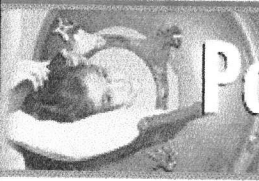


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Polio: Death of a Disease



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Decades later, a trauma revived

For polio survivors, a syndrome brings more than physical pain.

Fourth of five parts

By Huntly Collins
Inquirer Staff Writer
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Marty Abelson sat on the edge of an examining table at Albert Einstein Medical Center in Philadelphia and pleaded for reassurance that he was not imagining things.

A year earlier, he could jog five miles around his home in Mechanicsburg, Pa. Now, after mowing his lawn, he was lucky to be able to put one foot in front of the other.

"It's not that I'm being a wimp, is it?" Abelson asked orthopedic surgeon Mary Ann Keenan. "I'm not making anything up? This is really happening?"

Marty Abelson holds a picture of himself finishing the Pittsburgh Great Race (10K) in 1990. It's now impossible for him to run because of lost strength in his legs. [More Photos](#) (Peter Tobia/Inquirer)

This was Abelson's second visit to one of the nation's premier programs for polio survivors, attracting more than 400 patients, some from as far away as Hawaii.

Yes, Keenan told him, the fatigue was real, the result of muscles and nerves working on overload for decades. "It's like you are trying to run a marathon every day. Even marathoners don't do that."

Abelson, 47, is one of thousands of American polio survivors who have developed a medical condition known as post-polio syndrome. The symptoms, which do not appear until decades after people have recovered from polio, include weakened muscles, leg and shoulder pain, and exhaustion.

Like most of America's 400,000 to 600,000 polio survivors, Abelson thought his problems were behind him after he recovered from his childhood bout with the crippling disease.

Time and two surgeries seemed to heal his paralyzed leg, and he went on with life - college, marriage, two children, and a demanding job as a pharmacist.

But now his leg muscles were weak. His knees sometimes buckled, sending him crashing to

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Post Polio Syndrome
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the floor. His shoulders ached. Just walking through a mall was exhausting.

The problems - which came out of nowhere - forced Abelson to make dramatic changes.

He gave up the people-oriented pharmacy job he loved because he had to stand all day. Now, he had a desk job reviewing insurance claims for prescription drugs.

He had begun using a leg brace and a cane. Soon, he feared, he would need a wheelchair or motorized scooter.

"I feel like I'm on a roller coaster going down," Abelson told Keenan as he sat in his T-shirt and boxers during a checkup last fall. "The hardest part is, I used to be the one to fix the problem. Now, I *am* the problem."

Abelson and others who are twice victimized by polio are a poignant and costly reminder of the toll of disease and the miraculous benefits of vaccines.

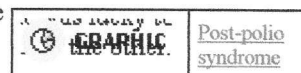
Even if the World Health Organization is successful in its drive to eradicate polio from the planet by the end of 2000, millions will continue to suffer from the late effects of polio decades from now.

When polio survivors first began complaining of these muscle problems in the late 1970s, doctors often dismissed them as hypochondriacs.

Few physicians had a firsthand knowledge of polio. The disease, conquered by the Salk and Sabin vaccines in the 1950s and '60s, was no longer taught in most medical schools.

Also, doctors had trouble distinguishing the symptoms of these older patients from normal aging.

But since the 1980s, when post-polio syndrome was named, the medical community has gradually come to accept the disorder as a bona fide neurological condition.



Doctors estimate that 20 to 40 percent of people who had acute paralytic polio develop problems later on.

And new research now points to a possible explanation - overuse of both the muscles and the nerves that activate them.

"It's still a theory, but we find that it's confirmed by the experience of our patients," said Dr. Alberto Esquenazi, a rehabilitation specialist at Einstein's clinic.

There is no definitive test to diagnose the disorder and no effective medicine to treat it.

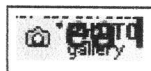
But surgery, strengthening exercises, and the use of braces, crutches, wheelchairs and scooters can help patients lessen the strain on muscles.

