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PAINFUL REMINDER

*Polio survivors fought a fierce fight in their youth.
Now, they're engaged in a second battle as the specter returns.*

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THEY'RE A PRODUCT OF THEIR TIMES.

Born before the middle of the last century, before the discovery of a miracle vaccine, polio patients drew the short stick in the health lottery, like heart patients stricken before the advent of bypass surgery or smallpox victims before the detection of a lifesaving inoculation.

People who battled back from paralytic polio are finding the ailment can exact another toll, an echo of their former illness. It's called post-polio, a syndrome identified two decades ago but still widely unacknowledged or misunderstood, partly because polio has been virtually eradicated in the industrialized world. There's no race for the post-polio cure, for example. But for an estimated 10,000-16,000 polio survivors in Michigan, post-polio remains a threat on the horizon, double jeopardy in a trial that already imposed one sentence.

Paula Lemieux says she can smell wet wool a mile away — an almost dream-like sensory remnant of childhood.

The memory rests in 1952 when Lemieux, then a kindergartner, entered a home for children with polio. She went home months later as a first grader with a lingering limp and muscle weakness in her abdomen and back. The rehabilitation had included the prevailing treatment of the time: application of hot, moist woolen packs combined with muscle stretching.

Three decades and an active life later, Lemieux — a wife, mother and nurse — began experiencing significant pain in her good leg. “The doctor said, ‘I’ll bet it’s related to polio,’ and I laughed,” she says. The symptoms included severe cramps and twitching or, as she describes it, “Like someone had stuck a knife in my quadriceps. I’d also had pain in my good knee. It was more irritating than disabling.”

Lemieux has post-polio syndrome. The condition strikes an estimated 20 to 40 percent of people who had paralytic polio. The syndrome, which appears 15 to 30 years after the original polio, is characterized by fatigue, pain, new weakness, sleeping difficulty and sensitivity to cold temperatures.

Patients, a fiercely independent population who fought paralysis as children, often deny the signs.

Lemieux now uses two forearm crutches for walking distances. “I had the double canes for a while,” Lemieux says. “They tried to talk me into forearm crutches and I fought it. You don’t want to ‘look’ disabled.”

Part of Lemieux’s attack on post-polio involved acknowledging her condition.

“I went to the ‘U’ [University of Michigan] and asked for a handicapped parking permit,” she says. “I was kind of hoping they’d say I don’t need it. I thought, ‘People are going to wonder why I was using the parking permit.’ [The nurse] looked at me and said: ‘You know, you do limp.’”

Lemieux’s process of realization continued, she says, when “a physical therapist had me walk toward a mirror with one cane and then with a second so I could see I walked better with two,” she says. Her grade-school-age son added his own matter-of-fact advice, saying: “‘Mom, you haven’t changed; you’re just using a cane.’ So I just hold my head up high.”

Still, in typical defiance of someone who’s won a hard-fought battle, Lemieux resisted physical therapy as well — until the back pain started last year. One of the troubling aspects of post-polio, she says, is that the symptoms are fickle. “It’s always changing,” she says. “It’s a little disconcerting.”

Before the Salk and Sabin vaccines made it nearly extinct, polio exceeded AIDS in scope and fear.

“Polio patients do feel a little lost in the medical community because they went through something so devastating and they’re forgotten,” says



SCENES FROM CHILDHOOD

“I had polio in 1941. I was 7 years old. I remember getting up on a Sunday morning. We lived in a beautiful old home in Marshall. I remember I loved the Sunday paper: ‘Red Ryder and the Little Beaver.’ I remember sitting in the living-room chair. I couldn’t bend down to read the paper. Sometime during the afternoon I began to feel really bad. I laid on the couch and never got back up.” — Jerry Hazel, Michigan Polio Network chairman



“My parents think I got it when we went to the beach one summer day when I was a toddler. My whole family came down with it. I was hardest hit. We lived in Birmingham and we’d gone to Kensington Park.” — Sunny Roller

Dr. Daniel Ryan, medical director of St. John Hospital’s new post-polio clinic in Shelby Township.

