

For Your Consideration: Guidance on Evaluating the Last Twenty Years

Sandra Hughes Grinnell has researched polio and PPS since 1984. She has a BA degree from the University of California, Santa Barbara, with a major in Sociology and a minor in Psychology with emphasis on Behavior Modification.

Sandra wrote a two part article entitled "A Post Polio Normal's Reconciliation with the Ghost of Polio Past" that was published in the Fall of 1989, Vol. 5, No. 4 and the Winter 1990, Vol. 6, No. 1, editions of Polio Network News. Then two years later, she wrote another two part article entitled "A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment for Polio Individuals in the 1990's". It was published in the Summer 1991, Vol. 7, No. 3 and Fall 1991, Vol. 7, No. 4 edition of Polio Network News.

*Now, after almost 20 years, Sandra decided that the latest April, 2008 National Institutes of Health Update on PPS provided a unique format in which to update information as to how she has dealt with PPS over the years leading up to the present. She has inserted her personal narrative *in blue print* though out the body of the NIH article itself. Her goal in sharing her own experiences with PPS in written form at PHI over the years has been and continues to be to help others better evaluate their own condition and get the help they need.*

The website for viewing the NIH 2008 Post Polio Update without Sandra's narrative is http://www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm

We at PHI would be very interested to know how others have progressed over the years, so at the end of the NIH 2008 Update with Sandra's commentary inserted, Sandra has included 4 multi-part questions that can serve as guidance for others who might be interested in evaluating their last 20 years. PHI invites you to send your comments and insights that result from your personal assessment.

Sandra can be contacted with any questions or comments by emailing info@post-polio.org. Please put "Grinnell" in the memo line.

My Last Twenty Years **Sandra Hughes Grinnell**

The late Dr. Frederick Robbins of Harvard had been President of NIH in 1984 when I was trying unsuccessfully to get my old polio medical records. He along with Drs. Enders and Weller had won the Nobel Prize for isolating the polio virus in monkeys which lead to the Salk vaccine in 1955. In 1953, he had been one of the Doctors heading up the Polio Unit at Metropolitan General Hospital in Cleveland, Ohio where I had been admitted with an acute case of Polio. Therefore, in 1984, after having been told by the hospital records dept. that my file was no longer available, I wrote to Dr. Robbins for confirmation of that fact. His response was that my records should still be available and gave me the name of a Doctor he worked with at the hospital in 1953 who was still there in 1984 to write to. Within two weeks my original polio medical records arrived in the mail.

In the ensuing months, he also took new interest in my case to the point of allowing me to use part of his ongoing correspondence to me to use for my

article about Post-Polio Syndrome in 1989. In the introduction he stated: "I enjoyed reading your article. Most of us were taken by surprise when the syndrome began to appear. We did recognize that some people might have weakness resulting in scoliosis but in those people who seemed to be perfectly normal, we did not anticipate any further difficulty. In retrospect, you are probably correct that people, who had recovered, apparently completely, should be followed, and their areas of weakness identified and, as you say, protected."

When Dr. Robbins left NIH, he became Professor Emeritus in the Dept. of Epidemiology and Biostatistics at Case Western Reserve in Cleveland, Ohio. In the early 1990's I had a chance to meet with him at his office while in Cleveland visiting my parents. It was an opportunity to personally thank him for his interest in my case and lending his prestigious name to my article which was published internationally and therefore helped many other people get the recognition they may have needed to get good medical care and attention.

He passed away a few years ago. I am sure he would be saddened to see in this report from NIH that many research questions still remain unanswered with no useful medications having been developed to alleviate the most troubling symptoms of PPS, let alone to stop the slowly progressive nature of PPS.

POST-POLIO SYNDROME

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http://www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm

What is post-polio syndrome?

Post-polio syndrome (PPS) is a condition that affects polio survivors years after recovery from an initial acute attack of the poliomyelitis virus. PPS is mainly characterized by new weakening in muscles that were previously affected by the polio infection and in muscles that seemingly were unaffected. Symptoms include slowly progressive muscle weakness, unaccustomed fatigue (both generalized and muscular), and, at times, muscle atrophy. **I have some muscle atrophy in mid-thoracic trapezius muscles that were initially damaged by polio.** Pain from joint degeneration and increasing skeletal deformities such as

scoliosis are common. [No problems with joints or skeletal deformities](#). Some patients experience only minor symptoms. While less common, others may develop visible muscle atrophy, or wasting.

