

This is the full article: *the article from the September 2010 Rotarian, the cover picture of the FDR older style wheel chair, and the 8 pages Bob Williams referenced in his Interview with Madison newspaper.*

This is the link to the September 2010 Rotarian. By leafing to page 30-38 you can read the entire article.

http://books.google.com/books?id=c3S1BCt2dZIC&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false

You should be able to click on the link above and get to the actual *Rotarian* for Sep 2010.

Below is the nexus of that article minus some other drawings [and without a close inspection maybe some of the prose?]

Polio's second act

by Kate Nolan

The Rotarian -- September 2010



Illustration by Bonnie Hofkin

Ina Pinkney has made the best of polio. Her baked goods win national acclaim, and foodies wait for seatings at Ina's, her culinary star turn in Chicago, where she is known as "the breakfast queen."

Diagnosed with polio at 18 months in 1944, she was treated by the famed Australian nurse Sister Elizabeth Kenny, whose then-controversial therapy involved boiling strips of wool, wrapping them around the affected limbs, and using massage to alleviate muscle spasms. After a month of the painful regimen, Pinkney was walking again, but the disease had caused lasting damage. For years, she exercised to retrain her muscles, but her right leg never caught up with the left.

Pinkney remembers going to a gala in New York as a young woman. Count Basie played, and her idol, movie star Fred Astaire, was there. She walked over to him, and Astaire said, "I see you have some difficulty walking. Let's just pretend."

"He took me in dance position, and we swayed, maybe 12 times – 12 sways with Fred Astaire, a very big moment," she recalls.

Pinkney now experiences "mind-numbing" fatigue, her leg feels weak, and she has tried exercising to strengthen it. She reluctantly agreed to be fitted with an ankle-foot orthosis (a brace) and wore it home from the doctor's office. Leaving the office, she fell in the street. Pinkney, 67, calls the episode a "gut blow."

"It told me I had a lot of work to do," she says. "I had to learn to walk with the brace and, more important, I had to accept it."

Postpolio syndrome

Pinkney's polio had not come back, but she had postpolio syndrome, a set of debilitating symptoms that strikes survivors at least 15 years after they've had the disease. As many as 55 percent of an estimated 775,000 polio survivors in the United States may be at risk of developing it.

"We'd see more support for polio eradication if people understood the long-range effects of the disease," says Ann Lee Hussey, chair of the Rotarian Action Group for Polio Survivors and Associates. Like many Rotarians who are polio survivors, she is a strong advocate for Rotary's US\$200 Million Challenge. "There are many polio survivors who serve as their district PolioPlus chair and are active in fundraising. I traveled to Hong Kong for an event that raised \$250,000."

Many people have not heard of postpolio syndrome. Compared with the 20th-century epidemics that spawned a national movement in the United States led by President Franklin D. Roosevelt, it's an understated illness. Many patients who have postpolio syndrome – an under-diagnosed, under-researched condition without broad-based advocacy from patients – don't even know it's related to the disease.

It has been 26 years since postpolio syndrome was identified, but often doctors don't know how to diagnose or treat it, Hussey says. Because polio is viewed as a conquered disease in the United States, its aftermath has been relatively unexplored in the research and in medical schools.

Post-Polio Health International, a St. Louis group that works closely with the Rotarian Action Group, addresses the dearth of information through a network on its website, www.post-polio.org. It connects patients with each other and the few health professionals experienced in treating the condition.

A new tide of potential patients rises in the developing world.

Most of the people who lived through the U.S. polio epidemics will die in the next 40 years – a fact that may offset the irony that the final phase of the most studied virus in history now gets modest public notice. But even greater resources may be needed in the future, as a new tide of potential patients rises in the developing world.

"They're going to have horrible lives. Who will address their pain and mobility issues?" Hussey asks.

For Daniel J. Wilson, having postpolio syndrome means managing a growing list of things he can't do anymore. "I can't walk all over Paris and take the metro," says Wilson, 60, a professor of history at Muhlenberg College in Allentown, Pa., and the author of a well-regarded history of polio in the United States, *Living with Polio: The Epidemic and Its Survivors*.

