

HAPPY 4TH OF JULY!

Once again we will be celebrating our independence on the 4th of July. All of America is still celebrating the fact that we are the land of the FREE, and by the Grace of God we will always answer to "one nation under God". May your 4th be filled with love of country and family and friends. Together we make a whole nation. Let us remain strong throughout all time. May God Bless you and your families, Remember our Service Men and Women where ever they are.

Your President at First Coast Post Polio
Janice

This is the view of Janice and not necessarily that of First Coast Post

In this issue:

- ***New Website !!***
<http://firstcoastpostpolio.com>
- **PPS Forum:**
Antibiotics for Fatigue?
- **A Member's Story**
- **Carpal Tunnel Syndrome**

Notes from the President.....

- We will NOT be having a meeting in July.
- We WILL resume meeting on August 16th.
- We have 2 new members who will try to be with us and would like to give their stories to you, and get feedback from you on how you are managing Post Polio Syndrome.
- We will have a special guest in September.
- We will have a special guest in October or November.
- At the end of 2007 in December we will have our annual Christmas Party.
- Come out and join our support group. We miss you and need all our PPS members to share their feelings with us.
- We are here to support YOU!



Dr. Richard L. Bruno's PPS Forum: Antibiotics for Fatigue?

Dr. Richard Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and

Medical Center. You can send him an e-mail at: ppsforum@newmobility.com.

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**Q:** *I read that a common antibiotic may prevent Parkinson's disease. Since the poliovirus damaged the same parts of the brain that are killed in people with Parkinson's, could this antibiotic prevent post-polio brain fatigue?*

**A:** This question gets to the heart of what's happening in the post-polio brain and spinal cord. Nearly 50 years ago, Dr. David Bodian found that anyone who had polio -- paralytic or "non-paralytic" -- on average had 95 percent of their brain stem and spinal cord neurons damaged, with half being killed. Neurons that produce dopamine, the main brain-activating neurochemical, were particularly hard-hit by the poliovirus. These are the same neurons that die in Parkinson's disease. After the poliovirus attack, remaining neurons, although damaged, took over for their killed colleagues and have done on average 16 times the work they did before the poliovirus infection. This overuse of damaged neurons is thought to have set the stage for post-polio fatigue and muscle weakness. The treatment for PPS is stopping the damage inside remaining neurons caused by overuse-abuse. But, what if there were something you could take that would protect the neurons from overuse-abuse?

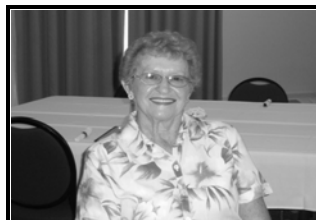
Several studies have looked into what are called neuroprotectives, substances that protect neurons from internal damage. A number have focused on degenerative diseases, such as Parkinson's and Huntington's disease, which also involves dopamine neurons. In 2007, the National Institutes of Health completed a study of 200 people in the earliest stages of Parkinson's and who weren't taking dopamine-replacement medications. The participants were given minocycline, a common antibiotic that is used to kill a variety of bugs (from acne, staph and strep to typhus and cholera), or creatine, which helps to provide energy to muscle cells. Participants who took minocycline did not have as rapid a decline in function as those taking a placebo. However, a 2006 study comparing creatine and a placebo in 60 participants with Parkinson's found that, while their mood improved and their need for medication decreased, their symptoms did not lessen.

## *A Member's Story*

### **I Remember Well**

by

Betty Loyd



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I can remember well when getting polio. It was the summer of 1946 in July, between 7<sup>th</sup> and 8<sup>th</sup> grade. An article in the Florida Times Union stated it was the 9<sup>th</sup> case of polio in Duval County that summer. I was spending the night with my best friend and after riding our bicycles all day I started feeling bad. My mother was called to come get me and by the next morning I had a very high fever and my neck was stiff.

The doctor was called and he said not to worry about my neck, it was just caused by the high fever. The next morning, still with the high fever, I could not move my left arm. The doctor came out and as soon as he saw me he called for an ambulance. After the isolation ward at St Luke's for two weeks they took me to Hope Haven Hospital in Jacksonville for seven months.