Ryan, who was born after the widespread polio threat, says one patient showed him a scrapbook crammed with newspaper clippings chronicling the viral epidemic. “You look at it and you realize how big it was, how big it was for the nation, and Generation X and Y have no idea,” Ryan says. “It would be like someone 100 years from now not hearing of AIDS — and polio was bigger than AIDS.” While patients do feel ignored by the medical community, Ryan says ongoing scientific research into nerve regeneration may help benefit polio survivors.

The need for treatments is significant. Before St. John’s post-polio clinic was even a year old, it had a months-long waiting list. About 400 patients visited the clinic in the first 11 months.

Because post-polio is a vague affliction, diagnosis can be difficult. St. John patients see a range of specialists, including physical therapists, orthopedists, occupational therapists, geriatric social workers, orthotists, internists and doctors of physical medicine and rehabilitation. The range is necessary for diagnosis because other illnesses with similar symptoms, such as multiple sclerosis and Lou Gehrig’s disease, must be ruled out.

Any treatment must address the emotional toll; a post-polio diagnosis kindles bad history. Ryan has seen patients whose parents surrendered them for adoption because they couldn’t bear the stigma associated with physical disabilities. “I had a patient who came to the clinic and when he saw some of the other people, he almost got up and walked out, dealing with the emotion,” Ryan says. “He’s a professional and well-to-do person. There was an ostracism.”

Ron Magnuson was a 9-year-old bookish boy when he contracted polio in the summer of 1952. The virus began with a fever. He began stumbling. At home his right leg gave out in the hall and he couldn’t get back up. He spent 11 months at a rehabilitation home. It was, he recalls, a sad time.

“I found that denial worked pretty well for me except then you never come to grips with it,” says Magnuson, who was a junior-high band teacher until post-polio forced him into early retirement.

Magnuson discovered during college, after his crutches were stolen, that he could walk without them. Getting around quite well with a cane, he took several European trips and maintained his 30-foot sailboat. Today, because of post-polio, he uses a wheelchair to travel distances any longer than car-to-building. He does physical therapy, “pedaling” a bike with his hands for an aerobic workout. Yoga and stretching also are part of the regimen designed to keep his body able.

One of his greatest pleasures remains listening to opera, studying operatic scores and reading their texts in French, German and Italian.

“With post-polio, I find a lot of the original feelings resurfacing, particularly at night. It’s an

anxiety," he says. Some of his emotion stems from what he sees as a lack of recognition by the medical community. "We're all getting older and dying off so there's no future for exploration or research," he says. "It's not growing."

But the late-night emotion is mostly personal, arising, he says, from "a primal fear I had originally that I never dealt with. I'm struck by the randomness of it all."

Polio was random for more than the way in which it plucked victims at will. It struck nerves and muscles with vast asymmetric variety. It attacked hips, knees, backs or lungs in some, withered arms and hands in others. It left young women forever reluctant to wear a sundress because of a humped back, men shy of wearing shorts because of reedy legs. Survivors thought those physical calling cards were the signature aftermath of the virus, the only "post" there was from polio.

The term post-polio didn't come into wide use until 1983-84. The University of Michigan's Dr. Frederick Maynard was one of the first doctors in the state to help diagnose and work with post-polio patients. He remembers attending a conference in Chicago in 1981, the first ever on post-polio. "It was inspiring," he says. "Probably a hundred polio survivors came; at least 30 of them were using ventilators. They had plug-ins and you could hear this swish, swish, swish in the ballroom.

"There were major limps and funny little arms, skinny necks — and nobody cared," says Maynard, who now is in private practice in Marquette. "Everybody just took each other as they were."

Such open acceptance of disability was not the day-to-day experience of people who had polio. "The mission was to appear as normal as possible," says Bonnie Levitan, a 61-year old polio survivor. "People got there by sheer determination. The therapist would say, 'Do you want people to think you're a cripple? Get up.' Your parents didn't want you to look crippled."

And for much of her life, Levitan managed that. Because of that mindset, she ignored the initial symptoms of post-polio.

Polio had left her unable to run or stoop. And if she bent her knees slightly, she would fall. She could not sit up from a lying position. With great difficulty, she managed to give birth to two children and worked as a student activity coordinator at Grosse Pointe South High School. But in the 1980s, she began to suffer debilitating fatigue.