PPS is rarely life-threatening. However, untreated respiratory muscle weakness can result in under ventilation, and weakness in swallowing muscles can result in aspiration pneumonia. The severity of residual weakness and disability after acute poliomyelitis tends to predict the development of PPS. Patients who had minimal symptoms from the original illness will most likely experience only mild PPS symptoms. People originally hit hard by the poliovirus and who attained a greater recovery may develop a more severe case of PPS with a greater loss of muscle function and more severe fatigue. It should be noted that many polio survivors were too young to remember the severity of their original illness and that accurate memory fades over time. [My hospital records, and especially my parents recollection of events, documented that I was admitted to the hospital in 1953 with bulbar \(upper respiratory/spinal\) involvement. The hospital prognosis based on my symptoms was that the first 24 hours were critical. It was a wait and see situation as to whether I would end up in an iron lung, or if I were one of the very lucky ones, turn things around. I was in isolation so my parents could not visit me. They spent that first night in a church near by, praying for my complete recovery.](#)

[My recovery indeed, after two weeks in isolation, appeared so complete that upon release from the hospital, one of the assistant doctors on staff downgraded the diagnosis from bulbar to non-paralytic polio. In more recent years, however, based upon observation and evaluation of my late emerging symptoms of PPS in 1984, Dr. Jacqueline Perry, \(renowned polio specialist located in So. California\), documented in a follow up letter to me regarding my hospital records: "the absence of arm and leg involvement led to the inappropriate diagnosis of non-paralytic poliomyelitis. Bulbar patients did recover. In fact, the more appropriate diagnosis would be bulbar-spinal polio to identify scattered involvement." Dr. Perry also wrote in another letter on my behalf upon reviewing my case history: "her initial symptoms indicated bulbar involvement \(difficulty swallowing and speaking and impaired gag reflex\)...less conspicuous was the weakness in her upper trunk and hamstring tightness, yet she received physical therapy for months and did not return to school for a year." The recommendation of Dr. Perry's in 1984 was "to minimize further loss by avoiding strain on her impaired muscles." Therefore, starting in 1984, all work or volunteer activity has been limited to part time hours and not involving consecutive days of prolonged repetitious activity. Pacing became then and continues, even more so today, to be critical to slowing down the progression as I age.](#)

According to estimates by the National Center for Health Statistics, more than 440,000 polio survivors in the United States may be at risk for PPS. Researchers are unable to establish a firm prevalence rate, but they estimate that the condition affects 25 percent to 50 percent of these survivors, or possibly as many

as 60 percent, depending on how the disorder is defined and which study is quoted.

Patients diagnosed with PPS sometimes are concerned that they are having polio again and are contagious to others. Studies have shown that this does not happen.

What causes PPS

The cause is unknown. However, the new weakness of PPS appears to be related to the degeneration of individual nerve terminals in the motor units that remain after the initial illness. A motor unit is a nerve cell (or neuron) and the muscle fibers it activates. The poliovirus attacks specific neurons in the brainstem and the anterior horn cells of the spinal cord. In an effort to compensate for the loss of these neurons, ones that survive sprout new nerve terminals to the orphaned muscle fibers. The result is some recovery of movement and enlarged motor units.

Years of high use of these enlarged motor units adds stress to the neuronal cell body, which then may not be able to maintain the metabolic demands of all the new sprouts, resulting in the slow deterioration of motor units. Restoration of nerve function may occur in some fibers a second time, but eventually nerve terminals malfunction and permanent weakness occurs. This hypothesis is consistent with PPS's slow, stepwise, unpredictable course.

In a quote from an article in the December 1997 Rancho Los Amigos Post-Polio Support Group Newsletter entitled "Ask Dr. Perry," Dr. Perry explained that "if you lose the nerve, you lose the muscle. We talk about problems of muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells." Now, for me in 2009, at age 66, it makes pacing and setting consistent parameters critical to maintaining my current levels of stability for as long as possible.

Dr. Julie Silver, a physiatrist and past director of The International Rehabilitation Center for Polio in Farmington, MA, offers a great illustration regarding the issue of rate of loss of reserve strength in post-polio patients in her 2001 book entitled "Post-Polio Syndrome-A Guide for Polio Survivors & Their Families."

