

Century after 1st major U.S. Polio Epidemic, Eradication Eyed

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DOYLESTOWN, Pa. (AP) – It rained hard the day before Nick Hovemeyer came down with polio in the summer of 1945. All the kids in his Trenton, N.J., neighborhood were out in the street, splashing in the water, just being kids. The next day, 8-year-old Hovemeyer developed a high fever and couldn't stand or walk. His mother called an ambulance, but the crew was reluctant to take him.

"They walked in and took one look at me and said, 'He's got polio.' And at that time, you were afraid to touch people because it was contagious," recalled Hovemeyer, who is now 79.

Nick and Barb Hovemeyer talk about polio and post-polio syndrome Fear gripped the country each summer in the early part of the 20th century, when thousands of children caught the poliovirus before two types of vaccines were developed in the 1950s. Many were paralyzed, left with disfigured limbs and experienced other physical and emotional pain. For some, the virus was fatal. No one knew what caused it or how to prevent it, only that it targeted children.

Health and humanitarian organizations hope the debilitating disease – and the fear it still creates overseas and among survivors – will be eradicated worldwide this year, the 100th anniversary of the first major polio outbreak in the United States.

But just because we may no longer see new cases of polio, doesn't mean it will no longer affect people. Decades after they had polio, survivors like Hovemeyer have developed post-polio sequelae, or post-polio syndrome, and are experiencing pain and fear once again.

Recalling his own experience, Hovemeyer said the ambulance crew who responded when he became ill took him to Mercer Hospital in Trenton – thanks to his mother's pleas. From there, he was transferred to Donnelly Memorial Hospital in Hamilton, N.J., where he was a patient for three or four months.



Nick Hovemeyer had polio when he was a boy, recovered, then later in life his symptoms came back

Hovemeyer was to be sent home, but because his father was fighting overseas in World War II and his mother was working, he was placed in the Betty Bacharach Home for Afflicted Children.

Bacharach was a rehabilitation hospital in Longport, N.J., for children with diseases such as polio and tuberculosis. Hovemeyer's mother was always proud of that, his wife, Barb Hovemeyer, recalled. "His dad was in the war and (she thought he deserved the best care he could get," Barb Hovemeyer said. The care at the Bacharach Home included whirlpool treatments, physical and hot packs, which were applied to the affected muscles. Hovemeyer, who was at Bacharach for two years, said the worst part was the no-visitors policy. "I never saw my mother from the time I went in until the day I left," he said. That wasn't unusual: Isolation was the first step when people heard the word "polio" in those days.

They knew the virus spread easily, but they didn't know how it spread – or when and where the next epidemic would occur. That led to summers of fear, said polio survivor Daniel Wilson, a history professor at Muhlenberg College in Pennsylvania who has written several books about the disease and its impacts.

Swimming pools sat empty, the gates to Little League fields were locked, and mothers left their kids at home when they went grocery shopping, said polio survivor John Nanni, a Delaware resident and a district chairman for Rotary International's Polio Plus program.

“People were frightened because polio was as easy as catching a cold,” Nanni explained during a recent presentation to the Doylestown Rotary Club.

Because polio is a virus that spreads from person to person and there is no cure, the Rotary formed Polio Plus in 1985 to eradicate it worldwide through the mass vaccination of children. At that time, there were about 1,000 cases every day outside the USA. As of the end of April, 10 cases had been reported worldwide in 2016 – two in Afghanistan and eight in Pakistan, Nanni said.

“We are this close to eradication,” he said. “But until polio is eradicated, it is a world threat, and because there’s no cure for polio, vaccination is the only protection.”

Polio lives in the digestive system and those who have it shed the virus in their stool. That’s why there was concern, before the vaccines were created, about it getting into the water supply or children spreading it if they didn’t wash their hands after they used the bathroom, Wilson said.

The poliovirus can infect the brain and spinal cord, and while most people who get it don’t have any symptoms, about one in 200 are paralyzed temporarily or permanently, according to the U.S. Centers for Disease Control and Prevention. The more serious paralytic polio can cause differences in length, size and function of limbs, and even death if the chest and muscles used for breathing are affected.

Many parents felt polio destroyed their children’s futures, Wilson explained. There was no Americans with Disabilities Act to protect their rights and most schools and many other public buildings didn’t have elevators to accommodate children who needed to use wheelchairs or leg braces and crutches.

“Parents were afraid that their child would never get educated, never get a job or that she wouldn’t get married,” Wilson said.

The fear also led to people to stigmatize families with a child who had polio. People often stopped visiting affected families. Some communities ordered households quarantined, and even posted warning signs on the front doors of families where someone had polio.

“Even after people returned from the hospital or rehabilitation, and even years later, people were afraid that they could get polio,” Wilson said.

During the country’s first major polio outbreak in the summer of 1916, local newspapers listed the names of children who had the disease, then known as infantile paralysis, along with their addresses and symptoms, on the front pages.

Hovemeyer, now a Bristol Township resident, regained the use of his legs and was able to walk out of the Bacharach Home on his own. And thankfully, he said, never experienced the stigma associated with polio.

“My mother brought me back home and I was just like any other kid on the block, running and everything,” he recalled.

