

POLIO: WHEN A NIGHTMARE COMES BACK

Effects of disease strike survivors anew

By **ROBIN ERB**
FREE PRESS MEDICAL WRITER

Dianne Dych-Sachs was in denial until her ankle snapped.

For years, the medical technologist noticed her muscles weakening and her body tiring much earlier than her colleagues'. Sure, she had heard of postpolio syndrome; her sister — also a polio survivor — had sent her clippings and research articles.

But after all these decades, could her childhood polio still exact such damage?

"You're afraid. You're afraid to go back into braces," the 59-year-old Mt. Clemens woman said. "You become successful, you go to college, you get married, and you have children, and you work, and you give your 100%. You don't want to go back."

But the syndrome, for which there is no cure, leaves no choice for up to half of the 440,000 polio survivors in the U.S. today.

It's unclear what triggers it. The syndrome can include new pain or weakness and daytime fatigue. It's generally diagnosed when doctors rule out other medical problems, said Dr. Ann Laidlaw, who cares for polio survivors at the University of Michigan's Physical Medicine and Rehabilitation clinic.

The poliomyelitis virus is long gone from their bodies, of course, but once-weakened nerves and muscles are finally giving out.

Some theorize that to cope with the original disease, the body rewired some neurons to muscles that were weakened or disabled during the original infection. Those nerves served those muscles well for years, but essentially were overworked, Laidlaw said.

"It's like hooking up wires to 50 different appliances instead of three. After a time, they burn out," Laidlaw said.

As they deal with the syndrome, survivors search for medical records that are a half-century or more old. They've had limited success individually but are beginning to share stories and dig deeper through the Michigan Polio Network.

Survivors hope the records provide insight into treatment for the syndrome, though doctors are skeptical. But the records still might offer an important starting point for doctors born into a postpolio world, said Bonnie Levitan of Grosse Pointe.

When Levitan's right hand began losing its grip several years ago and her fingers began freezing in awkward directions, doctors were perplexed.

Her 1951 admissions records from Children's Hospital of Michigan held the clue: Childhood polio paralysis had first settled in her right hand.

"When I went to doctors, they couldn't tell me what was going on," said Levitan, 70. "Now I could tell them."

Locating the decades-old records is like the proverbial search for a needle, but it's unclear where the haystack moved or even whether it exists anymore because of the many mergers and closings of hospitals over the years.

Plus, state law allows for medical records to be destroyed after seven years.

Children's Hospital of Michigan, which was affiliated with the former Michigan Hospital School, began destroying

Survivors reunion

It was known as the Michigan Hospital School, the Convalescent Center and Sister Kenny Hospital. Michigan's children checked in to rehabilitate from polio's crippling effects.

Many of those children will gather again at the campus — now Botsford Commons Senior Community — 11 a.m.-2 p.m. Saturday for a reunion picnic.

Polio survivors will be updated on the search for medical records and the ongoing work to archive their stories at the Walter P. Reuther Library at Wayne State University.

For information, go to www.botsfordcommons.org/reunion. Anyone wishing to attend is asked to call Kimberly Gimmarro at 248-426-6951.

Support groups

Polio survivors can access a number of support groups in Michigan. For more information on the Michigan Polio Network and to read polio stories, go to www.michiganpolionetwork.com. For more information on the Southeast Michigan chapter of the Michigan Polio Network, call 313-885-7855.

For more information about the St. John Providence Post-Polio Clinic, go to www.stjohnprovidence.org/postpolio, or call 586-778-4505. Postpolio patients are also seen at a University of Michigan clinic. Call 734-936-7175.

polio patient records years ago because of space issues, officials said.

Some documents and pictures from the Sister Kenny Hospital — part of a larger, national program that was located at the Michigan Hospital School — were transferred to the Bentley Historical Society at the University of Michigan. Patient records were not, but it's unclear why.

Some patient records ended up in storage lockers or transferred as one doctor left his or her practice for another.

When it comes to finding records, "some are lucky, some are not," said Sue Hoyt, a staff member who fields survivor's calls at the Minnesota-based Sister Kenny Foundation.

Trying to be normal

A return of physical failings is especially difficult for survivors still haunted by childhood horrors — they were sometimes cut off from their parents by doctors who felt the visits were disruptive.

Many remember spinal taps and hot wool soaked in boiling water and wrapped around their bodies to try to improve circulation and relax muscles.

"There are survivors who, to this day, can't stand the smell of wet wool," said Levitan, who remembers her hospital isolation room and the sight of her parents looking at her through a tiny round window in the door.

The goal as a kid with polio was clear: Be a "passer," said Levitan, a retired high school paraprofessional. "Your parents wanted you out of the hospital, to come back and become a passer. ... You wanted to become as normal-looking as possible, to pass for normal."

