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Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Survivor's Network

www.papolionetwork.org

June, 2021

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

Is Post-Polio Syndrome Progressive? In response to a reader's question, Dr. Richard L. Bruno, HD, PhD gave us a Bruno Byte on that topic for our May, 2021 issue. His answer to that question has been repeated and commented upon numerous times both by email and on social media. With the help of information from the NIH, Dr. Marny Euberg, MD has now written about it for you as well. To use a baseball term in June, both, Dr(s) Bruno and Eulberg have "hit it out of the park" with their helpful answers for a question that affects the vast majority of polio survivors. Once again, here is Dr. Bruno's Response:

"Saying that Post-Polio Sequelae reaches a point and does not progress any further is like saying you can drive your car and, when it reaches a certain point, it will continue going but doesn't use more gas.

PPS is caused by "overuse abuse" of remaining, poliovirus-damaged neurons. Overuse abuse damages those vulnerable neurons and causes PPS symptoms: overwhelming fatigue, muscle weakness, muscle and joint pain and difficulty swallowing and breathing. The more overuse abuse, the more neuron damage and the more new symptoms appear and old ones progress as your neurons "run out of gas."

So if you want to stop progression and actually feel better listen to your body and take your foot off the "accelerator" to **Conserve to Preserve** remaining, poliovirus-damaged neurons."

Dr. Eulberg's article begins on page two.

Abnormal Eye Movements – Can they be Polio Related? Dr. Richard L. Bruno, HD, PhD tackles this complex question. The answer is – "they could be". For those of you that have muscle weakness/issues in your eyes, this is a new article you can share with your ophthalmologist.

Jonas Salk – Eight things you may not have known About the polio vaccine. With thanks to history.com, we have an interesting new article. What was old, is certainly new again as we look at the past year. What will history say about the COVID-19 vaccine?

June, what a beautiful month. The last year has been difficult for us all. Now, with the COVID vaccine easily available (for many of us but not for all), life is returning back to our new "normal".

We're celebrating renewed life once again, with this sweet photo from survivor Bob Andersch. We love how his grandson is looking up at him with such wonder and awe.

It's time for us all to rediscover the beauty and newly returned freedom that is around us.

Is Post-Polio Syndrome Progressive?

An Answer to that Question from Primary Care Physician
Dr. Marny Eulberg, MD

Many polio survivors hear from health care professionals (and others) that Post-Polio Syndrome is *not* progressive, that it reaches a point and does not progress any further. I believe that they are incorrect. PPS is a slowly progressive disease process.

It is true that the original polio infection caused a certain amount of damage over the course of a few weeks, then patients had a certain amount of recovery that usually ceased after 3 - 4 years and then they neither got any worse or got any better for a period of several years. That is *not* true for PPS. In *most* cases it does slowly progress. Because no one can accurately measure someone's pain or fatigue, medical professionals can only measure the muscle weakness aspect of PPS. The studies done 30 or more years ago by Agre showed an average decrease in muscle strength of 1% per year in those with PPS. I personally can attest to it being getting worse over time although for me the worsening of muscle strength that required a change in bracing has occurred about every 10-15 years.

I would like to share the Post-Polio Syndrome Fact Sheet from the NIH.

What is post-polio syndrome?

Polio, or poliomyelitis, is an infectious viral disease that can strike at any age and affects a person's nervous system. Post-polio syndrome (PPS) is a non-contagious condition that can affect polio survivors usually 15 to 40 years after recovery from polio. Only a polio survivor can develop PPS, it is not contagious.

The polio vaccine has eradicated polio from the United States. However, polio still exists in some countries and cases of PPS still arise.

What are its symptoms?

Most often, polio survivors start to experience gradual new weakening in muscles that were previously affected by the polio infection. Some individuals experience only minor symptoms while others develop visible muscle weakness and atrophy. A person who was more acutely affected by polio and who attained a greater recovery may experience a more severe case of PPS.

