

CONNECTIONS

First Coast Polio Support Group Newsletter

Summer, 2010

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Beta-blockers Could Cause Fatigue In Polio Survivors

Better Alternatives May Reduce Hypertension

by Dr. Richard L. Bruno

Last column, we talked about types of tremor, essential tremor being one, which is often treated with beta-blockers. Beta-blockers have been a first-line drug to treat high blood pressure. The problem for polio survivors is that the side effect of beta-blockers—and of most antihypertension drugs—is fatigue, something polio survivors don't need more of. So, here are some suggestions to take to your doctor about drugs to lower your blood pressure that, hopefully, will not also put you to sleep:

- The first drug prescribed to treat hypertension used to be a diuretic, a “water pill.” Diuretics, like Diazide and Furosemide, lower blood pressure by decreasing the amount of fluid in your arteries. But diuretics work by making you pee...and pee and pee. Polio survivors with fatigue and weaker arms and legs shouldn't be running (or rolling) to the bathroom and getting on and off the throne a dozen times throughout the day and night.
- Those beta blockers I mentioned lower blood pressure by stopping adrenaline from stimulating the heart muscle. The problem is that these drugs block adrenaline from stimulating brain activation, too. Of all the antihypertensives, beta blockers are probably the worst offenders when it comes to producing fatigue. The drug companies' own studies show that fatigue was a side effect in a high percent of patients: Kerlone (3%); Corgard and Tenormin (4%); Trandate, Zebeta, Viskin (5%-8%); Sectral, Lopressor, Inderal (11%-17%); and Coreg (24%).
- Another older antihypertensive that causes fatigue is the alpha blocker. This drug stops adrenaline from stimulating blood vessels and thereby allows arteries to open, lowering pressure by increasing the size of the “pipes” blood can flow through. But, as with beta blockers, anything that blocks the stimulating effects of adrenaline can cause brain “deactivation” and fatigue. Fatigue was reported in more than 7% of subjects taking alpha blockers Cardura, Hytrin and Minipress;
- Newer antihypertensives have been developed that don't block adrenaline and are less likely to cause fatigue. The calcium-channel blockers (CCB) open blood vessels and reduce the force of contraction of the heart. CCB Procardia and Norvasc caused fatigue in from 4% to 6% of subjects. But, fatigue was not reported with CCB Cardene and Verapamil;

(Continued on page 5)

There is always a need for pictures and articles for both the newsletter and the historical archives.

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Our next meeting 8
**May 22 at
Marriott
Courtyard
By Mayo Clinic
11 am to 1pm**

From the President

Just Jim's thoughts.....

Lemonade, Anyone?

As I age with PPS I suddenly realize that I've lost, or at least



Jim Powell

slowed down, a function that I had hereto fore taken for granted. I've recently started using a power chair to get around outside the house,

refusing to give up my independence in the house.

Am I giving in to the weakness, the threat of stumbles and falls or am I embracing a new found friend? Have I been handed more lemons and will I find it possible to make lemonade?

I can now get around our large church campus and Super Wal-Mart without someone pushing my wheelchair – I can go faster, thanks to a five-speed transmission, than most people years younger than me! I have wind in my hair, well I'd have to get a toupe' to fulfill that dream. Get the idea I'm trying really hard to make lemonade?

I recently saw a Hallmark movie on TV titled "Front of the Class" about a young college graduate trying over and over to secure a position as an Elementary School teacher despite the fact that he has Turret's Syndrome. His condition has made him the lifelong recipient of ridicule, shame and discipline because adults thought the noises and

involuntary movements that plague him were his prankish ways to get attention.

This movie has the happy ending that we all would hope for, he is given a chance to prove that he could teach and relate to children in a way that totally overpowered his disability. We polio survivors need to capture this lesson of brave persistence that we are OK the way we are and we will find ways to triumph over our basket full of lemons called Post Polio Syndrome.

You may want to pick up the DVD of this movie at one of those famous greeting card stores so you can share in the encouragement of triumph over what many would call "Medically Induced Tragedy". Or is it really sweet but still faintly tart lemonade? I have to use Splenda to make my refreshment as sugar is another one of those pesky lemons in my life. Anyone wanna' race? I'll give you a head start.

Cheers, my friends!

Jim

Sue Bridges, Founder of First Coast Post Polio Support Group Is Recognized

The 20th anniversary of the formation of First Coast Post Polio Support Group was recognized with a dedication plaque to the group's founder. Sue Bridges is now in assisted living after a long hospital stay with pneumonia, and was unable to attend a ceremony. Vice President Janice Askwith and Secretary Sheila Kilgore represented the membership as they visited Sue to wish her well and present her with the plaque.