Wilson contracted the disease at age five, his mother doctoring him with the hot packs that had become common. The weakened muscles of his right torso led to scoliosis, a type of spinal disfigurement. At 10, he had spinal surgery that put him in a body cast for six months. He completed fifth grade at home in Wausau, Wis., and regained his strength. He later earned his doctorate from Johns Hopkins University.

The first signs

The first sign of postpolio syndrome came in the mid-1980s, when Wilson had trouble lifting his right foot off the gas pedal to brake his car. Soon his right leg began giving out while he walked, and he experienced increasing muscle pain. His wife, Carol, started carrying packages for him. Now he sits while he lectures, walks with a cane, and uses a scooter for longer distances. When his beloved wheaten terrier Abbey died at 16 last year, he decided against getting another dog because he couldn't walk one anymore. He installed a stair lift at home, preparing for when he can't handle stairs.

"I live with the certainty that I can't trust my body anymore," Wilson says.

Abraham Lieberman, 72, medical director of the Muhammad Ali Parkinson Center at Barrow Neurological Institute in Phoenix, started to have difficulty walking in the late '90s and sometimes used a walking stick. By 2001, his left leg was failing, and he diagnosed himself with postpolio syndrome. He has no joint or muscle pain but suffers weakness in his legs.

"I'm not happy about it, but I'm not going to die from it. I'd be happier if I were 10 years younger," says Lieberman, who was hospitalized with polio in 1944 at age six in New York with nearly full-body paralysis. His mother wrote to Roosevelt for help, and the sympathetic president wrote back, saying he would do what he could. Lieberman's young life became a cycle of braces, injury, and surgery, but left him with strong hands and the ability to walk without assistance. He finished medical school, served in the U.S. Air Force as a doctor in Japan, and later specialized in research on Parkinson's disease.

"You can manage the pain and fatigue, but there's no simple test for it," says Julie Silver, assistant professor at Harvard Medical School and former director of the International Rehabilitation Center for Polio at Spaulding Framingham hospital in Massachusetts. "It's a diagnosis of exclusion." After thyroid problems and sleep apnea have been ruled out as causes of fatigue, for instance, postpolio syndrome may be considered in a patient who has slowed down.

There's the shock of realizing that they aren't finished with polio.

At the rehabilitation center and the handful of other facilities across the country specializing in postpolio syndrome, an assessment typically includes an examination by a doctor experienced in the condition, a nerve and muscle study, and sessions with physical and occupational therapists, a brace specialist, and a psychologist.

The psychological fallout of a diagnosis can be dramatic. "It feels like a double whammy," says Silver, author of *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families*. First, there's the shock of realizing that they aren't finished with polio, and then that no recovery from postpolio syndrome is in view. Care recommendations can include home modifications, a brace, stress management for fatigue, lifestyle

changes such as reduced work hours, and devices to help with breathing and mobility, alleviate pain, or prevent falls.

In the 1950s, polio survivors learned to exercise during rehabilitation, often in great pain. The new field of physical therapy strongly linked determination with overcoming physical challenges. Charles Atlas was telling men they could build a muscular body through willpower and isometric exercises, and Norman Vincent Peale in *The Power of Positive Thinking* was saying attitude was everything. Both ideas were part of American culture then.

"When you went into rehab, the emphasis was on pushing as hard as you could, like the Little Engine That Could. Physical therapists and families pushed polio survivors to achieve the maximum results, and in many cases substantial recovery was possible," Wilson says. "We had won World War II, and we were moving forward. Men had a lot of concerns about masculinity and proving they could take it. Dealing with painful physical therapy demonstrated you weren't a sissy."

More harm than good

Pinkney recalls the pressure she felt from the public campaign against polio. "How could you let anyone down, with all of them on your side? Polio children learned to be such good children," she says.