The hospital included an accredited school so the staff would roll our beds into the school room and one teacher taught all grades. There were kids at Hope Haven from all over Florida with polio, several in iron-lungs. The nurses were very prompt in changing the Sister Kenny heat packs to keep them as hot as possible, wrapped around us. That along with physical therapy and a heated pool was all they knew to do.

I went back to Hope Haven in three years for surgery on my arm and hand and have five scars as a result. Once the incisions were made and the doctors saw that all the muscles and nerves were gone, They were unable to do what they had planned. Some doctors say they waited to long to operate.

I can use some fingers a little, but cannot use my thumb at all. Of course, over the years I learned my own way to do things. Some people do not notice anything wrong, although my arm is much smaller and my fingers curl.

When my children were growing up I did lots of sewing. I made five beautiful quilts and many gorgeous porcelain dolls. Nine years ago the Post Polio Syndrome started bothering me and my arm and hand have become much weaker. I know I overdo and still do too much.

The faithful heating pad gets wrapped around my arm each night. My husband rubs my arm with myoflex or biofreeze when it is hurting badly and that helps to relax it. Some days I wear a sling on my arm. That also helps and reminds me not to use it when it is hurting.

We can only hope and pray that one day the doctors will know more about the PPS and can help us.

Betty L.



**DON'T MISS THE NEXT MEETING.**

Reliv Nutrition made simple, Life made rich...

This will be our next topic at our meeting. No pressure. We will have a member from Georgia who is taking this product and would like to talk with others about how she is doing on Reliv.

She is a Polio Survivor and feels this could help others as it has helped her.

Please come and see what it is all about.

Also we will be having a new member talk with us about her experience with hot saltwater spa treatments.

**Quiz: How Old Are You Really? BE HONEST!!!**

From the following list of 25 items, count all the ones that you remember -- not the ones you were told about! How to score yourself is at the end.

- Blackjack chewing gum
- Wax Coke-shaped bottles with colored sugar-water
- Candy cigarettes
- Soda-pop machines that dispensed bottles
- Coffee shops with tableside jukeboxes
- Home milk delivery in glass bottles with cardboard stoppers
- Party lines
- Newsreels before the movie
- P. F. Flyers
- Butch wax
- Telephone numbers with a word prefix (e.g., Olive - 6933)
- Peashooters
- Howdy Doody
- 45-RPM records ... and 78-RPM records



- S&H Green Stamps
- Hi-fi systems
- Metal ice trays with lever
- Mimeograph paper
- Blue flashbulb
- Packards
- Rollerskate keys
- Cork popguns
- Drive-in theaters

- Studebakers
- Washtub wringers

If you remembered!

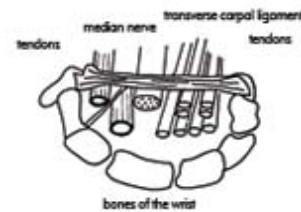
- 0 - 5 = You're still young
- 6 - 10 = You are getting older
- 11 - 15 = Don't tell your age
- 16 - 25 = You're older than you think!

Be sure to pass this along -- especially to all your friends with really good memories.

## Carpal Tunnel Syndrome

By Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

Doctors have been dealing with carpal tunnel symptoms for over a hundred years. The carpal (wrist) tunnel is a narrow corridor formed by bones and ligament on the palm side of the wrist. Its job is to protect the median nerve, which runs through it to carry feeling and movement to the thumb and all fingers except the little finger. When pressure is placed on that nerve, the result is the numbness, pain and weakness known as CTS.



### CAUSES

What causes this condition is the question. Median nerve compression is attributed to swelling or thickening in the carpal tunnel, which for years was blamed by some on repetitive use of the hand and wrist. Dozens of occupations (and even hobbies) require forceful and awkward hand intensive movements, and it was thought that overuse in this manner could bring on CTS.

A recent study by doctors in Boston takes a second look at this thinking. Although much is still unknown about the cause of increased median nerve pressure, this study suggests there is strong evidence to believe it has little to do with activity.

