syndrome-it-takes-a-team-approach?fb_ref=Default&fb_source=message

Adaptive classes for cooking with a disability

https://www.youtube.com/watch?v=zCLEgL49ZdU&feature=player_embedded

“I was devastated at receiving a diagnosis for a disease that has no cure”

<http://www.thejournal.ie/readme/ Diagnosed-polio-2461692-Nov2015/>

Surviving the Holidays When You are Chronically Ill

<https://www.psychologytoday.com/blog/turning-straw-gold/201411/surviving-the-holidays-when-you-re-chronically-ill?>

Polio Patients and Surgery

http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf

The Science Behind Power Naps

<http://www.davidwolfe.com/science-behind-power-naps-good-for-you/>

A LITTLE BIT OF HUMOR

Computer Error

Young Susie was having trouble with her computer so she called Wes, the computer guy, over to her desk. Wes clicked a couple buttons and solved the problem.

As he was walking away Susie called after him, "So, what was wrong?" And he replied, "It was an 'ID ten T' error." A puzzled expression ran riot over Susie's face. " 'An ID ten T' error? What's that, in case I need to fix it again?" He gave her a grin. "Haven't you ever seen an 'ID ten T' error before?" Susie replied, "No." "Write it down," he said, "and I think you'll figure it out." I D 1 0 T