PPS MEDICAL INSIGHTS, EVALUATIONS AND A PLAN OF ACTION THAT FOR ME, HAVE STOOD THE TEST OF TIME

Sandra Hughes Grinnell 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 editions of Polio Network News.

Then, in 2009, she 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. In the Networking Section of Post Polio Health International under 'What Works for Me' entitled "Guidance on Evaluating the Last Twenty Years", she inserted her personal narrative in blue print though out the body of the NIH article itself.

Currently, she has consolidated her thoughts for this essay in Polio Place focusing in hindsight on the internationally known medical professionals and concepts she feels have had the strongest and most long lasting impact on the quality of her life presently.

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. Therefore, Sandra has included 4 multi-part questions that can serve as guidance for others who might be interested in evaluating their PPS history. 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.

A brief history of my initial polio experience and circumstances leading to a most influential Doctor from my polio past helping me years later.

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 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." (In the 1990's I had a chance after Dr. Robbins left NIH to meet with him at his office at Case Western Reserve in Cleveland, Ohio where he was a professor emeritus and thank him for his advise and support in my efforts to help others with my articles.)

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.

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."

Diagnosis of PPS in 1984:

Around 1980 I began finding tasks requiring repetitive use of my upper body muscles more and more difficult to sustain and I had to give up hobbies like tennis and painting. Upon evaluation and diagnosis of PPS at Rancho Los Amigos in Downey, Ca. in 1984 the recommendation of Dr. Perry 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. (Dr. Perry was so kind to make time in her incredibly busy schedule to edit my early articles for PHI and always had some additional suggestions and advise that continue to serve me so well.)

Based on recommendations that 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, I followed through on further testing. I had already decided that because of the medical professionals I had been so fortunate to have involved in my polio and post polio care, I wanted to write articles helping others and for research purposes alone, ruling out other health issues was important for my credibility going forward.

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. I have some muscle atrophy in mid-thoracic trapezius muscles that were initially damaged by polio. No problems with joints or skeletal deformities**.**

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 2012, at age 69, it makes pacing and setting consistent parameters critical to maintaining my current levels of stability for as long as possible.

Best description of PPS progression I have ever read:

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.

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.”

Best explanation of labored breathing issue I have ever read:

Since 1984 with gradually shorter parameters over the years leading up to the present, 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.) 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.

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."

The 'Plan of Action' involving physical therapy and how the plan evolved that changed the course of PPS for me in an extremely positive way:

In 2008, NIH posed the question: 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 personally had 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. **Dr. Anderson 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?"

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 23 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.

Having said all that, I must conclude here in this essay that the advice on exercise in the 2008 NIH PPS report is very important to be incorporated into ANY plan involving physical therapy. My fervent hope is that based on my own personal PT experience, EVEN IF IT IS CURRENTLY TOO LATE FOR MANY AGING POLIO SURVIVORS TO TAKE ADVANTAGE OF DR. ANDERSON'S SUGGESTIONS THAT I OUTLINED IN MY OWN PHYSICAL THERAPY EXPERIENCE IN THIS ESSAY, HIS ADVISE ALONG WITH NIH GUIDELINES COULD AT THE VERY LEAST BE HELFPFUL FOR THE YOUNGER SURVIVORS AROUND THE WORLD – THEREBY HOPEFULLY AVOIDING SOME POST-POLIO PROBLEMS.)

The 2008 NIH PPS exercise guidelines are as follows:

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.

In conclusion, regarding pain management and my general overall health currently:

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 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 pain medication very sparingly.

Fortunately, I have no additional medical conditions requiring 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 further erosion of my stamina levels for as long as possible. Obviously with aging, at some point I will be dealing with some arthritis issues so I will continue to do all that I can to postpone those types of problems.

On behalf of PHI and myself, we hope you will take some time to answer these questions and let us know how you have fared over the years. Your answers may help others in ways you don't realize and how others respond may help you AND me!!

Suggested Questions to help you assess your past and current situation.

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?