Then, years later, came postpolio syndrome. Research showed that the exercise that had been recommended actually did more harm than good. Unlearning the old rules was as much a cultural shift as a medical one, says Wilson, whose book devotes a chapter to the illness. De-emphasizing exercise initially strikes many survivors as backward.

To overcome her postpolio fatigue and weakness, Pinkney went back to the old playbook. "But it hurt me," she says. "I'd be in better shape now if I hadn't exercised." Today she walks with a cane and predicts she will rely on a wheelchair full time within six years.

These realities are familiar to Lauro Halstead, director of the postpolio program at the National Rehabilitation Hospital in Washington, D.C., and a key figure in the story of postpolio syndrome. In 1984, Halstead organized the first medical conference devoted to the condition.

In the 1970s and '80s, survivors started reporting symptoms reminiscent of polio. Patients and doctors feared the virus was back. Other doctors suspected the chronic condition fibromyalgia or multiple sclerosis. Some told patients the symptoms were in their heads. To make sense of the reports, Halstead, then a doctor at the Institute for Rehabilitation and Research at Baylor University in Houston, organized a national meeting of experts at the Roosevelt Warm Springs Institute for Rehabilitation in Georgia, the polio center founded by Roosevelt.

The neurological system makes adaptations that can wear out the surviving motor neurons.

A polio survivor in his late 40s, Halstead was having unexplained leg pains himself. He had polio after his freshman year of college and split the next year between an iron lung and a wheelchair until he regained his strength. He lost the use of his right arm and hand but taught himself to write left-handed and finished his schooling. Becoming a spinal cord injury specialist at Baylor, he assumed polio was behind him until the pain returned.

"The leg pains were very like the leg pains I experienced during the acute phase of polio. Fortunately, there were a lot of hotshots at Baylor to look into it. It wasn't polio, but nobody could figure out what it was," says Halstead, 74, editor of *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome*. Then he read an article by David Wiechers, a researcher at Ohio State University who was working with electromyographic diagnosis, which monitors electrical activity in the muscles to diagnose neuromuscular problems. Wiechers had tested some polio survivors who had the same symptoms and noticed surprising neurological changes. His work raised more questions than it answered, though.

Media were riveted to the notion that polio was back, which generated plenty of publicity for Halstead's conference. But the triumph of the event was setting a research agenda. Studies would show that polio was not back. Fragments of the virus were found in patients but weren't reinfecting them. Researchers soon named the new disorder and clarified its characteristics.

Now the pathology is clear. During the acute phase of polio, patients can lose motor neurons, the nerves that carry signals to the muscles. More than 50 percent of them can experience weakness and possibly paralysis. The neurological system makes adaptations that can wear out the surviving motor neurons.

Imagine a right arm attacked by polio and an unaffected left arm, Halstead says. The right arm's dead nerve cells no longer stimulate the muscle, so the muscle atrophies but still sends out a chemical signal that instructs the healthy left arm to develop more "axon sprouts" – the endings on the motor neurons where chemical changes take place for muscle stimulation. Catastrophically, the number of sprouts increases.

Neurons

"Think of the tremendous metabolism it takes to generate the chemicals needed by each axon sprout. The motor neurons get worn out. That accounts for the new weakness in the muscle," Halstead says. Exercise is thought to spur the unwanted growth of new sprouts.

Questions about postpolio syndrome still outnumber the answers: Why do some people get it while others don't? What might cure the condition? Can it be prevented?

There's not much new in the research. Postpolio syndrome has always been an orphan disease – the crisis of the few since polio became a footnote in U.S. history. Before the illness was even identified, the once polio-centric March of Dimes had changed its focus to birth defects.

Some work continues. The John P. Murtha Neuroscience and Pain Institute in Johnstown, Pa., is exploring nonfatiguing exercises and stress-reduction behaviors at its polio-survivors clinic. Studies in Canada, France, Norway, and Sweden show that the immune system may have an influence on postpolio syndrome, and interest in a long-term U.S. clinical trial to replicate them is growing. Research may lead to a gamma globulin shot to reduce symptoms.