Quoting Dr. Silver, "A loss of reserve strength from the initial polio illness is a confounding variable in how polio survivors' strength is maintained as they age. Here is the example I often use:

"A certain threshold of strength is needed to do any given activity. Imagine that it takes 30 percent of your total arm strength to lift a gallon of milk. This means that 30 percent is the threshold of strength your arm needs to be able to lift the milk; if your strength falls below that mark, you are unable to lift the milk. If you had polio

and lost 50 percent of your strength, this is still an easy task to accomplish. After all, you only need 30 percent, so you have 20 percent in reserve. But suppose through normal aging, disuse, overuse, and perhaps some other factors, you lose 1 to 2 percent of your arm strength per year. If you are gauging your arm strength by how easily you can lift a gallon of milk, you might not even notice this subtle loss of strength for many years.

“However, when the amount of strength you have lost (from polio and other factors) start to get close to 20 percent; you will likely notice that lifting a gallon of milk is becoming more difficult. And if one year you are at 30 percent and the next year you drop to 29 percent, you will go from being able to lift the milk to not being able to do it. This is the ‘all of the sudden’ phenomenon because polio survivors tell me that all of the sudden they cannot perform a particular activity. In fact, this loss of strength is not sudden (it occurs over years), but the inability to do the task frequently does occur all of the sudden. This reserve strength is something we all count on to sustain us as we age. In polio survivors, it is often markedly diminished and contributes to increasing disability that may present without much warning.”

Through years of studies, scientists at the National Institute of Neurological Disorders and Stroke and at other institutions have shown that the weakness of PPS is a very slowly progressing condition marked by periods of stability followed by new declines in the ability to carry out usual daily activities. Now in hindsight, this is exactly the course my own case has taken. As documented in my first article published in 1989, I had, back in 1984, been attending a very moderately paced exercise class in a swimming pool 3 days a week. (I had signed up for the class due to frustration with having found golf, tennis and general exercise I had participated in over the years and enjoyed so much, becoming more and more difficult to pursue. All my friends my age were continuing to increase endurance and skill, not lose it!! (This was an age group of people in their late 30's and early 40's!)

So, in 1984, in this exercise class I enrolled in, I was attempting to tone and condition my upper body. The first week things went well but by the second week I started losing stamina and strength instead of the other way around. I was forced to quit entirely with symptoms including labored breathing, swelling and severe cramping of upper spine and neck muscles, with throat muscle fatigue. Symptoms also radiated into the arms and hands impacting their normal function. These symptoms required complete bed rest for the better part of 2-3 days to recover normal function. A local M.D. who knew I had polio as a child, happened to have read an article at the local hospital library about late effects of polio just starting to be reported around the country sounding a lot like mine. This information led to my referral to be evaluated by Dr. Jacqueline Perry at Rancho Los Amigos later that year.

Now in 2009, looking back in hindsight, I found myself, gradually over a 20 year period, in 2004 experiencing the start of all the same kinds of symptoms if I could not rest, as had become so incapacitating after a couple weeks of the swim class in 1984, just as described by NIH in this 2008 article of PPS inherently involving slow progression with periods of stability and then further subtle declines. But now they were happening almost daily, and not after a week or two like in 1984, but after just 3-4 hours a day of activities involving a good deal of sitting and/or standing!! This further loss of stamina was discouraging because I had pretty consistently been active and exercising well within parameters deemed safe for me to pursue since 1984 balanced with supine rest as needed. Now in 2009, I find it takes all of my ingenuity and effort to keep up my stamina and maintain my reserves to continue to enjoy my daily life right here at home to the fullest for as many years as I can with no further loss of function. Now with normal aging issues on top of already accelerated aging going on for so long, it makes wise, realistic decisions of what to pursue and not to pursue more important than ever.

Again quoting Dr. Julie Silver regarding the labored breathing problem I experience with overuse: "In individuals who have normal lungs and respiratory muscles, the age-related changes in respiratory function are hardly noticeable. Unfortunately polio survivors often have significantly less reserve strength owing to initial polio. When bulbar nerves were destroyed in those with bulbar involvement initially, the muscles of the throat are weakened. In cases of bulbar-spinal polio, involvement of the upper part of the spinal cord weakened key auxiliary breathing muscles in the diaphragm and chest musculature."