At the St. John Providence Post-Polio Clinic in Warren, Dr. Daniel Ryan's patients are history lessons.

Some happily recall days at summer camps for disabled children, support through the national March of Dimes campaign and kind neighbors.

They bring photos. Sometimes they cry. It takes a while, he said: "A lot of them are in de-

nial. They were ostracized as children."

At last, a cure

In 1952, fear surged like never before: Reported cases peaked at 57,628 that year. In Michigan, doctors reported 3,912 new cases; 213 people died.

But on April 12, 1955, in the Rackham Building on the U-M campus — at a news conference crammed with reporters from around the country — news broke with nine words: "The vaccine works. It is safe, effective and potent."

U-M epidemiologist Dr. Thomas Francis Jr. had been given \$7.5 million by the National Foundation for Infantile Paralysis — money primarily collected through the March of Dimes — to put Dr. Jonas Salk's breakthrough polio vaccine through field tests. The announcement was carefully guarded; the information was delivered by police car.

The U.S. licensed the vaccine the same day.

Later, Salk's vaccine would be replaced by Albin Sabin's vaccine, carrying the live poliovirus and licensed in 1960. The two men would be forever credited with essentially eradicating the virus from the country and most of the world. The last case of polio reported in Michigan was in 1986.

All this was too late for Dych-Sachs and Debby Bookout, then 13-month-old twins from what is now Eastpointe. Dych-Sachs was diagnosed and hospitalized. A visiting nurse later saw her sister limping.

Both spent their childhood in braces paid for by the March of Dimes, the campaign created by another polio survivor, President Franklin D. Roosevelt.

Now Bookout is in a wheelchair and legally blind. Those and other health problems, she said, are part of tangled diagnoses of postpolio syndrome and multiple sclerosis. The latter — she's convinced — was brought on because of her polio-weakened body she had tried so hard to strengthen decades ago.

"Your dream as a kid is growing and being out of these braces," she said.

Dan Matakas, 74, who contracted polio when he was 2 years old and later became a designer for Ford, remembers the day he ditched his crutches. He had just started at Cass Technical High School in Detroit, and the young teen left his crutches at home, opting for a slower, grueling gait so he wouldn't have to juggle crutches with heavy books.

He has always been active — using his stronger muscles when he swam or bowled to compensate for those weakened by polio. But within the past year, he has noticed he can no longer lift his stronger, left leg to his bike pedal. He uses crutches again.

The drive that was built into kids with polio, he said, also makes them unwilling today to give up easily on a search for medical records.

"A lot of polio survivors have a stubborn streak or a survival streak," he said. "Polio was a black mark on you, and so you tried to be as normal as you could. If they told us we couldn't do something, we'd find a way to do it."

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PATRICIA BECK/Detroit Free Press



ABOVE: Bruce Sachs, 71, and 59-year-old twin sisters Debby Bookout of Warren and Dianne Dych-Sachs look through a scrapbook at Sachs' and Dych-Sachs' home in Mt. Clemens last week. All three are polio survivors now dealing with postpolio syndrome, which causes pain, weakness and mobility issues.

LEFT: Bookout and Dych-Sachs are seen in a 1953 photo published in the Detroit News about how the twin sisters had both contracted polio. Both spent their childhood in braces. "You're afraid. You're afraid to go back into braces," Dych-Sachs said. "You become successful, you go to college, you get married, and you have children, and you work, and you give your 100%. You don't want to go back."

The continuing fight against polio

One of the most feared diseases of the 20th Century, poliomyelitis attacks the nervous system. Vaccines developed in the 1950s and 1960s eliminated it from the U.S., but it still exists in some parts of the world. Years later, polio survivors may suffer aftereffects that are equally debilitating. Here are facts about the struggles to find a permanent solution.

ABOUT THE DISEASE

How it is spread: There are three types of poliovirus, and each are spread through contact between people, by nasal or oral secretions, and by contact with contaminated feces. Poliovirus enters the body through the mouth, multiplying along the way to the digestive tract.

Symptoms: In most cases, polio is a mild illness with viral-like symptoms. In paralytic polio, the virus enters the bloodstream, attacking nerve cells. In severe cases, the throat and chest may be paralyzed. Death may result if the patient does not receive artificial breathing support.

Polio survivors: Some survivors may develop postpolio syndrome. They will experience new weakening in muscles previously affected by their polio and also in muscles that were unaffected. Along with fatigue, there is muscle atrophy, pain and skeletal deformities.