Symptoms include:

- Slowly progressive muscle weakness
- Fatigue
- A gradual decrease in the size of muscles (muscle atrophy)
- Loss of muscle function
- Pain from joint degeneration and increasing skeletal deformities such as curvature of the spine (scoliosis)

PPS is rarely life-threatening, but the symptoms can significantly interfere with an individual's ability to function independently. Respiratory muscle

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weakness, for instance, can result in trouble with proper breathing, affecting daytime functions and sleep. Weakness in swallowing muscles can result in aspiration of food and liquids into the lungs and lead to pneumonia.

What causes PPS?

The cause of PPS is unknown. The new weakness of PPS appears to be related to the degeneration of individual nerve terminals in the motor units. A motor unit is formed by a nerve cell (or motor neuron) in the spinal cord or brain stem and the muscle fibers it activates. The polio virus attacks specific neurons in the brain stem and spinal cord. Surviving cells sprout new nerve-end terminals and connect with other muscle fibers. These new connections may result in recovery of movement and gradual gain in power in the affected limbs.

Years of high use of these recovered but overly extended motor units add stress to the motor neurons, which over time results in the slow deterioration of the neurons and leads to loss of muscle strength.

Restoration of nerve function may occur in some fibers a second time, but eventually nerve terminals malfunction and permanent weakness occurs. This may be why PPS occurs after a delay and has periods of relative stability combined with periods of decline with progressive weakness.

How is PPS diagnosed?

There are no laboratory or diagnostic tests specific for PPS. Physicians diagnose the condition after completing a comprehensive medical history and physical examination, and by excluding other disorders that could explain the symptoms.

Physicians look for the following criteria when diagnosing PPS:

- *Prior paralytic poliomyelitis with evidence of motor neuron loss.* This is confirmed by history of the acute paralytic illness, signs of residual weakness and muscle atrophy, and signs of motor neuron loss on electromyography (EMG).
- *A period of partial or complete functional recovery after acute paralytic poliomyelitis*, followed by an interval (usually 15 years or more) of stable neuromuscular function.
- *Slowly progressive and persistent new muscle weakness or decreased endurance, with or without generalized fatigue, muscle atrophy, or muscle and joint pain.* Onset may at times follow trauma, surgery, or a period of inactivity, and can appear to be sudden. Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.
- *Symptoms that persist for at least a year.*
- *Exclusion of other neuromuscular, medical, and skeletal abnormalities* as causes of symptoms.

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Diagnostic tests include:

- Magnetic resonance imaging (MRI) and computed tomography (CT) of the spinal cord
- Electrophysiological studies and other tests to investigate the course of decline in muscle strength and exclude other diseases that could be causing or contributing to the new progressive symptoms
- Muscle biopsy
- Spinal fluid analysis to exclude other, possibly treatable, conditions that mimic PPS

How is PPS treated?

There are currently no effective treatments that can stop deterioration or reverse the deficits caused by the syndrome itself, but there are recommended management strategies. Individuals with PPS should seek medical advice from a physician experienced in treating neuromuscular disorders.

A number of research studies have demonstrated that non-fatiguing exercises (those that do not cause pain or fatigue lasting more than 10 minutes) may improve muscle strength and reduce tiredness. Cardiopulmonary endurance training also is helpful. Exercise should be considered under the supervision of an experienced health professional.

Mobility aids, ventilation equipment, and revising activities of daily living activities can help to avoid rapid muscle tiring and total body exhaustion.

Counseling may help individuals and families adjust to the late effects of poliomyelitis. Support groups that encourage self-help, group participation, and positive action can be helpful.

Physicians recommend that polio survivors get a good night's sleep, maintain a well-balanced diet, avoid unhealthy habits such as smoking and overeating, and follow a prescribed exercise program. Lifestyle changes, such as weight control, the use of assistive devices, and taking certain anti-inflammatory medications, may help with some of the symptoms of PPS.

What research is being done?

At the National Institutes of Health (NIH), the National Institute of Allergy and Infectious Diseases (NIAID) is the leading funder of PPS research. The National Institute of Neurological Disorders and Stroke (NINDS) is the leading funder of research on neuromuscular disorders. NIH is the leading supporter of biomedical research in the world.