Since 1984 with gradually shorter parameters over the years leading up to the present in 2009, when I have used up my reserves in any given day and my breathing becomes somewhat labored; my chest muscles begin to tire, forcing me to hold my spine more and more rigidly in an attempt to remain sitting or standing. (NOTE: Interestingly, my parents remembered that before having polio my spine was very flexible but after polio, I had lost that flexibility in my spine.) Getting back to 2009, if unable to lie down and rest, arm and hand function are impacted with muscles swelling in upper back close to the spine with intense burning and cramping making mental concentration very difficult. Physical activity then has to be curtailed alternately applying heat and cold packs and with supine (lying down) rest until I regain my reserves to resume normalcy within my current parameters of strength.

How is PPS diagnosed?

Physicians arrive at a diagnosis of PPS by completing a comprehensive medical history and neuromuscular examination and by excluding other disorders that could explain the symptoms. Researchers and physicians typically use the following criteria to establish a diagnosis:

Criteria for diagnosis of post-polio syndrome*

Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neuromuscular examination, and signs of nerve damage on electromyography (EMG). Rarely, persons have sub clinical paralytic polio, described as a loss of motor neurons during acute polio but with no obvious deficit. That prior polio now needs to be confirmed with an EMG. Also, a reported history of non-paralytic polio may be inaccurate.

A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neuromuscular function.

Gradual onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. Onset may at times follow trauma, surgery, or a period of inactivity, and can appear to be sudden. Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.

Symptoms that persist for at least a year.

Exclusion of other neuromuscular, medical, and orthopedic problems as causes of symptoms.

Modified from: *Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care*. March of Dimes, 2001.

In 1985, I made arrangements to be tested for other neuromuscular conditions including antibody tests confirming the original classification of polio I had. The tests were coordinated by Dr. W. King Engel, renowned physician in the field of Neurology at The Hospital of the Good Samaritan in Los Angeles, CA. The antibody tests for polio virus strain 1 and 3 were positive for previous infection. Strain No. 3 was positive for non-paralytic but Strain No. 1 was also positive for bulbar-spinal, thereby proving Dr. Perry's assumption based solely on the kinds of symptoms I was having in 1984 alone, was correct. My records upon release from the hospital in 1953 should never have shown a downgrade and elimination of the initial bulbar polio diagnosis upon admission. Fortunately, all other neuromuscular conditions I was tested for in 1985 were ruled out.

PPS may be difficult to diagnose in some people because other medical conditions can complicate the evaluation. Depression, for example, also is associated with fatigue and can be misinterpreted as PPS or vice versa. Depression has never been even remotely a problem for me....anxiety at times in my life, but never depression. For this reason, some clinicians use less restrictive diagnostic criteria, while others prefer to categorize new problems as the late effects of polio-- for example, shoulder osteoarthritis from walking with crutches,

a chronic rotator cuff tear leading to pain and disuse weakness, or breathing insufficiency due to progressive scoliosis. Fortunately, I have no additional medical conditions and require no daily medications on an ongoing basis of any kind. By eating a very healthy diet, doing daily stretching exercises and being active within my safe parameters of activity, my goal is to avoid any serious secondary illness to further erode my stamina levels for as long as possible. Obviously with aging, at some point I will be dealing with some secondary issues so I will continue to do all that I can to prolong that inevitability for as long as possible.

Polio survivors with PPS symptoms need to visit a physician trained in neuromuscular disorders to clearly establish potential causes for declining strength and to assess progression of weakness not explained by other health problems.

Physicians may use magnetic resonance imaging (MRI), computed tomography (CT), neuroimaging, and electrophysiological studies as tools to investigate the course of decline in muscle strength. Less commonly, they will conduct a muscle biopsy or a spinal fluid analysis. These tests are also important to exclude other, possibly treatable, conditions that mimic PPS, but the tests do not identify survivors at greatest risk for new progression of muscle weakness.

It is important to remember that polio survivors may acquire other illnesses and should always have regular check-ups and preventive diagnostic tests, such as mammograms, pap smears, and colorectal exams.

How is PPS treated?