Halstead says studies have fallen off in the past 5 or 10 years, as U.S. polio survivors die and the medical complications of aging make it harder to research them. But the syndrome could continue for years.

"It is just now becoming an issue in India, and it will be eventually in all areas of the developing world as the average lifespan increases," says Hussey, of the Rotarian Action Group. While Rotary's eradication efforts have dramatically slowed the rate of polio infection, the World Health Organization estimates that survivors number between 10 and 20 million worldwide. "Long after the last polio case, postpolio syndrome will persist as a significant personal, social, medical, financial, and political challenge," Hussey says.

11 Comments:

At 10:02AM on 20 August 2012, **J. Doyle Pinholster** wrote: I am a 74 yr. old white male, and contracted Polio in 1949 in a small S. GA. town. About 6 kids in town came down with the disease within about a 6 month period. Fortunately, our family Dr. (who made house calls at that time) diagnosed my case almost immediately - the same day my symptoms hit me like a bolt of lightning !!! He thought the disease was contracted at the local city swimming pool - which at that time keeping pools clean and sanitary was not the norm. There were probably 50 - 75 people in the pool at the same time, and the water was changed only about once a week. I was 11 yrs. old when I caught polio in 1949. I was among a very few that didn't die or have lifetime disabilities. My entire left side was temporarily afflicted but I rec'd immediate treatment at a hospital in Atlanta, and after 2 mos. in Grady Hosp. with intensive treatment I was released without disabilities. However, at age 55, I began having arthritic-like pains in all my joints. A Rheumatologist put me on prednisone for approx. 90 days and my pains left me for about 10 yrs. I then started experiencing numbness in my feet and hands, and a few months later my joints started aching again. After being referred to a Neurologist, a new Rheumatologist, and other Doctors, I explained to all of them about having polio as a child and I wondered if I could have PPS. Every Dr. I've seen knew nothing about PPS. As a result, I had Carpal Tunnel Syndrome surgery, as well as being treated for degenerative arthritis, and polymyalgia rheumatica. Less than 2 yrs. later my hands are becoming numb again along with ever-increasing numbness in my feet and legs. The only medicine I've taken that relieves the pain is PREDNISONE. However, it only relieves the pain, but not the numbness in my feet, legs and hands. I started out with 30 MGS. per day, and slowly worked down to 2 1/2 MGS. per day over a period of 1 yr. and 8 mos. I have tried to leave off the Prednisone on two occasions, and within a week I was reeling with pain again in my joints as well as my leg and arm muscles. I'm convinced that I suffer from PPS. Nearly all my Drs. have recommended that I exercise more vigorously, but when I exercise on a regular basis it seems to worsen my problems rather than to help. I am still mobile, but on a few occasions I was unable to get out of bed due to the pain, and two or three times I didn't have the strength to get up out of my chair. Is anyone taking different medications that have helped your pain or numbness ??? Perhaps someone could share specific diets that help. I suggest you talk to your Dr. about trying Prednisone if your symptoms are like mine - and hopefully you may find some relief. I've been very active most of my life, and know that I was blessed with such an early diagnosis and quick treatment, as some of my friends were substantially afflicted. May God bless all of you that live with this horrible disease, and hopefully a cure will one day be available for PPS.

At 10:10AM on 21 February 2011, **Pam Ashe** wrote: My husband is 68 yrs old and a polio victim from the 1950-1951 years. In the last 5 years he has experienced continuing issues with pain, less movement in his right side. He has had numerous surgeries, knee replacement left knee, back fusion on vertebrae etc. Problem is that his Drs keep making different suggestions on cause. Some say yes to the syndrome, others don't seem to know much. My problem is getting him to at least consider this as maybe seek answers.

At 8:58AM on 14 February 2011, **Willa Sweeney** wrote: I had polio at 9 months. I was very lucky in that my only visual effect was the muscle in my lower right leg. In the past few years I have noticeable weakening in my left leg. I am convinced it is post polio. I am now using a cane and have always pushed through exercise...this makes me wonder if I am making it worse.