The plaque featured a picture of the broad membership group put together from photos from many different meetings. The collage appeared to be one large group in one large meeting, thanks to Janice's artistic talent.

"Many have benefited greatly from her efforts," said Janice. "We owe Sue Bridges a great round of applause for all of her hard work in the past years to get this support group started." *Send cards and letters for Sue to Janice at the newsletter address.*

Wade M. Nield, C. PED.
President

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Ann's Story

My name is Ann Hazard. I was raised in La Jolla, California — the town where the Salk Institute is located. I am 57 years old and confirmed that I'd had Polio about 10 months ago (I had it when I was almost 3).

When I questioned my 87-year old father about it, he admitted that I "might have had a mild case of Polio," and then promptly went back into denial and refused to speak of it again, until recently. He still thinks I can go to a really good doctor and get a better diagnosis...one that means I can be fixed!

It took about a decade for me to finally put the puzzle pieces together. Back in 2000, I had a Mexican dentist who had to cap my two front teeth because of yellow bands of discoloration. She said these were from being given massive doses of antibiotics when I was about 3. She asked me if I remembered any major illness at that age and also asked me if perhaps I'd had polio. She was quite familiar with the disease.

That got me to thinking. I had some odd memories of being kept in a dark room, unable to walk and naming my legs after two of my parents' best friends. I remembered that I was about 3. These are my first memories! After my conversation with my dentist, I asked my mom about it...but all she told me is I had some kind of problem for a short while where I couldn't walk.

. No big deal. Never in my home was the "P" word mentioned.

I obviously recovered from the Polio and lived a normal, active life until I turned about 50. My only problems were a slightly off-balance gait.

But after 50 I began to slow down and experience increasing pain. After swimming 5 miles a week for over 20 years, I had to stop. I didn't think much of it, just figured I was wearing out certain muscles and joints and it was time to scale back. I figured I had arthritis.



Ann Hazard

But, over the next five years there was more joint and muscle pain, fatigue and some degeneration in the muscles in my right leg, which is the one that doesn't work so well. At this point my husband and I had left San Diego and were spending 2/3 of the year in Baha California Sur, Mexico and the other 1/3 in McCall, Idaho. We did this for six years, traveling back and forth between two countries.

In 2007 we moved into a three story house in Idaho (which would be funny if it wasn't) and a 2 story house in Mexico.

Ironically, that's about the time I pulled my groin and all of a sudden was in quite a lot of pain. I figured it was just the injury but I began having more and more unrelated leg pain.

I did a lot of research on the internet and the whole Polio thing kept coming up. Then I found out about PPS. I was pretty freaked out and wanting to go back to thinking I had an injury that would heal in time...or something surgery could fix...not a bunch of neurons that were dying off!

I told a few of my close friends about having had Polio. I was shocked by the responses...most everyone listens, makes a few appropriate remarks and then changes the subject, pretending I never said anything. Some friends even accused me of making it up, saying because I'm 57 should have had the Salk vaccine and been immune. Especially since I grew up in La Jolla!

But 99% of the time, people just pretend the conversation never happened. I can only conclude that polio is so creepy and scary that it's just not a word anyone wants to hear. And there isn't much information out there. This needs to change!

(continued on next page)

From MediNurse

Now is the time to clean out those medicine cabinets!

- Almost everything in your medicine cabinet, including sunscreen and over-the-counter medications, has an expiration date and should be thrown out and replaced when they become outdated.
- Holding onto unused medication increases the chance of unintentionally grabbing a bottle and taking the wrong medication.
- Traditional advice has been to dispose of unused drugs by flushing down the toilet or putting in the trash. Neither is a good idea. It is best to check with your local pharmacy to find out if they

will take back unused or expired prescriptions. Another option, better than putting in the sewer system, is crushing the pills, dissolving them in water, then mixing in some-



thing to absorb the ingredients such as coffee grounds, flour, cat litter or sawdust, and placing the mixture in a sealed plastic bag before disposing in the trash.

- Do not use pills if they appear discolored or powdery.
- Do not use capsules that are cracked, leaking or sticking together.
- Do not use liquids that have become cloudy, filmy or hardened; do not use any creams that have cracked. Liquids and creams can also be mixed with coffee grounds, flour, cat litter or sawdust and then sealed in plastic bags for disposal in the trash.
- It is not recommended to keep any medication for more than one year. The medication could become less potent or more potent depending upon the drug. This could create a harmful situation.