There are currently no effective pharmaceutical or specific treatments for the syndrome itself. However, a number of controlled studies have demonstrated that non fatiguing exercises can improve muscle strength. Quoting Dr. Lauro Halstead, Director of the Post-polio Program, National Rehabilitation Hospital, Washington, D.C, in the Foreword to Dr. Silver's 2001 book "Post-Polio Syndrome": "While numerous treatments have been proposed, definitive therapies for most problems are unlikely for years to come". Part of the problem according to Dr. Halstead was the way polio historically was perceived and helps to explain why no effective treatments are on the horizon even now in 2009. Again, in 2001, he went on to say, "Unlike the rest of the world the history of polio in the United States is packed into a span of only 39 years beginning with the first epidemic in 1916 in New York City and ending in 1955 with the announcement that the Salk vaccine was effective. Only when thousands of people experiencing late effects of polio started to attract the attention of the medical community in the early 1980's was the term Post-polio Syndrome coined. It really is not a new disorder at all. It was first described in French medical literature in 1875 and over the next century approximately 35 reports of post-polio were reported around the world, but as often happens in medicine, they were forgotten. Possibly because

of the rapid and dramatic onset of symptoms, often followed by near miraculous recovery of function, polio was classified in medical textbooks as a static or stable neurological disease with no need for follow up care."

Researchers at the National Institutes of Health (NIH) have tried treating PPS patients with alpha-2 recombinant interferon, but the treatment proved ineffective. Another study in which PPS patients received high doses of prednisone demonstrated a mild improvement in their condition, but the results were not statistically significant. This, in addition to the drug's side effects, led researchers to recommend that prednisone not be used to treat PPS.

In an effort to reduce fatigue, increase strength, and improve quality of life in PPS patients, scientists conducted two controlled studies using low doses of the drug pyridostigmine (Mestinon). These studies showed that pyridostigmine is not helpful for PPS patients.

In another controlled study scientists concluded that the drug amantadine is not helpful in reducing fatigue. And other researchers recently evaluated the effectiveness of modafinil (Provigil) on reducing fatigue and found no benefit.

Preliminary studies indicate that intravenous immunoglobulin may reduce pain, increase quality of life, and improve strength. Research into its use is ongoing.

The future of PPS treatment may center on nerve growth factors. Since PPS may result from the degeneration of nerve sprouts, growth factors can target these and help to regenerate new ones. Unfortunately, one small study that NINDS scientists participated in showed that insulin-like growth factor (IGF-1), which can enhance the ability of motor neurons to sprout new branches and maintain existing branches, was not helpful.

It is quite disheartening to think absolutely nothing has proved effective to date, but there may be one ray of hope! Probably not in my lifetime and although not mentioned in the NIH article-- that hope comes from the Salk Institute in San Diego, California. They are doing stem cell therapy research for post-polio syndrome and in 2003 they stated in an article published by Post-Polio Health "many polio survivors have weak paraspinal and deep muscles that support the spine which can be very disabling. The spine is destabilized, resulting in impingement on adjacent nerves, which cause pain and new weakness. Because of their close proximity to the spinal cord, these muscles may be enervated by newly grafted motor neurons. These new ideas in remediation of post-polio syndrome should be considered in the context of stem cell therapy."

Although there is no cure, there are recommended management strategies. Seek medical advice from a physician experienced in treating neuromuscular disorders. Do not attribute all signs and symptoms to prior polio. Use judicious exercise, preferably under the supervision of an experienced professional. Use

recommended mobility aids, ventilatory equipment, and revised activities of daily living. Avoid activities that cause pain or fatigue that lasts more than 10 minutes. Pace daily activities to avoid rapid muscle tiring and total body exhaustion.

Learning about PPS is important for polio survivors and their families. Management of PPS can involve lifestyle changes. Support groups that encourage self-help, group participation, and positive action can be helpful. For some, individual or family counseling may be needed to adjust to the late effects of poliomyelitis, because experiencing new symptoms and using assistive devices may bring back distressing memories of the original illness.

What is the role of exercise in the treatment of PPS?

The symptoms of pain, weakness, and fatigue can result from the overuse and misuse of muscles and joints. These same symptoms can also result from disuse of muscles and joints. This fact has caused a misunderstanding about whether to encourage or discourage exercise for polio survivors or individuals who already have PPS. I had over \$5000 of ongoing physical therapy between April 1989 and May of 1991 by therapists using a reference textbook called "Muscle Testing and Function", 1983 edition by Florence Kendall, P.T. and Elizabeth Kendall McCreary, BA. My health insurance did cover most of the treatment costs due to physical therapists detailed documentation of the ongoing improvement of my condition over time. They argued, successfully, that the ongoing treatments could help to avoid much more expensive medical intervention, orthopedically, later on. It turned out that Florence Kendall, PT and her late husband, Henry Otis Kendall, PT, first co-authored this textbook in 1949 and 1971. After her husband died, later editions in 1983 and 1993 were co-authored by Florence and her sister-in-law, Elizabeth. It was the Kendall's extensive experiences working with muscle problems in polio patients initially that lead to writing this textbook which would have a profound impact on the entire physical therapy profession that we take for granted today. The Kendall's have been role models for countless PT's in the United States.

