

Polio Perspective

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Up to 20 million polio survivors around the world face the threat of new disabilities 15 to 40 years after their original illness, which could leave them using wheelchairs or ventilators for the rest of their lives, says a new report from the March of Dimes.

A major problem confronting millions of polio survivors is that too few doctors, in both industrial and developing countries, recognize this slow moving and little understood secondary illness, called post-polio syndrome (PPS). The main symptoms of PPS are new progressive muscle weakness that gradually worsens, together with severe fatigue and pain in muscles and joints. It is often accompanied by decreased muscle endurance during activities.

No cure exists for PPS. Doctors advise patients to curtail physical activities and take rest periods during the day, including during working hours. Many doctors also advise more severely affected patients to use wheelchairs part-time or full-time, even if they can walk without them.

As many as 40 percent of polio survivors may get PPS, according to some estimates. The March of Dimes, a nonprofit agency founded by U.S. President Franklin D. Roosevelt, who was a polio survivor, now is alerting medical systems around the world to PPS with its new report, *Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care*. It is also releasing a second report to assist people with PPS: *Guidelines for People Who Have Had Polio*.

As many as 250,000 U.S. polio survivors may have PPS, the March of Dimes says. Some 40,000 polio survivors have PPS in Germany, 30,000 in Japan, 24,000 in France, 16,000 in Australia, 12,000 in Canada and 12,000 in the United Kingdom, according to local polio support groups and doctors. The World Health Organization estimates that 10 to 20 million polio survivors are alive worldwide, and some estimates suggest that 4 to 8 million of them may get PPS.

"In developing countries, where polio outbreaks still occur or have ended much more recently, medical systems will be facing PPS for decades into the future and have little knowledge or understanding of it," says Christopher P. Howson, Ph.D., director of Global Programs for the March of Dimes. "Even in advanced countries, and this includes the United States, many doctors are not trained to recognize PPS or are reluctant to treat it as a new condition."

Grassroots groups of polio survivors in North America, Western Europe, Japan, Australia and New Zealand have been the main advocates for increased medical and government attention to post-polio syndrome.

"The situation is less clear in developing countries, where the syndrome is even less recognized," says Dr. Howson. "Perhaps PPS is underreported because health care providers are not recognizing it. Or perhaps people who are more at risk of PPS in developing countries tend to die before they reach the age of recognized disease onset. Also, PPS seems to be more common and severe in people who have successfully rehabilitated themselves from the initial polio attack. Perhaps a lower percentage of people in developing countries have had the opportunity for rehabilitation and, thus haven't put themselves at additional risk of PPS."

More than 40 years ago, the March of Dimes completed its original mission to combat epidemic polio by supporting the development and widespread use of two effective vaccines, one by Dr. Jonas Salk and one by Dr. Albert Sabin. Today, the March of Dimes works to improve the health of mothers and babies, but it has not forgotten its historic legacy.

Two Survivors' Stories

Lucile Harford, an American, and Zohra Rajah of Mauritius are two polio survivors from different regions of the world whose history with PPS is similar to many with this little-understood condition.

Lucile Harford, now 88 years old and retired in Florida, contracted polio (then called "infantile paralysis") in 1925 in her hometown of Geneva, New York, when she was 12 years old. A large red quarantine sign was placed on her front door, causing her nearly as much fright as the disease, and making the days and nights lonely for her, since no one wanted to go near her. Lucile's arms, legs and back were paralyzed. It was two years before she could return to school.

"I couldn't walk, I couldn't use my arms," she says. "I couldn't even sit up. It was a very painful disease, too. No physical therapy was available, like there is now. I was treated at home. My doctor didn't have a clue how to help me."

"The emphasis was to get me to walk again," she says. "That perhaps was a poor judgment call. I walked before my hips and knees were strong enough, causing irreparable damage. I have never since been able to climb steps without holding onto the railing or rise easily from a chair."

Mrs. Harford finally regained full use of her arms and back, and could walk with a cane. She graduated from college, had a successful career and a happy marriage.

Feeling the stigma of polio-caused disability, she seldom spoke of her limitations or acknowledged that she had had polio. During the 1950s, when the polio epidemics were at their peak, she suffered new difficulty in walking and fatigue that her doctors assured her had nothing to do with polio. Reading of post-polio syndrome, she tried to interest her doctors in the disorder. "To this day," she says, "it is difficult to find a doctor who will say there is such a thing as PPS."

"It got slowly worse," she says. "Not overnight, but over months, years. It was very frustrating. I went from using one cane to two canes, then a walker, and finally fulltime to a wheelchair."