For many, however, that brings back the nightmare of their past.

"We have boxes of tissues in each examining room," Esquenazi said. "Emotionally, it's very hard for people to accept."

Paul Radvansky was slouched in a chair when Keenan walked into the examining room to greet him. He was a new patient, so the doctor wanted to hear his whole story.

"You're going to get me out of the nursing home, aren't you?" Radvansky asked Keenan. "I want to go to work so bad."



Post-polio
syndrome

Radvansky's situation was complex. He contracted polio in 1945, when he was 7. With braces and surgery, he had recovered, but his spine was left with an extreme curvature, known as polio scoliosis.

That was not his only problem. Radvansky had been in and out of state mental hospitals much of his life with manic-depressive disorder. He landed in a Doylestown nursing home last spring after suffering a severe bout of depression over his physical condition. It was getting harder and harder to walk, he said.

"These shoes came from Kmart," Radvansky told Keenan as he pointed to his white tennis shoes. "They're supposed to be sort of orthopedic."

Keenan had Radvansky walk barefoot down the hallway, observing his contorted spine. She pushed and pulled various muscles, asking him to push and pull back. Then she ordered X-rays.

The results were not good. Radvansky would need braces on both legs to stabilize his body.

"Oh, please don't!" he yelled. "Don't! You know what's going to happen? You're going to put braces on my legs and I'm going to quit."

Radvansky explained that he had been getting better and had begun taking short walks every day up and down a hill near the nursing home, pushing a wheelchair in front of him for support.

His hero, he said, was Oliver Bierhoff, the German soccer player. He had cut out Bierhoff's photo from Sports Illustrated and pasted it near his bed. "I said to myself, 'This is your role model each and every day, every time you go up and down that hill.'"

Keenan tried to assure Radvansky that he could still walk with the braces, that they were lightweight plastic, not the heavy metal braces that he had as a child.

Esquenazi, who had come in to consult, was also a soccer fan. "Did you know that Bierhoff hurt his knee and wore a brace?" he told Radvansky. "He used a brace so he could protect himself. You have to think about it the same way."

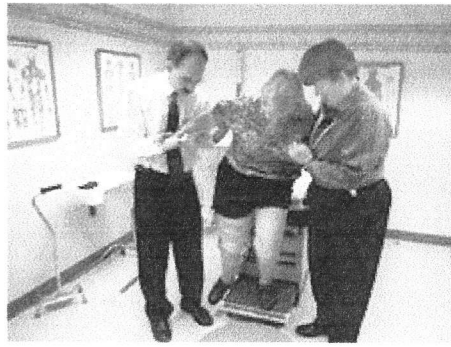
"There is no better athlete than the polio patient," Keenan chimed in.

Radvansky grew quiet, as if weighing his options.

Esquenazi left and came back with something under his arm. "There's a brace," he told Radvansky, thrusting a piece of smooth white plastic in front of him.

Radvansky was stunned. "It's like a big shoe," he said. "Wonderful, wonderful. I'll buy that."





At Albert Einstein Medical Center's post-polio clinic, Dr. Alberto Esquenazi and Dr. Mary Ann Keenan help Barbara Goldstein, 64, to her feet after an examination. [More Photos](#) (Peter Tobia/Inquirer)

The Einstein doctors liken polio to a Jackson Pollock painting, with oil splattered on canvas in no obvious pattern.

Most people who contract polio virus don't even get sick; a few, however, develop disabling paralysis, and some die. No one knows why.

Similarly, there is no predicting which muscles will be affected or how severely. It could be the arms, the legs, the diaphragm or some combination.

Post-polio syndrome doesn't hit everyone who had polio. It seems to develop in those who were most severely paralyzed.

In recent years, some scientists have come up with a possible explanation:

Once the polio virus gets into the body, it travels to the spinal cord, where it attacks large numbers of motor neurons, the nerve cells that activate voluntary muscles, such as those in the arms and legs.

Some neurons recover from a polio attack, but others die, causing atrophy of the muscles they control.