I had a chance to interview Florence Kendall over the phone at her home in Maryland several years ago. She told me that in 1938 at the request of Dr. James P. Leake, Surgeon General of the US Public Health Service, she and her husband wrote the US Public Health Bulletin #242, *Care During the Recovery Period of Paralytic Poliomyelitis*. She and her husband also taught body mechanics at The John Hopkins Hospital School of Nursing from 1943 to 1961. As a cover story in an issue of PT Magazine in the year 2000 about Florence Kendall pointed out, most people don't realize that the entire field of physical therapy as we know it today, owes most of its beginnings to the observations and care of polio patients during the epidemics of the 1940's and 50's. Most interestingly, the Kendall's physical therapy approach emphasizes that where there is muscle weakness there is opposing muscle tightness causing imbalance and pain.

The Kendall's great concern about muscle tightness in their textbooks regarding the general population was specifically cited by Dr. Thomas P. Anderson, Spaulding Rehabilitation Hospital, Boston, MA, to be very important in evaluating post-polio patients. He wrote in the Fall, 1990 issue, Vol. 6, No. 4 of the Polio Network News: "Many people feel that tightness plays a greater role in producing deformities after polio than weakness...the tightness that was present in acute polio tends to recur...many people including a lot of physicians tend to overlook this...and there is something that can be done about that. There is a phenomenon that occurs in polio where the weakness tends to be new. It occurs 30 years or more after the onset of polio and people know they were never that weak in that muscle before. An explanation is that the muscle may be antagonistic of the one that has tightness...in the management of the residuals of polio, we should remember to check for tightness and when present, institute correction". *In fact, Dr. Anderson lamented that the physical therapy exercises we had for tightness in the acute phase of polio should have been continued throughout our life time to protect us from recurrence of tightness as we aged.* He again wrote in the Fall, 1990 issue of *Polio Network News* that "many were told that they should be doing these every day for the rest of their lives. My guess is that very few people took this seriously and after awhile they forgot why they were doing the exercises. In addition, they were not getting any stronger and wondered, why exercise?" (Note: EVEN IF IT IS CURRENTLY TOO LATE FOR MANY AGING POLIO SURVIVORS TO TAKE ADVANTAGE OF DR. ANDERSON'S SUGGESTIONS, HIS ADVISE COULD AT THE VERY LEAST BE HELPFUL FOR THE YOUNGER SURVIVORS AROUND THE WORLD – THEREBY HOPEFULLY AVOIDING SOME POST-POLIO PROBLEMS.)

Also, with regard to muscles tightness and stretching, in 2001, in a chapter in Dr. Julie Silver's book "Post-Polio Syndrome--A Guide For Polio Survivors & Their Families," entitled "Exercise Essentials," she states that "muscles, tendons and ligaments have a tendency to contract or get shorter when not stretched regularly." She illustrates the importance of those types of problems being evaluated and corrected with physical therapy if possible to promote better flexibility and range of motion. Fortunately for me, the guidelines used as reference from the Kendall's textbook, to evaluate and treat me a few years after I was initially diagnosed with PPS in 1984 were very successful in restoring flexibility and lessening pain. And reading a copy of their textbook myself helped me to visualize my problems areas more clearly and make adjustments as necessary in all the years going forward.

I continue on a daily basis to do stretching and flexibility exercises every morning geared to my level of endurance so that I don't lose the benefits I gained during therapy 20 years ago. Over all these years, I have also continued on my own to get massages by properly trained therapists. *That has been a very important part of maintaining flexibility and alleviating painful tightening of muscle tissue due to unavoidable overuse at times.* So, again, looking back in hindsight, without my knowing it at the time, the Kendall's polio guidelines for therapy published by the U.S. Government in 1938 helped me return to normal function from acute polio in

1953. Then again, almost 35 years later in the late 1980's, the guidelines in their textbook "Muscle Testing and Function," 1983 edition, got me through the initial stages of PPS. And, not unlike my chance to thank Dr. Frederick Robbins personally for all his help in 1984, I was able to do the same with Florence Kendall directly the day I interviewed her over the phone in the year 2000. She was 90 years old and still holding part time office hours.