As a child, he played baseball and basketball; as an adult, he was an avid bowler and saltwater fisherman. But he knew there was something wrong about three or four years ago when he was 75 or 76. That’s when he began noticing renewed muscle pain and weakness in his legs and trouble with balance, he said.

A fellow polio survivor encouraged Hovemeyer and his wife to attend an area support group and told them about the possibility he could develop post-polio syndrome.

Post-polio syndrome isn’t a return of the original disease, but rather some of the original symptoms, including fatigue, muscle weakness, pain, atrophy and the decrease in some physical functions, said Dr. William DeMayo, a specialist in physical medicine and rehabilitation from Johnstown, Pa. DeMayo used to operate a weekly post-polio clinic and he still treats many survivors in his regular practice.

Survivors also may experience sensitivity to some medications and anesthesia. In fact, several years ago, the New Jersey Department of Health distributed anesthesia warning cards that many survivors across the country now carry. The diagnosis of post-polio syndrome is one of elimination, meaning doctors have to rule out all other possible causes first, explained Dr. Richard Bruno, a research and clinical psychophysicologist in Hackensack, N.J., who has studied and treated polio survivors for decades. His specialty deals with the interactions of the mind and body. Conditions such as thyroid disease and severe anemia are among those that can cause symptoms similar to post-polio syndrome, so it’s important to be sure of the diagnosis, said Bruno, who runs the International Centre for Polio Education, which serves as a resource for survivors and clinicians.

“That’s a great danger that polio survivors think, ‘I have these symptoms, it must be PPS,’ when it may be something else and something else that’s readily treatable,” Bruno explained.

The theory is that when a polio survivor's nerves were damaged by the initial infection, other nerves took over for them. Post-polio syndrome occurs when the nerves that took over begin to die from age or overuse, DeMayo explained. To put it simply, he said, polio survivors have two nerves doing the same job three nerves used to do. "As you get old, there is a normal dropout of nerve fibers," DeMayo said. "If you had one of the three nerves drop out before, you still had two. But if you have one of the two drop out, you have one nerve left."

The nerves also are more likely to die because they've been doing so much more work, and when they do die, there's a much bigger impact, DeMayo said.

Bruno said it's important for survivors to "conserve (energy) to preserve (mobility)" and listen to their bodies. That's not always easy for the survivors, he said, because they're generally Type-A personalities.

"When we discover we have this, the problem is not only being diagnosed with it, but having our heads treated to accept the fact that we got sick, we got better, we grew, we changed, we had families, we had fabulous careers, and then suddenly, post-polio syndrome hits," said Carol Ferguson, founder of the Pennsylvania Polio Survivors Network at www.papolionetwork.org. It provides resources and information to people who had polio and post-polio syndrome and their loved ones in Pennsylvania and other states and countries.

"A lot of polio survivors were encouraged to take President (Franklin D.) Roosevelt as their role model," Wilson said, which is why survivors have higher rates of marriage and employment than the general population. "People would say, 'If President Roosevelt can become president after having polio, you can do anything you want.'" Hovemeyer and his wife will celebrate 55 years of marriage early next year. They attend a monthly post-polio survivors support group at Abington Hospital-Jefferson Health, but Hovemeyer didn't want to go at first. He also didn't want to begin using a wheelchair or walker or stop going on walks in nearby Falls Community Park. He only recently gave away his bowling balls and said he no longer has any use for his fishing gear.

"They're (polio survivors) Type-A personalities; they are really pushers and think everything's fine," Barb Hovemeyer said.

"It kind of hurts when you can't do nothing anymore," Nick Hovemeyer added. "I just can't do nothing. I can't even cut the grass now."

Being a caregiver has changed his wife's life as well. "You have to take care of each other," she said. "It's not easy, but you do what you have to do."

People with post-polio syndrome should think about what they can do in a day as a line, De-Mayo said. The goal is to work up to that line, but not past it, although many end up on one side or the other, he said.

"They end up really getting into a situation where they overdo it and cause increased pain and weakness and then they may have a period where they just can't function and then they have to rest. Then they get frustrated with their level of inactivity (while) resting," he said. "A lot of times it's an issue of just being smart and budgeting how you do things and what you do in order to get the most done during the day."

Nick Hovemeyer still struggles with that from time to time.

"Even the doctor told him, you've got to know your limitations," his wife said.

"The best thing you can do," Nick Hovemeyer added, "is when you feel your legs getting weak, rest. Sit down and rest. Stop what you're doing. And that helps."

Ferguson had to come to that realization as well after doctors told her she needed to wear a leg brace and use a wheelchair. She didn't know she had polio as a child and her parents did not discuss her early illness until she was older.

"That did not work," the Carversville resident said of her initial reaction to doctors' orders about the brace and wheelchair. "That did not work for my head or my family."

She adapted and now uses a power wheelchair.

Carol Ferguson, founder of a polio survivors network, talks about the disease "This is the reality – this is what we've experienced – but we're alive and we're very much alive," she said of the country's more than 1 million survivors.

And although the hope is that there will be no new cases of polio after this year, Ferguson said the epidemic is still felt by those who've had the disease.

"It's not over. The survivors exist," she said, "and we're real."