Data used to determine the cause of CTS was evaluated according to Bradford Hill-based criteria, a well established method for demonstrating causal relationships. Average scores for such factors as genetics, race, age and other biological components were double those of occupational factors, which involve repetitive and vibrating hand use and other such elements. Furthermore, the average strength of a cause-and-effect association was about three times as strong for biological factors as it was for occupational ones.

The strongest risk factors for CTS were genetic. Many in the medical community now contend there is a genetic predisposition to CTS. They say there never was strong scientific evidence linking repetitive stress to CTS. Indeed, a Mayo Clinic study in 2001 found heavy computer use did not increase the chances for developing CTS. Clearly, not everyone who does a particular action has carpal tunnel problems.

How do we account for the fact that two similar polio survivors could continually use the same hand/wrist motion in the same forceful way to propel their manual chairs for the same period of time each day – and yet one of them might get CTS related to this activity, but not the other one? ***Is the incidence of CTS higher among polio survivors using manual chairs than for the general population?***

### OTHER PREDISPOSING FACTORS

Not all carpal tunnel swelling is related to repetitive hand/wrist use. Certain physical conditions such as diabetes, arthritis, hypothyroidism, uremia, obesity, high blood pressure, pregnancy, menopause and other disorders that may be associated with swelling are sometimes linked to CTS and could place one at higher risk. Or, some people simply have a much narrower carpal tunnel. Or, others may have injured their wrists.

Not long ago, if the topic of carpal tunnel syndrome (CTS) came up, someone would likely say, “Oh yeah, that’s what people get when they sit at their computers typing too long. You know – all that repetitious activity that causes big problems in the wrist and hand.”

## Carpal Tunnel Syndrome

*Continued from page 5*

Since a Boston research team presented their study findings at the 74th Annual Meeting of the American Academy of Orthopaedic Surgeons in February, however, people are beginning to think differently about CTS. There is even the suggestion that individuals with “a generalized nerve problem” may be susceptible to developing CTS. Could this group include those who had polio? ***Could polio be considered a predisposition that adds up to CTS when triggered in certain polio survivors*** by, for example, repeated flexing of the wrist as we force weight onto our canes/crutches?

### INCIDENCE

The US National Institutes of Health reports that three times more women than men develop CTS. The condition occurs most often in people between the ages of 30 and 60, seldom in children.

### SYMPTOMS

Symptoms often occur in the night (or upon awakening) or when using the hands in a certain way over a period of time, like grasping a steering wheel or a newspaper when reading it. They generally begin mildly, perhaps with aching, tingling and numbness in the palm and all fingers except the little finger. Pain can extend from the wrist on the palm side to the fingers or up the arm. Weakness may make it difficult to grip objects or to continue certain hand/wrist activities, and reflexes may become impaired. In untreated cases, muscles at the base of the thumb may atrophy or people may lose the ability to feel the difference between hot and cold.

### DIAGNOSIS

A variety of methods are used to test for carpal tunnel problems: u A physical exam – checking hands, arms, shoulders and neck to determine their condition and to rule out carpal tunnel mimics. Checking wrists for tenderness, swelling, warmth and discoloration; fingers and hands for sensation, strength and deterioration. Lab tests and x-rays can show such problems as fractures, arthritis, diabetes and other conditions.

u Tinel test – use in the fingers occurs when a doctor presses on the median nerve. u Phalen test – a wrist-flexion test used to see if various symptoms appear when the hands and fingers are held in a certain position for a length of time. u Electrodiagnostic tests – an electromyogram checks for muscle damage when a needle is inserted into a muscle to record electrical activity in that muscle at rest and when contracted. A nerve conduction study uses electrodes taped on the hand and wrist to measure the speed at which electrical impulses are transmitted in the carpal tunnel. Ultrasound can show impaired movement in the median nerve. u NC-stat – a controversial automated device supposedly used by over 12,000 physicians, often general practitioners, to check patients for nerve disease and help diagnose such conditions as CTS.

