

POLIO PERSPECTIVE

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IN THIS ISSUE

Trip to Greece

by Laine King

Bruno Bytes

by Dr. Richard L. Bruno

Thoughts on Freeing a Stranded Swallow

by George Alan

Round 'em Up, Move 'em Out

by Millie Malone Lill

Web Corner

Other Polio Newsletters

A Little Bit of Humor

Trip to Greece

by Laine King

I went on what might have been my last excursion, this fall, with my daughter and her strong arm. We went to the Greek island of Rhodes for two weeks, staying in Afandou and Haraki. It was a glorious trip, full of sunshine, Aegean seas, Greek food, music and people who welcomed us with smiles and real conversations. But I am not a good strong walker, so it was difficult at times, and my daughter's support was very much welcome and required. The trip started at Atlanta International, went through Frankfurt, and then to Athens. There we boarded a smaller plane for the flight to Rhodes. As Harry Nilsson sang, Good, Bad, good, bad, good badgoodbadgoodbad.....

I had requested from Lufthansa, a very good airline, a wheelchair for moving through the airports. This is a recent surrender for me, which turns out to be very beneficial, so I'm handling it much better each time. At Atlanta, I had a very pleasant attendant who made sure I stopped at each place I needed, such as Travelex to exchange currency, on the way to the gate. I'm with you, she said. So that was a good experience and we were easily settled with no pain or stress.

At Frankfurt, when we disembarked, there was one wheelchair waiting, several passengers milling about and a couple of confused attendants. Eventually after they spoke to each other and ignored me, we were all told to Walk this way. And we all trundled off, pulling our luggage, limping and

struggling, while one attendant pushed an empty wheelchair among us! We walked a long way until, reaching an empty space with seating, they told us all to sit down and wait. Then they talked, made calls, played on their phones, and occasionally someone would come with a wheelchair and take a person away. But they never spoke to me, or made a group announcement about what was going on. I finally got impatient and went up to them and inquired. They acted like I was hysterical, told me that people were transported in the order that their connecting flights were scheduled and I should just sit down and wait. I pointed out that there were shuttles passing us by right and left and that my daughter and I would be happy to ride a shuttle instead of a wheelchair. That seemed to be a new idea for them. They made calls, put the last people in wheelchairs, told me a shuttle was scheduled to pick us up, and left us there all alone. Eventually, one came and we were taken as far as we could go, offloaded to stand and wait for an elevator, walked to another waiting area where we again waited for a wheelchair. My advice: don't layover in Frankfurt. Their airport is in too many sections and they are not prepared for more than one passenger needing transport.

In Athens, the metro system is excellent, wheelchair accessible, good surfaces, lighting, signage, elevators, chair lift, etc. But, as expected, ancient cities and villages are not made for less than able travelers. The uneven surfaces are difficult for walking. Even stepping up into shops and restaurants is a challenge and I required my daughter's strong arm each time. There are flat spaces, but more slanting ones, and lots of hills and stairs. There were many sites that I could not visit. In restaurants, the toilets are often down stairs. When we boarded a bus, I put one foot up to the bottom step, grabbed the side railings, brought my other foot up and found I was in a dead squat, unable to move. Thankfully my daughter was with me, or it would not have been a pretty ending. I was having an adventure, and kept my humor, but I have to say that it was emotionally distressing to be unable to do what I wanted and needed to do, what I used to be able to do. But we had a wonderful time. It was gratifying to her to be able to help me. We are blessed to have each other and to have the love and understanding we have developed. But it might have been our first and last big excursion, depending on how my body lasts. Stay tuned.

Bruno Bytes

by Dr. Richard L. Bruno

[On the topic of Post-Polio Neuropathy \(?\)](#) (10/12/2016)

Original Post: Is there a way of distinguishing between diabetic neuropathy in motor neurons vs. polio / post- polio neuropathy? I've had diabetes for 20 years and PPS for about 2, but yet some specialists just off-handedly dismiss my motor neuropathy in my legs as "probably" diabetes.

Dr. Bruno's Response: A Nerve conduction study should've told the tale. There is no such thing as a post-polio or polio neuropathy. The poliovirus damages the neuron in the spinal cord, not the axon going to the muscle. What's more the polio virus doesn't damage sensory neurons or their axons. So if you have "nerve pain" it's not due to having had polio.