Scientists are working on a variety of investigations that may one day help individuals with PPS. Some basic researchers are studying the behavior of motor neurons many years after a polio attack. Others are looking at the mechanisms of fatigue and are trying to learn more about its possible causes. Researchers also are developing and refining interventions to help people with chronic conditions

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more effectively manage fatigue and sleep disturbances.

Determining if there is an immunological link in PPS also is an area of interest. Researchers who discovered inflammation around motor neurons or muscles are trying to find out what causes this immunological response.

Marny Eulberg, MD.

Source:
NIH Publication No. 12-4030 "Post-Polio Syndrome Fact Sheet", NINDS, Publication date May 2012.

National Institute of Neurological Disorders and Stroke (BRAIN) :
P.O. Box 5801
Bethesda, MD 20824
800-352-9424

Abnormal Eye Movements and PPS

Dr. Richard Bruno, HD, PhD
Director, International Centre for Polio Education

In the nearly 40 years I have been studying and treating polio survivors, I have never seen a patient with vision problems that could be explained by having had polio. And I wasn't surprised. In the 1940's, polio savant David Bodian performed hundreds of human autopsies on those who died after having had polio. He stated, "All available evidence shows conclusively that every case of polio exhibits damage in the brain." However, as part of his research into how the poliovirus found its way into and damaged the brain and spinal cord, Bodian injected poliovirus directly into monkeys' vision neurons at the back of the brain…and absolutely *nothing* happened. The vision neurons could not be infected with the poliovirus and just kept working! So, in humans, the poliovirus' lack of interest in other than motor neurons prevented polio survivors from having any impairment of vision.

But, Dr. Bodian's research did make clear that the poliovirus did damage motor neurons in the brain stem that controlled swallowing, breathing and blood pressure, causing what was clinically diagnosed as "bulbar" polio. Although the numbers vary from year to year, epidemic to epidemic, approximately 15% of patients had clinical "bulbar" polio. But if the poliovirus could kill the above-mentioned motor neurons, could it attack other brainstem motor neurons, for example those controlling eye movements? The answer: sometimes.

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Abnormal Eye Movements and Polio

Going back to my well-thumbed copy of the 1948 proceedings of the First International Poliomyelitis Conference, I could find only two sentences buried in the discussion section on bulbar polio that mentioned eye movements. It referred to polio expert A. B. Baker's description of one of the largest polio outbreaks, the 1946 Minnesota epidemic, during which 23% of children had clinically diagnosed bulbar polio: 90% had damage to the vagus nerve, causing problems with breathing and swallowing, while 6% had cardiovascular collapse, 83% of whom died. But among those bulbar polio patients 12% were found to have loss of eye muscle control and even paralysis.

It turns out that Baker's finding of abnormal eye movements in bulbar polio patients actually was 41 years old. Ivan Wickmann, in his famous 1907 paper on *Heine-Medin's disease* (the original name for what in 1840 Heine himself called "infantile spinal paralysis") mentioned cases of bulbar polio where there was damage to the brain stem's sixth cranial nerve, which controls the muscles that move your eyes outward, away from your nose, causing "crossed eye(s)". Adding to this finding, Baker reported that the most common eye movement abnormality in bulbar polio wasn't crossed eyes but nystagmus, the back-and-forth or up-and-down small "twitching" movements of the eyes.

But if eye movement abnormalities with bulbar polio had been seen as far back as 1907, why have they been given such short shrift in the medical literature? In a 1955 paper describing the extensive epidemics in Israel during 1949 to 1954, the authors explained why eye movement abnormalities in bulbar polio survivors were so infrequently documented; eye muscle abnormalities might occur more frequently than was reported, they said, "but being often transient, can hardly be included in clinical statistics." The authors conclude that, "Since most of the cases involving the muscles of the eye are accompanied by other serious, often dangerous symptoms, the affection of the eyes tended to frequently be overlooked . . ."