Mrs. Harford can still walk short distances, but uses a wheelchair most of the time now. She says that even though she cannot regain her muscle strength, she is glad that attention to PPS is growing. "Just hearing that the March of Dimes and medical experts are holding conferences on PPS tells me that people really care," she says. "Even though there may not be a cure for PPS, just knowing that there are those looking for a cure is a boon to all of us with this condition."

Zohra Rajah says she always lived an active life, despite the polio she had as a child in 1945. "In 1985, I started having new problems -- extreme fatigue and pain, especially in the back. I visited three different doctors here in Mauritius and they all said I was just getting old," she says. In California during a family visit, she saw doctors who diagnosed her with PPS. She later founded a PPS support group in Mauritius, which now has 75 members. "I mostly treat myself, using what I learn from books, magazines and the Internet, because doctors here just do not recognize PPS," Mrs. Rajah says.

"The problems of these two women are consistent with what many polio survivors experience when they develop PPS," says Dr. Howson. "The most distressing psychological aspect for people with PPS is the unexpected change in their health status, and this is magnified when they can't find a doctor who will help them or even acknowledge that they have a new condition."

"Some people with PPS go from independent breathing to needing a ventilator. Others go from walking unaided, to walking with the assistance of a cane, to using a wheelchair. Both of these pieces of equipment may improve the quality of life of the individual," says Kristian Borg, M.D., Ph.D., a neurologist who heads Huddinge University Hospital in Stockholm, Sweden.

What Causes PPS?

"The causes of PPS are not thoroughly understood," says Lewis P. Rowland, M.D., professor of neurology at Columbia University College of Physicians and Surgeons in New York City and chairman of the March of Dimes Steering Committee on Post-Polio Syndrome.

"In the initial acute polio episode, patients can lose up to 60 or 70 percent of their motor nerve cells. The surviving nerve cells find muscle fibers that still work and attach to them, restoring function. After 15 to 40 years," Dr. Rowland says, "the ability to maintain function seems to be lost, but no one is certain why this happens."

The most widely accepted hypothesis is that PPS results from a degeneration of motor nerves that sprouted new connections years earlier to make up for other nerves killed by polio. Because the surviving motor nerves have been supplying many more muscle fibers than nature intended, they may wear out prematurely.

The normal aging process and the overuse or disuse of muscles may be contributing factors in development of PPS.

"We are having difficulty in alerting the world medical community to the problems of PPS," says Dr. Rowland. "The problem will go on much longer in other countries, especially in the developing world, so it is important that people learn about PPS. Most doctors in their 40s or younger in developed countries have never seen a case of polio, or recognized a case of PPS."

The March of Dimes Steering Committee found that medical knowledge and commitment to treating PPS varies widely in industrial countries, while knowledge is much lower in the developing world.

United States

PPS first came to wide attention in the medical community during the 1980s -- three decades after the worst polio epidemics in the United States, which struck more than 50,000 people in 1952 alone. Up to 250,000 U.S. polio survivors may have PPS, the March of Dimes says.

"After the vaccines came out, the medical profession and the public in general all thought polio was over with," says Lauro Halstead, M.D., of the National Rehabilitation Hospital in Washington, D.C. and a member of the March of Dimes Steering Committee. Dr. Halstead was struck with polio as a college student in the 1950s. The disease temporarily paralyzed his right arm and put him in an iron lung and then a wheel chair.

"I made a good recovery, finished college and medical school," Dr. Halstead says. "But I began experiencing new weakness in the early 1980s. Doctors had no idea what I had, with some suggesting multiple sclerosis and others, Lou Gehrig's disease. I think a million dollars was spent on tests, but doctors just couldn't figure it out. I had new weakness in my legs and very intense muscle pain that was reminiscent of the pain I had with polio. I began to wonder if it was connected." When he met David Wiechers, M.D., who was studying polio, the pieces of the puzzle came together. Dr. Halstead was diagnosed with PPS.

In 1999, in response to requests from a growing number of physicians and polio survivors, the March of Dimes convened an international steering committee of experts chaired by Dr. Rowland. The committee was charged with addressing an issue of critical importance: the need for improved knowledge among health care providers and polio survivors of the best practices in diagnosis and care for PPS. This steering committee drafted the two reports released today by the March of Dimes.

"These reports represent the collective wisdom from post-polio syndrome research and experienced clinicians," says Joan Headley, executive director of the International Polio Network. "The information contained in them is invaluable. Individuals and professionals who have read confusing and conflicting information about PPS will find these reports clarifying."

STEM CELL THERAPY NOT FOR POLIO SURVIVORS

Dr. Richard L. Bruno, Chairperson
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Stem cells are remarkable, embryonic "baby cells" that will grow up to be any kind of cell that the body makes. With all the excitement about stem cells curing spinal cord injury, many polio survivors are asking if stem cells could cure PPS, or even reverse the damage caused by polio itself.