"I began to fall for no reason," she says. "My muscles would sting and burn. I had a great deal of difficulty going up the stairs. I had to pull myself up. By the end of the day I could hardly function. I couldn't cook dinner. I would collapse. I thought if I would just try harder, it would get better. My husband said, 'You know, you're having a lot of trouble getting into the car.' He said, 'You're hanging onto me an awful lot.'"



"I was 11 when I contracted polio. We were coming home from vacation in Pennsylvania in 1951. I got sick in the car. My sister and I were in the car together licking each other's suckers and sharing sandwiches. By the time we got home, I couldn't get into the top bunk. I put a *Life* magazine in the freezer and then laid on top of it to keep cool. The first thing the doctor asked was, 'Can you put your chin to your chest?' I couldn't. They sent me to Children's Hospital for a lumbar puncture and by the time I got there I was going into a coma, which I was in for two weeks. The day I left Children's they tried to stand me up and it was like trying to stand up a rag doll." — Bonnie Levitan



"I was only 6 when I had polio. I remember waking up in the middle of the night and going in to my mother. I remember walking back to my bedroom and looking back at my mother and she had a horrified look on her face." — Paula Lemieux

THE FACTS ON POST-POLIO

DEFINED: A disorder of the nervous system (also called the late effects of polio) that appears in many survivors of a paralytic attack of the poliomyelitis virus, usually 15 years or more after the original illness. Its main symptoms are new progressive muscle weakness, severe fatigue, pain in muscles and joints. *Source: The March of Dimes*

CAUSE: Polio attacks the nerves of the spine. People who had polio have just enough surviving nerves to walk, for example. But in all people, nerves die off in the natural aging process. In someone with a short supply, that nerve reduction may be enough to tip the scales. In addition, symptoms may stem from a lifetime of muscle overuse to compensate. *Source: Dr. Daniel Ryan, St. John Hospital Post-Polio Clinic.*

MANAGEMENT: Orthopedic devices, energy conser-

The University of Michigan Hospital Post-Polio clinic diagnosed her. "I was sitting there on the table in my little gown and [the doctor] was talking about my deltoids," she says "I almost had a complete emotional breakdown and I'm a person who doesn't cry even at things worth crying about. You think you're through with that part of your life and it's a progressive thing."

Levitan says she has slowed the progression of her post-polio by facing it and educating herself. She does prescribed exercises and paces herself. She also was a driving force behind St. John Hospital's decision to create a post-polio clinic.

She and other polio survivors are dedicated to educating the public on the dangers that remain. "A lot of young people are opting out of the vaccine," she says. "The polio virus is alive and well around the state of Michigan in sewer backups."

Don Varley survived polio in 1931. At age 3, he spent 90 days in the hospital, his parents able only to peer at him through a window. He was brought home strapped to a board. Varley became a husband, father, freelance writer and golfer.

And as facilitator of the The Southeast Michigan Post-Polio Support Group, he works to educate the public on polio and post-polio. It's a turnabout from the days when he worked to conceal his disease. "If I was limping a little bit and someone said, 'Did you hurt yourself?' I'd say 'Yeah, I turned my ankle.' I've had pretty heavy depression for the past 15 years. My major thing is the future. There are things out there coming at me, and they have my name on them."

Varley speaks publicly. He wants people to consider: "In 20 to 30 years we'll all be dead, so who cares? I suspect that's impacted research money.

"They think polio is eradicated. They talk about eradicating polio by 2005, but what about people who've had it [in Third World nations] in the past 20 to 30 years?"

Polio still exerts its viral terrorism. Its random nature continues to confound Pat Fasseel, a 62-year-old Eastpointe woman who contracted polio in 1949 and post-polio in the 1980s.

"I had been kind of sickly that summer," she says. "My parents had gone shopping and left my 14-year-old brother in charge. I was so sick he gave me the [less active] job of watching my baby brother, who was 6 months old. I was feeding him. I had a stiff neck and my arms and legs ached real bad. All down my back was really stiff. I had a hard time holding my brother, but I did because it was my job. I just hurt so bad. When my mother got home, she called the doctor. She knew.

"I walked up the steps to the doctor and I never climbed stairs again regularly. I never walked again without help."

Fasseel had seven brothers and a sister. One