

From Henry's Desk:

The Time Line of Polio and Post-Polio Syndrome

The Central Virginia Post-Polio Support Group was honored to have Dr. Lauro Halstead spend two days with us in mid September at our annual Retreat at Camp Easter Seal East in rural Caroline County, VA. Dr. Halstead is a polio survivor, physician and recognized expert on PPS. His PPS clinic is at the National Rehabilitation Hospital in Washington, D.C. He has written many articles about PPS and a book about living with PPS as well as being a frequent speaker around the country on various aspects of PPS. At the Retreat we all learned that Dr. Halstead has a keen wit and a good sense of humor. His spoken presentation to our group focused on his pilgrimage with PPS. He had a power point presentation in which he demonstrated his life adjustments in living with PPS. For example he uses a scooter at work, uses several pillows to get comfortable in his bed, takes a short nap daily in his office and has made many individually unique adjustments as have most of us.

He had created a graph for himself that charted over time the significant events that have occurred since he began having symptoms of PPS. This is a worthwhile endeavor for all of us to do. The typical pathogenesis of polio and PPS usually reads something like the following course. Most of us had acute polio before the development of the Salk vaccine in 1955, almost a half a century ago. After surviving acute polio we were left with varying degrees of muscle weakness and muscle strength. Some were fortunate enough to recover all of their muscle function and others had to use assistive devices such as braces, crutches, canes, wheelchairs and in some cases, iron lungs. Most of us had thirty to forty years of stable functioning before the onset of Post-Polio Syndrome. For some PPS has been a rapidly progressive reality and for others it has been a slowly progressive condition. For a growing smaller percentage PPS has not occurred. To demonstrate how a Polio/PPS time line can be done, I will do my own.

Birth__# 1 Acute
Polio

L #2 good function
e with leg brace

v #3 pneumonia
e (#4) respiratory failure
l & tracheostomy

of #5 onset of
PPS-scooter

f #6 brain
u fatigue

c #7 vent 24/7
t power w/c

i
o
n

1939 #1 1950 #2 1960 #3 1967 #4 1970 #5 1990-91 #6 1996 #7 2002-04

On the vertical plane of this graph is a measurement of the level of my functioning. The greatest level of functioning was prior to polio. My level of function is estimated by the height of events on the vertical plane. On the horizontal plane are the significant years of my life with polio and PPS. From birth to age eleven my functioning was essentially active and normal. In 1950 I had acute paralytic polio (#1) causing weakness from the neck down with the right side being more severe. I had to use a long leg brace on my right leg. I maintained a steady physical function (#2) with my maximum functioning occurring around 1960. This improved level of functioning continued until 1967 when I contracted pneumonia (#3) during my hospital rotating internship. I essentially recovered but had to have a tracheostomy performed in 1970 and had to use a ventilator at night to prevent recurrent respiratory failure (#4). I remained stable for twenty more years until the onset of gradual leg weakness and general fatigue in 1990. In 1991 I had a CT brain scan, attended my first post-polio support group meeting, diagnosed myself with PPS and got a scooter and a van with a hoist to carry the scooter (#5). This step resulted in an immense saving of energy and I was able to continue practicing including daily hospital rounds. In 1996 the onset of debilitating fatigue (#6) began on June 21. I was hospitalized and underwent lots of tests with no unusual findings. I moved my office home and continued to practice part time. Over the next six years my muscles continued to weaken as did my respiratory muscles. In June 2002, my oxygen saturation levels were dropping below 88% and I was advised to use a ventilator 24/7. I began doing this by carrying a heavy battery on my scooter along with a heavy vent. In March 2003 I was able to get a Newport ventilator which has an internal rechargeable battery and the entire vent weighs only 17 lb. This was a tremendous advantage in mobility and reduction of weight to carry. In October 2003 I acquired a Jazzy power wheelchair and purchased a Dodge Caravan Entervan (electric fold down ramp). All of these necessary adjustments were not inexpensive, but the advantages gained made the cost a worthy investment.

None of us know how long we will live with PPS, but the preservation and maintenance of a good quality of life does a lot to improve one's mood and provide some peace of mind. I did not share all of this information to prove any particular point, but rather to demonstrate how each of you could do a similar Time Line of Polio and PPS graph for yourself. It may help one better understand the various struggles and necessary adjustments one has to make in order to live longer and more comfortably with PPS. Do your own Time Line graph and share it with others when an opportunity presents itself. I just did it with you, the reader.