Could Abnormal Eye Movements be PPS?

Yes, eye movement abnormalities could be PPS. If someone had clinically diagnosed bulbar polio, remaining, poliovirus-damaged brain stem neurons that control eye movements could be "browning out" and causing abnormal eye movements. Based on the Minnesota data, such movements would be seen in less than 2% of bulbar polio survivors. But if seen they could be.

However, although muscles are constantly moving the eyes, it takes about 10,000 times more force for a non-polio survivor to walk on a level surface than it does to move your eyes. Muscles moving small "weights" (the eyes, eyelids, facial muscles) are less likely to experience "overuse abuse" than are muscles used to

lift bags of groceries or to walk, which is probably why we've never seen abnormal eye movements even in bulbar polio survivors.

But, as with all PPS, other causes of eye movement abnormalities must be ruled out before PPS is accepted as the cause. What's more, *any* abnormal eye movements must be evaluated without delay since they may be symptoms, not of PPS, but of a neurological disease that requires immediate treatment.

Richard L. Bruno, HD, PhD

There is lots of information in the Post-Polio Syndrome Section of our Website.

Dr. Bruno's series of Articles and Videos are in the "Encyclopedia of Polio and PPS".
www.papolionetwork.org/encyclopedia

Dr. Eulberg's series of Articles and Videos are in "Primary Care Perspective".
www.papolionetwork.org/primary-care-and-pps

Do you have a question for Dr. Bruno (or) Dr. Eulberg ?
Their biographies are clearly visible on the referred to pages of our website.
Email your question to us at: info@papolionework.org

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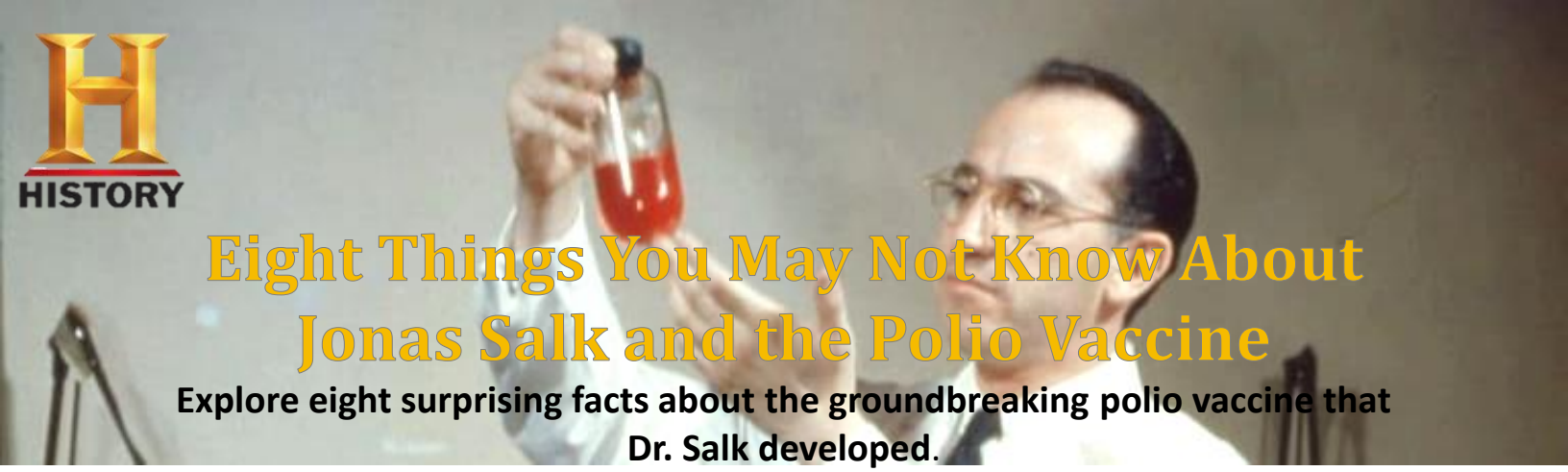

Eight Things You May Not Know About Jonas Salk and the Polio Vaccine

Explore eight surprising facts about the groundbreaking polio vaccine that Dr. Salk developed.