Eradication of the disease in the U.S.: Today, the U.S. is polio-free, and two men are credited: Dr. Jonas Salk, who developed the inactivated polio vaccine (IPV) in the early 1950s, and Dr. Albert Sabin, who developed the oral polio vaccine (OPV) in the early 1960s. U.S. children are recommended to receive the inactivated polio vaccine at 2 months and 4 months of age, and then twice more before entering elementary school.

Where it still exists: Polio remains endemic in four countries — Afghanistan, India, Nigeria and Pakistan.



DEVELOPING A CURE

1894
First U.S. polio epidemic

Eighteen deaths and 132 cases of permanent paralysis were reported in Rutland County, Vt.

1905
Contagious nature of polio discovered.

1908
Poliovirus identified

1916
New York epidemic
More than 2,000 died in New York and about 6,000 total in the U.S., with thousands more paralyzed.

1921
Franklin D. Roosevelt is stricken with polio.



Franklin D. Roosevelt contracted polio at age 39. He had permanently paralyzed legs, but concealed it so well that millions of Americans never realized it.

1929
The iron lung is created.

An artificial respirator was developed to assist polio patients' breathing.

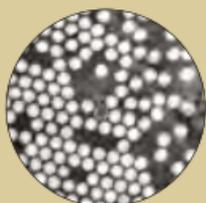
1938
March of Dimes is started.

Initially, more than 2 million dimes are sent to the White House to help fund the search for a vaccine.

Late 1940s and early 1950s
Polio cases surge.

In the late 1940s and early 1950s, polio crippled an average of more than 35,000 people in the U.S. each year. In 1952, 57,628 were diagnosed with polio in the U.S. and 3,912 in Michigan. Though most people recovered quickly, others suffered temporary or permanent paralysis, and even death.

Sources: U.S. Centers for Disease Control and Prevention and the National Institute of Neurological Disorders and Stroke, the College of Physicians of Philadelphia



Electron micrograph of the poliovirus from 1975. The virus was not visible to researchers until the electron microscope was developed in the 1950s.

Photo by DR. FRED MURPHY and STAVIA WHITFIELD/Centers for Disease Control



Dr. Jonas Salk



Dr. Albert Sabin

U.S. Postal Service images

Early 1950s
Successful vaccine created.

Dr. Jonas Salk develops the inactivated polio vaccine (IPV).

In Michigan: The world learned of Salk's success at a much-anticipated news conference in Ann Arbor that announced successful vaccine trials, funded by \$7.5 million from the March of Dimes. University of Michigan epidemiologist Dr. Thomas Francis Jr. led the trials.



Dr. Jonas Salk administering a vaccination, 1954

Associated Press

Early 1960s
Oral vaccine created

Dr. Albert Sabin develops the oral polio vaccine (OPV).

2011
Campaign for a global cure

Since the 1990s, there have been public and private efforts to eliminate the disease.



Volunteers administer polio drops to a 4-month-old in Mumbai, India, in 2000.

SHERWIN CRASTO/Associated Press

Text by ROBIN ERB, medical writer/Detroit Free Press; Graphic by MARTHA THIERRY/Detroit Free Press



Hygeia

ABOVE: Bruce Sachs is shown as a boy when he fought polio.

RIGHT: Now 71 and living in Mt. Clemens, Sachs is trying to piece together what happened during his childhood fight with the disease.



Survivors who beat polio must fight again

Michiganders seek records for clues to resurfacing ailments

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Somewhere, someone may have the records. In some file cabinet, warehouse or library.

For a survivor of what was once a whispered horror — *polio* — those documents might fill in gaps of a childhood fractured by comas and surgeries, isolation rooms and iron lungs, braces and grueling rehabilitation.

They also might provide clues for doctors trying to understand postpolio syndrome, a disorder that develops decades after the virus is gone. It happens when disease-weakened nerves and muscles — and even their stronger counterparts — finally give out. Many survivors are now returning to the braces and crutches they had worked so hard to leave behind.

Bruce Sachs, one of Michigan's estimated 12,000 polio survivors, said parents today can't understand the fear that seized the nation before April 12, 1955 — the day a University of Michigan epidemiologist let the world know that Dr. Jonas Salk's vaccine was working. Six days later, the first Detroit kids lined up for shots.

Sachs, 71, of Mt. Clemens, who wears braces again, began looking for his records in 2003, about the time postpolio syndrome set in.

He's had more success than others, locating 15 pages from a northern Michigan hospital — documents that outline surgeries, including one in which ivory was used to even the lengths of his legs.

"I think a lot of it goes to the fact that for so many years, we denied it," he said. "Now we all want to know more, to fill in the blanks from something that we tried to leave in our past."

■ **WHEN POLIO STRIKES AGAIN. 6A**