The hope with SCI is that stem cells, injected into the spinal cord, would "bridge the gap" in cut spinal cord axons, which are like long telephone wires that connect brain motor neurons to spinal cord motor neurons and allow the brain to "tell" muscles to move again. This notion requires intact motor neurons below the cut in the cord. And here lies the problem with stem cells "curing" polio or PPS. Even in "mild" cases, the poliovirus killed off least 50% of neurons throughout the spinal cord. Stem cells injected into a polio survivor's spinal cord would not have to just bridge a gap, but have to become new, functioning motor neurons.

What's more, those new neurons would have to send out their own axons to find and activate the specific muscles that were paralyzed when the original axons disappeared 50+ years ago after poliovirus-infected neurons died, by burrowing inches, or in the case of the leg three feet, through the tissues inside the arms and legs.

Finally, the brain's motor neurons would have to send out new axons as well, since the brain's neurons and axons also died. These axons would have to burrow through the entire brain, the brain stem and down through spinal cord to get to the newly-implanted motor neurons, indeed a tremendous tunneling task!

So, the idea of rebuilding a polio-damaged spinal cord would require a "hat trick" of creating new brain and spinal motor neurons, new axons tunneling from the brain to the spinal cord and from the spinal cord to the muscles. Reconnecting a lesioned spinal cord would "only" require the physiological "goal" of bridging the gap between cut axons.

Yes, a possible use for stem cells would be to inject them into the brain, as is done in Parkinson's disease (PD) patients, where they could produce the main brain activating neurochemical, dopamine, which is decreased in polio survivors and causes post-polio fatigue. But, such injections are not widely accepted even in PD patients yet.

So, if stem cells aren't the answer, is there anything polio survivors can do to help their remaining poliovirus-damaged neurons? Recently, there has been research on "neuroprotective" drugs, medications that protect neurons' innards from overuse-abuse that causes post-polio symptoms. Several studies have focused on degenerative diseases, such as Parkinson's and Huntington's diseases, which involve damaged dopamine neurons. Minocycline, a common antibiotic used to kill a variety of bacteria, and creatine, which helps, to provide energy to muscle cells, have been given to PD patients, who showed a less rapid a decline in function compared to those taking a placebo. However, a study comparing creatine and placebo in 60 PD patients found that, while their mood improved and their need for medication decreased, their symptoms did not lessen.

Vitamin E has been found in eight studies to have some neuroprotective effect in PD, while vitamin C and beta carotene were not helpful. Some research even links coffee's ability to limit blood vessels from opening to protecting neurons against PD, with one cup a day cutting the risk of developing PD by as much as fifty percent. Another dietary supplement, coenzyme Q-10, is being tested to see if it protects PD patients' neurons.

Huntington's Disease patients have also benefited from potential neuroprotectives. Huntington's patients given minocycline had slower progression or no decrease in physical ability, thinking and memory. Creatine had similar beneficial results in HD.

Should polio survivors take minocycline, creatine and Vitamin E, or order a Starbucks' grande, three-

shot cappuccino to prevent post-polio brain fatigue? Not yet. There aren't enough studies to prove that any of these is truly neuroprotective in Parkinson's or Huntington's disease, let alone helpful for polio survivors, in which these substances haven't been studied at all.

Double-blind, placebo-controlled studies of potential neuroprotectives are warranted in polio survivors. For now, the only neuroprotective that we know works in polio survivors is "The Golden Rule:" If anything causes fatigue, weakness or pain, DON'T DO IT! (Or do less of it.)

One 'Flu Over *by Millie Malone Lill*

This has been a very bad winter for the 'flu. Or maybe it's been a great year for the 'flu but much less wonderful for its victims. One couple in my building spent weeks in the hospital and in rehab after contracting the Real 'Flu...Influenza A. We were all told that if we started coughing or ran a fever or had any of the other 'flu-like systems, to see a doctor. My brother's girlfriend mentioned during a phone call that Jerry had been coughing all night. I insisted he go right to the doctor and be checked. It was not at my suggestion that the doctor did a nasal swab on him. I want that perfectly clear...not my idea at all.

I, of course, never get sick so I assumed, as I usually do, that the rules were meant for the rest of you. Not for me. I never get sick, remember?

Fast forward to Sunday morning, January 25. I coughed myself awake and looked around for the freight train that had obviously run over me, backed up and did it again. My head was pounding, someone had taken all my bones out and rapped them on some cement till they were misshapen and reinserted them in the wrong spots. While they were at it, they sandpapered my eyeballs to a glossy sheen. I staggered to the bathroom and found some Aleve, took two and went back to bed. This exercise repeated itself on Monday, Tuesday, and Wednesday. By Wednesday afternoon, I could be up for short periods, but my legs were very wobbly. (I know, at my age, everything is pretty wobbly, be nice to me, I'm sick.) By Thursday, I could be up, but I was either freezing or sweating. Sometimes both at the same time. Every small effort brought forth buckets of sweat.