At 9:05AM on 28 October 2010, **Carol Ferguson** wrote: This article is fantastic. I'm grateful to be discovering a form of 'survivors' - not victims. I had polio age 2. PPS was officially diagnosed maybe 10 years ago - symptoms of weakness, primarily left leg go back way longer. Now it's left arm as well. I live in PA (near Philadelphia) (responding to above). My best treatment came from International Post Polio Center (formerly Englewood NJ, now Hackensack, I believe). Dr Bruno's team still is my primary PPS eval person - no one else seems to know the deal. As part of my treatment there, diet is huge. I've found great success on the high protein, high fiber, low fat diet they prescribed. Long term, getting a good PT has been a major issue. Most of them just don't 'get it'.

At 9:28AM on 25 October 2010, **David Rodriguez** wrote: I got polio at age 1 (1948). My parents treated me like the other kids. Went to public schools and graduated in 1965. I learned to play the drums left handed because I wore a leg brace on my right leg. My mom and dad never felt sorry for me. I married and had 2 kids. I never did pay attention to people staring at me. I grew up with the attitude, if they don't like it, it's to bad. Maybe it was my up bringing, the way my parents gave me the attitude, we all have either a mental or physical problem, but don't let anyone take your joy. I'm retired now and have a good pension thanks to the State of Calif. There is so much to say, but I always thought it was a mental thing.

At 10:17AM on 22 October 2010, **Vivienne Lewis** wrote:I contracted post-polio syndrome 17 years ago. All I could do was crawl around my home. I was told by doctors there was nothing they could do and I was headed for a wheelchair. Fortunately, I found a way through nutrition to avoid that wheelchair for all these years. I thought I was an isolated example until recently I have come to learn that many people have been helped with PPS using nutrition. Does anyone know if there are any research studies about nutrition and PPS?

At 10:58AM on 11 October 2010, **Evelyn Balmer** wrote:I had polio when I was 10 years old (1954).I am now showing some weakness in my legs. I am debating an exercise program, but after reading this article I don't know what to do. I live in Pa. is there a Dr. I could go to for an evaluation?

At 10:33AM on 4 October 2010, **margaret digney** wrote:I just read the year-old article re Polio. Does Rotary in U.S. provide any funds to people who have had Polio and now need to make changes to their bayhrooms, kitchen counters, etc. to accommodate a wheelchair?

At 8:49AM on 14 September 2010, **Sieglinde Stieda** wrote:A Rotary Club in Montreal, Quebec, Canada, in 1985, gave me \$200 or \$300 in seed money to help towards the establishment of the self-help group POLIO QUEBEC. Twenty-five years later the group is still thriving! Ckeck them out at <http://www.polioquebec.org/indexE.html> Thank you Rotary. the March of Dimes of Quebec refused to help me at the time. BUT YOU let me make a presentation to your group. You listened and you helped. I continue to be thankful for that help.

At 10:40AM on 13 September 2010, **Becky Overmyer** wrote:My mother passed away on June 15, 2010 at 82. She had Polio as a child and recovered. The last ten years of her life she saw all the specialists, Mayo clinic etc. etc. and nobody could diagnos her problem. After reading this article I'm convinced that she suffered from this. Her back looked like she had scolios although she was never officially diagnosed and she had unexplained weakness in her legs. At times she would be walking along and they would just give out.They prescribed therapy but it only made it worse and she was in a lot of pain. Thank so much for this article because at least I feel I now know what could have been going on with her.

At 4:35PM on 7 September 2010, **Bobbie Long** wrote:An excellent article on Post Polio! My husband is a Post Polio victim after spending time in the Iron Lung in Charleston, S.C. in 1955. It is very difficult for family and friends to understate this condition. My husband is a Paul Harris Rotarian and maintained a 30 yr. perfect attendance at Rotary. People need to be educated about this condition. i am glad that the Rotary published this article. I only wish it could be widely published!