By CHRISTOPHER KLEIN

1. Although polio was the most feared disease of the 20th century, it was hardly the deadliest.

"Polio was never the raging epidemic portrayed in the media, not even at its height in the 1940s and 1950s," writes David M. Oshinsky in his Pulitzer Prize winning book "Polio: An American Story." During those decades, 10 times as many children died in accidents and three times as many succumbed to cancer. Oshinsky notes that polio inspired such fear because it struck without warning and researchers were unsure of how it spread from person to person. In the years following World War II, polls found the only thing Americans feared more than polio was nuclear war.

2. Franklin D. Roosevelt proved instrumental in the vaccine's development.

A year after his nomination as a Democratic vice presidential candidate, rising political star Franklin D. Roosevelt contracted polio while vacationing at his summer home on Campobello Island in 1921. The disease left the legs of the 39-year-old future president permanently paralyzed. In 1938, five years after entering the White House, Roosevelt helped to create the National Foundation for Infantile Paralysis, later renamed the March of Dimes Foundation, which became the primary funding source for Salk's vaccine trials. Employing "poster children" and enlisting the star power of celebrities from Mickey Rooney to Mickey Mouse, the grassroots organization run by Roosevelt's former Wall Street law partner Basil O'Connor was raising more than $20 million per year by the late 1940s.

3. Salk challenged prevailing scientific orthodoxy in his vaccine development. Elvis Presley makes an appearance in support of the March of Dimes, 1950s.

While most scientists believed that effective vaccines could only be developed with live viruses, Salk developed a "killed-virus" vaccine by growing samples of the virus and then deactivating them by adding formaldehyde so that they could no longer reproduce. By injecting the benign strains into the bloodstream, the vaccine tricked the immune system into manufacturing protective antibodies without the need to introduce a weakened form of the virus into healthy patients. Many researchers such as Polish-born virologist Albert Sabin, who was developing an oral "live-virus" polio vaccine, called Salk's approach dangerous. Sabin even belittled Salk as "a mere kitchen chemist." The hard-charging O'Connor, however, had grown impatient at the time-consuming process of developing a live-virus vaccine and put the resources of the March of Dimes behind Salk.

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4. Salk tested the vaccine on himself and his family.

After successfully inoculating thousands of monkeys, Salk began the risky step of testing the vaccine on humans in 1952. In addition to administering the vaccine to children at two Pittsburgh-area institutions, Salk injected himself, his wife and his three sons in his kitchen after boiling the needles and syringes on his stovetop. Salk announced the success of the initial human tests to a national radio audience on March 26, 1953.

5. The clinical trial was the biggest public health experiment in American history.

On April 26, 1954, six-year-old Randy Kerr was injected with the Salk vaccine at the Franklin Sherman Elementary School in McLean, Virginia. By the end of June, an unprecedented 1.8 million people, including hundreds of thousands of schoolchildren, joined him in becoming "polio pioneers." For the first time, researchers used the double-blind method, now standard, in which neither the patient nor person administering the inoculation knew if it was a vaccine or placebo. Although no one was certain that the vaccine was perfectly safe—in fact, Sabin argued it would cause more cases of polio than it would prevent—there was no shortage of volunteers.

Salk inoculating a patient (Credit: Al Fenn/ The LIFE Picture Collection/Getty Images)

6. Salk did not patent his vaccine.

On April 12, 1955, the day the Salk vaccine was declared "safe, effective and potent," legendary CBS newsman Edward R. Morrow interviewed its creator and asked who owned the patent. "Well, the people, I would say," said Salk in light of the millions of charitable donations raised by the March of Dimes that funded the vaccine's research and field testing. "There is no patent. Could you patent the sun?" Lawyers for the foundation had investigated the possibility of patenting the vaccine but did not pursue it, in part because of Salk's reluctance.