Knowing I couldn't do anything requiring much effort, I decided to start working on this issue of Polio Perspective. When just sitting in my chair thinking caused perspiration to sluice off my face and hair, forming a small lagoon under my desk, I decided maybe I should go to the doctor. My son Jim took my keys, loaded my chair and my sweaty, clammy self into the van and we were off.

I may as well confess right now that I lied to my doctor's nurse. Yes, I did, mea culpa. I came into the office in my power chair because my son Jim is wonderful but expecting him to carry me would be asking too much. So, the nurse, seeing the power chair, assumed I could not walk. She led me past the scales, only hesitating a minute while asking if I thought I could stand long enough to get weighed. I probably could have, but this looked like a great opportunity to skip that part of the torture, so I said No. With a straight face. My doctor and I have already hashed the weight thing out. The first time I ever saw him, I started out by saying that I know I'm overweight but that as a polio survivor, exercise was not exactly recommended, so let's just work on the stuff that can be fixed. We reached an understanding that I'd never had with a doctor before.

The sweet little nurse took my blood pressure which was surprisingly lower than normal for me and left the room. My doctor came in, checked my ears, my throat, listened to my lungs and said that he could do a nasal swab but didn't think it was necessary. (Ha ha, Jerry. Also neener neener.) The doctor said I probably didn't have that serious Influenza A, but I did have Parainfluenza. My understanding is that this form of 'flu is sort of the knockoff WalMart version of the real 'flu. Very fitting for this woman who always shops the clearance racks. Oh, I didn't feel I'd been cheated by getting this cheaper version of the illness. It didn't have all the bells and whistles of Influenza A, lacking the high fever component as well as the pneumonia attachment, but it had lots of coughing, sneezing, wobbliness...all your main features without which it would not dare to call itself even a knockoff type 'flu.

I was also told that even though I'd already been sick for most of a week, I still had at least a week of this nonsense left. Tylenol, rest, lots of fluids. Thank goodness for Meals on Wheels so I get at least one good well balanced meal a day.

If only this 'flu caused weight loss. Wouldn't that be great? But no, that never happens for me. But it is a great excuse to pamper myself, loll around in my jammies, have the grandkids wait on me a little bit. Life could be worse. Meanwhile, I hope the rest of you stay well. If you feel you must have the 'flu, I'd say go for the kind I got. You don't need all the attachments that come with Influenza A. Trust me.

WEB CORNER

107 Children Struck by Polio-Like Illness

<http://www.wfaa.com/story/news/health/2015/01/28/107-children-stricken-by-mysterious-polio-like-illness/22506265/>

Disabilities and gadgets:

http://disabilityhorizons.com/2015/01/disability-gadgets-using-technology-accessibility/?fb_ref=Default&fb_source=message

One copy of PHI newsletter is free, and here's where you can get it:

<http://www.post-polio.org/edu/pphnews/topic1.html>

Online program aims to help women with mobility limitations to lose weight:

<http://momentumblog.bcm.edu/2015/01/20/online-program-aims-to-aid-in-weight-loss-for-women-with-physical-limitations/>

A list of drugs for polio survivors to avoid:

<http://members.upnaway.com/~poliowa/alerts.html>

Why The Theory of Everything is a disappointing depiction of disabilities

http://www.slate.com/blogs/browbeat/2015/01/20/the_theory_of_everything_and_disability_why_eddie_redmayne_shouldn_t_get.html?wpsrc=fol_fb

Doctors' ignorance gets in the way of treating the disabled

<http://www.npr.org/blogs/health/2014/05/17/313015089/doctors-ignorance-stands-in-the-way-of-care-for-the-disabled/>

Developing a Personal Philosophy about disabilities:

<http://www.polioplace.org/personal-philosophy-disability>

President of India launches Polio immunization program:

<http://post.jagran.com/president-launches-polio-immunization-programme-1421487978>

My day with my mother's right hand:

<http://mydaywith.com/2011/04/02/mothershand/>

A LITTLE BIT OF HUMOR

Pauly went to the doctor, because he had developed a nasty, persistent cough from being outside battling the snowstorms for so long. "Doctor, you've *[hack, hack]* just got to help*[hack, hack]* me. I cough *[hack, hack] *and I cough and*[hack, hack]* I cough. Just *[hack, hack]* incessantly! I cannot*[hack, hack]* stop coughing."

"But, my dear Mr. Pauly," said the doctor. "People who cough as you do never go to see the doctor!"

"And*[hack, hack]* where do they *[hack, hack]* go?" asked Pauly?

"They go to the theatre, to concerts, to the opera...."