Exercise is safe and effective when carefully prescribed and monitored by experienced health professionals. Exercise is more likely to benefit those muscle groups that were least affected by polio. Cardiopulmonary endurance training is usually more effective than strengthening exercises. Heavy or intense resistive exercise and weight-lifting using polio-affected muscles may be counterproductive because they can further weaken rather than strengthen these muscles.

Exercise prescriptions should include:

the specific muscle groups to be included,

the specific muscle groups to be excluded, and

the type of exercise, together with frequency and duration.

Exercise should be reduced or discontinued if additional weakness, excessive fatigue, or unduly prolonged recovery time is noted by either the individual with PPS or the professional monitoring the exercise.

Can PPS be prevented?

Polio survivors often ask if there is a way to prevent PPS. Presently, no intervention has been found to stop the deterioration of surviving neurons. But physicians recommend that polio survivors get the proper amount of sleep, maintain a well-balanced diet, avoid unhealthy habits such as smoking and overeating, and follow an exercise program as discussed above. Proper lifestyle changes, the use of assistive devices, and taking certain anti-inflammatory medications may help some of the symptoms of PPS.

What research is being conducted?

Scientists are working on a variety of investigations that may one day help individuals with PPS. Some basic researchers are studying the behavior of motor neurons many years after a polio attack. Others are looking at the mechanisms of fatigue and are trying to discover the role played by the brain, spinal cord, peripheral nerves, the neuromuscular junction (the site where a nerve cell meets the muscle cell it helps activate), and the muscles.

Determining if there is an immunological link in PPS is also an area of intense interest. Researchers who discovered inflammation around motor neurons or muscles are trying to find out if this is due to an immunological response. This would seem to be important to determine because inflammation and swelling of deep muscle tissue in areas close to the spine certainly has been an ongoing and a most debilitating symptom in my own personal experience with PPS. NSAIDS like Aleve or Naprosyn are recommended but I have allergic reaction to them. Therefore if absolutely necessary, I do take Tylenol. Quoting from the Rancho Los Amigos Post-Polio Support Group, May 2000, Dr. Perry said in response to a question regarding treatment for muscle pain in PPS: "Pain is a sign of injury. The first reaction to injury is inflammation." She suggested NSAIDS but did not recommend any other pain medications because as she said "they mask the pain." She explained that when muscles fatigue too quickly our systems get overused. Where there is fatigue, there is pain which is an important signal to cut back on activity to minimize further damage to the muscles. This is why you don't want to constantly just "cover up" the pain. Her advice has served me well over the years. Her additional recommendations regarding use of either heat or ice massage for pain is most effective for me and has allowed me to use Tylenol very sparingly over the years.

Other investigators have discovered that fragments of the poliovirus, or mutated versions of it, are in the spinal fluid of some survivors. The significance of this finding is not known and more research is being done.

Where can I get more information?

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

Information also is available from the following organizations:

Post-Polio Health International
4207 Lindell Blvd., #110
St. Louis, MO 63108-2930
info@post-polio.org
<http://www.post-polio.org>
Tel: 314-534-0475
Fax: 314-534-5070

And

March of Dimes Foundation
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Tel: 914-428-7100 888-MODIMES (663-4637)
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Suggested Questions to help you assess your last 20 years.

1. Do you have visible residuals from acute polio? Did you have hospital records documenting that you had an acute case of polio? Were those documents helpful?
2. What type of evaluation did you have to determine a diagnosis of PPS? Did it include testing to rule out other neuromuscular conditions that could be causing your symptoms? Were the tests conclusive in your case?
3. Have you had any physical therapy or massage treatments over the years? Were you evaluated for muscle tightness as well as muscle weakness? If you do stretching exercises for tightness, are they passive (with therapist assisting you) or active (on your own) or a combination of active and passive stretching? Have you had significant and long lasting improvement in function and overall well being from this type of therapy?
4. Do you routinely do other types of therapy? If so, what are they? Have you had significant and long lasting improvement in function and overall well being from this type of therapy?
5. If it has been many years since you were diagnosed with PPS, in hindsight, what level or rate of progression have you experienced? Do you feel that you have had more periods of stability and much slower progression of symptoms by following standard PPS guidelines over many years?