7. Although a tainted batch of the Salk vaccine killed 11 people, Americans continued vaccinating their children.

Just weeks after the Salk vaccine had been declared safe, more than 200 polio cases were traced to lots contaminated with virulent live polio strains manufactured by the Cutter Laboratories in Berkeley, California. Most taken ill became severely paralyzed. Eleven died. In the haste to rush the vaccine to the public, the federal government had not provided proper supervision of the major drug companies contracted by the March of Dimes to produce 9 million doses of vaccine for 1955. Although the United States surgeon general ordered all inoculations temporarily halted, Americans continued to vaccinate themselves and their children. Outside of the "Cutter Incident," not a single case of polio attributed to the Salk vaccine was ever contracted in the United States.

8. A rival vaccine supplanted Salk's in the 1960s.

Once Sabin's oral vaccine finally became available in 1962, it quickly supplanted Salk's injected vaccine because it was cheaper to produce and easier to administer. Ultimately, both vaccines produced by the bitter rivals nearly eradicated the disease from the planet. According to the

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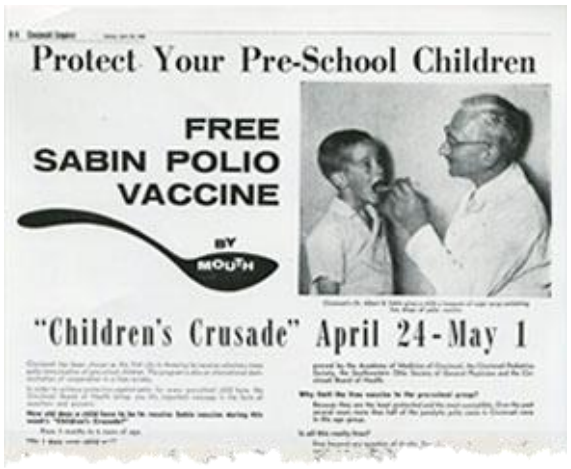
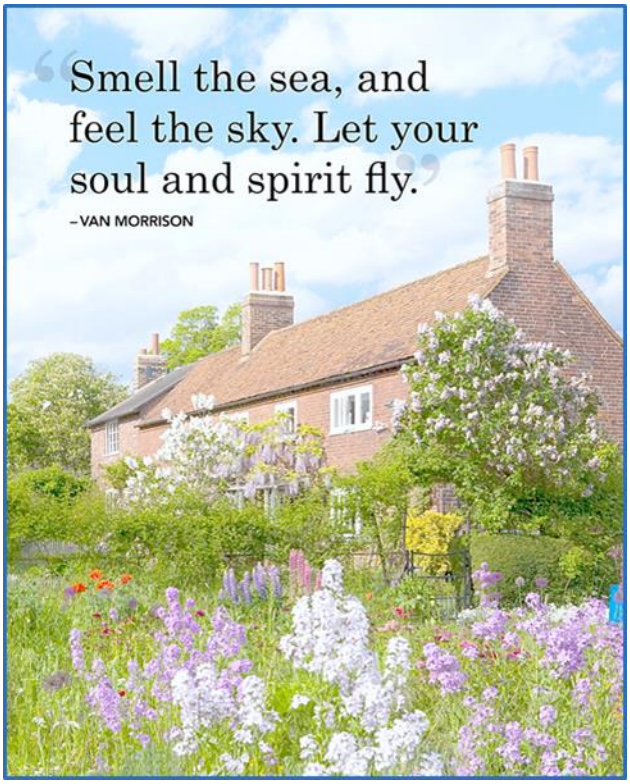
Eight Things – the Salk Vaccine (continued . . . .)

World Health Organization (WHO), there were only 416 reported cases of polio worldwide in 2013, mostly confined to a handful of Asian and African countries. Since Sabin's live-virus vaccine, which is responsible for about a dozen cases of polio each year, is seen as the final obstacle to eliminating the disease in most of the world, the WHO has urged polio-free countries to return to Salk's killed-virus vaccine.

Source



Dr. Albert Sabin and a poster promoting Sabin's oral polio vaccine. Source: History.com



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