Ann's Story (continued from page 3)

I have learned not to share that information anymore. Now, when people here ask me why I limp, I just tell them I had a childhood illness that caused some nerve damage and leave it at that. Somehow that one works and I don't get treated like a leper.

My husband and I recently decided that I needed to be in a warm, flat place with access to a pool. The living in two countries wasn't working anymore. Nor were the stairs. So we moved to St. Augustine, Florida, into a one story house with a community pool less than 100 yards away.

Our other homes are on the

market. Not a great time economically, but our priorities have changed and now quality of life is at the top of the list.

I am so grateful to have found this website. I will do anything I can to help get the word out.

I have no doubt that too many of us are either unaware, misdiagnosed or have been mistreated when we get to the truth.

More research needs to be done.

More doctors need to become aware of PPS. It seems to me it's like Fibromyalgia was in the '90s. No one ever heard of it and those people who said they had it were too often treated like they were slightly crazy

- Actually, the medicine cabinet in your bathroom is one of the worst places to store medications! The temperature and humidity are typically higher than other rooms in your house, creating a hostile environment that can make medicines less potent.
- Medicines are best stored in cool, dry places out of direct sunlight and always out of the reach of children. A dresser drawer may be a good alternative

Drugs and Fatigue (continued from page 1)

- Differences in fatigue reports were also seen among members of another class of newer antihypertensive, the angiotensin receptor blockers (ARB). These drugs block angiotensin, a hormone that causes blood vessels to narrow. ARB Diovan and Avalide caused fatigue in 4% to 5% of subjects. Fatigue was not reported with ARB Atacand, Micardia, and Cozar;
- A varying ability to produce fatigue was also seen among the angiotensin converting enzyme (ACE) inhibitors, which block the production of angiotensin. ACE inhibitors Accupril, Lotensin, Vasotec and Zestril were found to cause fatigue in about 2% to 5% of subjects. However, fatigue was not reported with ACE inhibitors Aceon, Altace and Monopril.

Should polio survivors never take certain antihypertensives and always use others? First, some of these “antihypertensive” medications have applications other than lowering blood pressure, like beta blockers, which treat abnormal heart rhythms.

Calcium-channel blockers also treat angina and can prevent migraines. And alpha blockers treat enlarged prostates and can help to warm cold hands and feet.

Second, since some people have hypertension that is difficult to manage with only one medication, a combination of drugs may be needed that might necessarily include a beta or alpha blocker

When taking any medication, it is important that polio survivors keep a log of side-effects and discuss these with their doctors.

The dose or time of day when you take a drug—taking a fatigue-producing medication before bed or taking a long-acting, slow-release form of a drug—may minimize fatigue. As we’ve discussed before, don’t let doctors tell you that a drug couldn’t cause fatigue because “other patients” have not complained.



Memorial 

We would like to thank
**The Class of 1954 and
 the Class of 1958
 Of Callahan High School**
 And the **DiMaria Family**
 for their generous donations to our group in memory of Gerry.

Read more of our dedication to Gerry on www.firstcoastpostpolio.com

Polio survivors are not like other patients. If your doctor doesn’t listen to you, get another. If you’re not comfortable with the medications your doctor is using to treat your hypertension, or if your blood pressure isn’t coming down in spite taking a combination of drugs, don’t hesitate to consult a cardiologist who’s also a hypertension specialist.

Remember: The stroke you prevent by keeping your blood pressure down will be your own!

Geraldine Jordan passed away on April 8, 2010, after complications from a fall. Our deepest condolences to her family. Gerry’s husband, also a polio survivor, preceded her in death. Gerry and her husband had a watch repair business for many years, which Gerry continued until her death. We’ll remember her soft words and warm personality. She was much admired and loved by us all.

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

March 16th, 2010 Reprinted with permission from United Spinal Association’s “Action Online Magazine”

For the Anesthesiologist

Polio results in wide-spread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients.

Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is due to **central neuronal changes**, especially in the Reticular Activating System, from the original disease.

Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants.

Also, many patients have a **significant decrease in total muscle mass.** Neuromuscular monitoring intra-op helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

Succinylcholine often causes severe, generalized muscle pain post-op. It's useful if this can be avoided, if possible. There is no experience with Raplon yet.

Pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over"

of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multimodal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.

The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given. Patients who use **ventilators** often have worsening of ventilator function post-op, and some patients who have not needed ventilation pre-op have had to go onto a ventilator (including long-term use) post-op.