In a process called "remodeling," the body has an ingenious way of repairing itself. The neurons that recover from polio sprout new growths that reach out like tentacles to the muscle cells that were left stranded when their own neurons died.

These stranded muscle cells then rely on the recovered neurons to get the signals they need to function. As a result, a smaller number of motor neurons shoulder the work previously done by many. After years of expanded duty, these neurons begin to break down.

Some scientists now believe it is the breakdown of these overtaxed neurons that triggers the muscle weakness.

"Post-polio syndrome is not a reinfection with polio virus," Keenan said.

The surgery that Keenan recommends to patients is aimed at relieving a number of problems.

Many patients, she said, have torn their rotator cuff, the tendons in the shoulder, after years of using their arms to push up out of chairs. A relatively simple operation can repair the damage.

Another surgery is aimed at correcting a common foot deformity that can cause patients to fall. Doctors make small incisions in the Achilles tendon, which can then stretch and allow the foot to be flat on the floor.

The braces - handcrafted in a hospital workshop that resembles an artist's studio - support weakened muscles so patients can conserve their energy.

But along with all the external supports, patients are asked to make a monumental change in their mental attitude.

Instead of trying to do everything, they are urged to slow down and make judicious use of their strength.

"I tell each patient: 'You have an energy budget,'" Keenan explained. "'Where do you want to spend it? In the parking lot trying to get into the mall, or getting around your yard?'"

It isn't just the doctors who hand out advice. Patient volunteers act as peer counselors, sharing their experiences with newcomers.

"I've been here eight years, ever since the clinic opened," said volunteer Ann Silcox, as she buzzed up and down the hallway in her motorized cart. As a young girl, Silcox spent years at the Home of the Merciful Saviour in West Philadelphia, a residential facility for children with polio.

Silcox had brought in a big platter of what the doctors call "polio food" - watermelon, low-fat angel-food muffins, and rye bread topped with cucumber slices. Because they can't do vigorous exercise, many post-polio patients become overweight. The polio food is meant to encourage low-fat snacks.

The volunteers also run a support group, in which post-polio patients can work through what may be years of denial about their disability.

Like President Franklin D. Roosevelt, who did his best to hide his paralysis from the public, people with polio were supposed to be strong. If they tried hard enough, they could get out of their wheelchairs, throw away their braces, and be just like everybody else.

And many did. They became super-achievers who went on to college in disproportionate numbers, entered the professions, and developed reputations for excellence in virtually every field.

But it came at a cost.

"Most patients have the traditional view: 'No pain, no gain,'" Esquenazi said. "We spend years trying to turn this around."

Bill Lambert arrived for his clinic appointment with a long list of questions. His wife, Eileen, a former teacher, sat at his side taking careful notes. "She's my secretary," Lambert joked.

A few months earlier, Lambert, 58, learned that he needed corrective surgery on his right foot and that he would have to wear a brace for the rest of his life. He thought he had rid himself of his brace nearly 50 years ago.

Even more troubling were the lifestyle changes the doctors recommended.

Instead of walking a mile, he was to walk only half a mile. He should limit climbing stairs to once or twice a day. He had to sit, not stand, at his workbench.

This for a man who loved spending hours in his basement playing with his model railroad; who completely renovated his Phoenixville townhouse, doing all the demolition, carpentry and electrical work himself; and who spent many a weekend afternoon going on historic walking tours with his wife.

"It just caught me out of the blue that we were going to face so many changes," said Lambert, a retired draftsman.

Now, before he went ahead with the surgery and brace, Lambert wanted a few answers: Would he still be able to drive? How about "potty calls" in the middle of the night? What about bathing?

Keenan assured him that, with a few modifications, he could do all of that.

After methodically working down his list of questions, Lambert came to the big one.

“What are we looking at, totally, best guess, in 15 years?” he asked.

Keenan answered with the only information she knew for sure: “Our goal is to keep you active and functioning.”

Part Five: Vaccines offer help for conquering other diseases

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