### TREATMENT

Methods of treatment vary, depending on the severity of the problem. Any underlying conditions will be treated first. Nonsurgical treatments – Mild to moderate cases may be helped by wearing a wrist splint. Nonsteroidal anti-inflammatory drugs (NSAIDs such as aspirin or ibuprofen) may help if an inflammatory condition is present. Corticosteroids (such as prednisone) or the drug lidocaine

Carpel Tunnel Syndrome, Diagram of the Carpal Tunnel, [www.post-polio.org](http://www.post-polio.org) POST-POLIO HEALTH  
 ?? Spring 2007 ?? Vol. 23, No. 2, *A list of the twelve resources used in writing this article are online at:*  
[www.post-polio.org/ipn/pph23-2ctsresources.html](http://www.post-polio.org/ipn/pph23-2ctsresources.html)

## Dr. Richard L. Bruno's PPS Forum: Antibiotics for Fatigue?

*Continued from page 2)*

Another natural substance, vitamin E, has been found in eight studies to have some neuroprotective effect in Parkinsons, 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 Parkinson's, with one cup a day cutting the risk of developing the disease by as much as one-half. Currently, the NIH is testing another dietary supplement, co-enzyme Q-10, to see if it protects neurons in those with Parkinson's.

Eleven Austrians with Huntington's were tested in a two-year study of minocycline. Like the study participants with Parkinson's who took minocycline, there were no major side effects and, remarkably, no decrease in physical ability and a slower progression -- or no change -- in thinking and memory in those with Huntington's. These same researchers tested creatine in people with Huntington's during a one-year study and found similar beneficial results.

Should polio survivors ask their doctors for a minocycline prescription, go to the health food store and load up on creatine or coenzyme Q10, or order a Starbucks' grande, three-shot, non-fat, extra hot cappuccino to prevent post-polio brain fatigue? Not yet. First, over-the-counter preparations of creatine or coenzyme Q10 may not be of the same strength as those being studied, so you wouldn't know how much to take. And there are not yet enough studies to prove that any of these substances are truly neuroprotective in Parkinson's or Huntington's disease, let alone in PPS, in which none have been tested.

Double-blind, placebo-controlled studies of potential neuroprotective drugs and supplements are warranted in polio survivors. But, they must be carefully designed and measure PPS symptoms daily, not before a month or months after a substance is given, as have previous drug trials in polio survivors, all of which have failed to decrease PPS symptoms. For now, the only neuroprotective that we know works to stop internal damage in overworked, polio-damaged neurons is self-care and "The Golden Rule: "If anything causes fatigue, weakness or pain, DON'T DO IT! (Or do much less of it.)



We have a polio survivor who is looking for someone who might be able to wear her opposite shoe size. She has lots of NEW shoes that she can not use still in the box.  
I believe the sizes are 6-1/2 and a 2.  
Call if anyone is interested in having these shoes.  
904-333-3457 or e-mail at: [firstcoastpostpolio@yahoo.com](mailto:firstcoastpostpolio@yahoo.com) (Please type "shoes" in the subject line.

Thank you.

PS: I also have shoes 8 1/2 on left and 7 1/2/ on right. Janice



**First Coast Post Polio Support Group**

13119 Blackhawk Trail Ct.  
Jacksonville, FL 32225  
(904) 333-4567

Firstcoastpostpolio@yahoo.com  
<http://firstcoastpostpolio.com>

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We appreciate and thank The March of Dimes for the mailing of our newsletter.

## Next Meeting August 16th

I apologize for the mix up on our June meeting. We had several who showed up only to find there wasn't a meeting. We talked about it in May after the last news letter had come out and decided not to hold a June and JULY meeting.

Thank you for showing up and we are sorry to have missed you. Please note we will not have a JULY meeting but have decided to take a well deserved vacation. **SEE YOU IN AUGUST.**

TAKE A LOOK!

<http://firstcoastpostpolio.com>

We'd love to see you at our next meeting.  
Don't forget when and where.....  
Every third Thursday of the month  
Courtyard Marriott across from Mayo Clinic  
San Pablo Road in Jacksonville  
Meetings begin at 12 noon.

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Questions?

Call our president, Janice Askwith,
at 904-333-3457

Or Vice President & Editor, Sandra Rodrigues
At 904-824-2056

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