The marker for real difficulty is thought to be a VC < 1.0 liter. Such a patient needs good pulmonary preparation pre-op.

Another ventilation risk relates to obstructive sleep apnea in the post-op period. **Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.**

Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning.

There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves may be unprotected by the usual muscle mass or tendons.

Selma H. Calmes, M.D. is Chair, Anesthesiology and Clinical Professor of Anesthesiology at USCL (retired)

Suitable for giving to your anesthesiologist—this will also be located on the website: www.Polioepic.org.

Minutes for March 27, 2010

The First Coast chapter met on March 27th of 2010 at the East Coast Sushi and Grill at Regency. There were 11 present including 1 new member and 5 guests. Our new president, Jim Powell, called the meeting to order at 12:00. Jim informed us that April 12th is the 55th anniversary of the Jonas Salk vaccine. He also informed us that the Rotary club is very involved in health issues, especially the problem of polio in the third world countries. He is trying to get exposure for us and these issues with the paper and television. He is looking for ways to get the word out of our existence. The next item was the issue of funds. He encouraged everyone to make sure to pay their dues. We have lost funding from the March of Dimes and Winn Dixie for this year so our resources are way down.

Mark Your Calendars

Remaining 2010 Meetings

- May 22** Guest Speaker
- August 28** Guest Speaker
- October 30** Guest Speaker
- December 18** Holiday Party

. We must be responsible in the handling of our limited resources. Someone mentioned selling ads in the newsletter. We were able to gain access to a free stamp to use on the newsletter which will help with costs. Janice mentioned the idea of the cookbook again for 2010. It was also mentioned about creating a pamphlet about polio and post polio syndrome to place about in doctors' offices to make people more aware.

Dr Thorsteinsson said he would endorse it. We have a number of our people who live in St. Augustine and it was suggested that maybe an extra meeting might be scheduled for all of those members. Ideas were mentioned for our Christmas meeting in the form of entertainment. Several possibilities were suggested and will be followed up with. It was a very profitable meeting. Our next meeting will be held on May 22. Jim is lining up a speaker from the Rotary club. Meeting closed.

P
e
c Respectfully submitted,
Sheila Kilgore, Secretary

2010 Update of Members and Dues

Name: _____

Address: _____

Phone: _____ E-mail: _____

Join our Birthday Club Month: _____ Day: _____ Year: _____ (optional)

Dues: \$20.00 Payable to ***First Coast Post Polio.***
Send Dues only to: First Coast Post Polio % Eulie Nahm
13047 Rocky River Road N.,
Jacksonville, FL. 32224

Please send this back with your check for updating our mail list. The cost of mailing has gone up as well as our website. This money also supports our door prize and gifts throughout the year. Thank you!

We would like to have a family member or friend who we can contact if you are in the hospital or nursing home. We at First Coast Post Polio care about you and want to stay in contact with you. Please permit us to have their name and phone number.

Name _____ Phone _____



First Coast Post Polio Support Group

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We're on the web!

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Officers 2010

President: Jim Powell

Vice President: Janice Askwith

2nd VP & Newsletter Editor: Frances Powell (no relation to Jim Powell)

Secretary: Sheila Kilgore

Treasurer: Eulie Nahm

Sunshine Chair: Sue Massey

Historian: TBA

Board Members

Bill Hamilton

Carolyn Jones

Dr. Stuart Caplin



**Printed Matter for the
Blind and Handicapped
Postal manual Part 138**

Please call if you are not the person
to whom this is addressed, please call
904-333-3457

**Our Next Meeting is
Saturday, May 22, 2010
From 11 a.m. to 1 p.m.**

Light lunch will be served and paid for by FCPPSG (First Coast Post Polio Support Group)

COURTYARD MARRIOTT

By MAYO CLINIC

14390 Mayo Blvd (Mayo Clinic) off San Pablo Road

Guest Speakers will be:

Mr. Joe Anzalone, President of Mandarin Rotary Club

and

Mr. Dan Pinto, also from Rotary Club Jacksonville

DISCLAIMER: The articles, opinions, ideas and suggestions presented in this news letter and from our meetings is not to be taken as an endorsement or approval of any medication, product or individual. Always check with your Doctor first about your condition. First Coast Post Polio Support Group of Jacksonville, Florida does not assume any responsibility for individual reader's action. Information in this newsletter was obtained from various national and local sources which are considered reliable and /or reflect the opinion of the authors. Medical advice must be sought from competent licensed physicians.