Dr. Bruno's Additional Response: There are conditions that cause motor nerves to lose their myelin. In people who are middle-aged a common cause is an autoimmune process. Slowed conduction along motor nerves can be associated with muscle weakness because not all of the muscle fibers are being stimulated at the same time; think of listening to someone...speaking...very...slowly & you not being able to quickly understand the speaker.

Your doctor should be looking for some cause for the motor demyelination other than polio.

On the topic of Marijuana and Osteoporosis (10/12/2016)

Dr. Bruno's Original Post: The use of Pot creates stirring debates. Here's some new information: <http://www.independent.co.uk/news/science/cannabis-marijuana-thin-bones-osteoporosis-lower-weight-munchies-a7357056.html>

On the topic of EMG and "Old" Polio (10/11/2016)

Original Post: I had an EMG done yesterday on my right leg. The doctor that did the EMG told me I had "old polio". I didn't even think much about it till I got home because I was talking about PPS. Has anyone else had PPS referred to as "old polio"?

Dr. Bruno's Response: What should have been said is, "Your EMG shows damage consistent with having had polio". This is a reason polio survivors shouldn't have EMGs unless ANOTHER diagnosis is suspected. EMGs hurt and are very expensive.

On the topic of Choosing a Drug Plan (10/10/2016)

Dr. Bruno's Original Post: October 15th is almost here and it's time to start thinking about health insurance for 2017. I want to warn you about changes in your drug plan that you may not be aware of (I realize they may not make sense).

All medications in Medicare part D drug plans are assigned a "Tier." Tier 1 is the least expensive, often older generic drugs, Tier 3 is for brand-name drugs while Tier 5 is expensive specialty drugs. What the insurance companies don't tell you that they can change a drug's Tier every year.

For example, one drug plan has listed generic diazepam (brand name Valium, which has been around since 1963) as a Tier 1 drug. But, in 2017, the same generic diazepam will be listed by the drug plan as a Tier 4 drug, a "non-preferred drug." The price for Tier 1 generic diazepam had been \$15 for 3 months. Come 2017, the price for Tier 4 generic diazepam will be \$343 for 3 months!

Why, you ask, would a generic drug that's been around for 53 years be switched from Tier 1 to Tier 4? For that question I have no answer. But imagine how you would feel if you didn't check the Tiers and prices for 2017 and bought generic diazepam through your drug plan. You would go from paying \$60 a year to \$1,372!

So call your prescription drug plan and find out the Tiers and costs for all of your medications. But remember that you don't have to buy all of your medications through your drug plan. You can go to <http://www.goodrx.com/> and find the prices you would pay for your medications at local pharmacies, pharmacies inside big-box stores (Target, Walmart, Stop & Shop) and by mail. Using diazepam as an example, a three-month supply bought through one supermarket's drugstore would be \$19 for 3 months. What's more, some of the big-box stores and pharmacies also have discount cards that can reduce the price even further.

If you find that your drug plan charges more for some medications than does a local pharmacy, you can ask your doctor to send prescriptions for reasonably priced medications to your drug plan while you take a handwritten prescription to your local Walmart and pay cash.

On the topic of another "Polio Like" Virus (10/6/2016)

Original Post: What is this "Polio like" disease that has no cure that I heard about on this morning?

Dr. Bruno's Response: There are more than 100 enteroviruses (viruses that live in your intestines), many having the same or similar neuron damaging capabilities as the 3 polioviruses. "Polio-like virus" is a short-cut way of saying neuron-killing enteroviruses. There are 60,000 cases of AFM in India each year, caused by "polio-like viruses," but no cases of polio.

Enterovirus-68 caused about 100 cases of muscle weakness and some paralysis a few summers ago, if you remember the terrifying headlines: POLIO RETURNS TO AMERICA! Last summer? There were few or no cases.

From CDC.gov: What is enterovirus D68?

Enterovirus D68 (EV-D68) is one of more than 100 non-polio enteroviruses. This virus was first identified in California in 1962.

How common is EV-D68 in the United States?

Small numbers of EV-D68 have been reported regularly to CDC since 1987. However, during 2014 the number of people reported with confirmed EV-D68 infection was much greater than that reported in previous years. We can't predict whether EV-D68 will be a common type of enterovirus detected this year or in future seasons. That's because a mix of enteroviruses circulates every year, and different types of enteroviruses can be common in different years.

What time of the year are people most likely to get infected?

In the United States, you are more likely to get infected with enteroviruses in the summer and fall. However, you can get infected year round.

What is happening with EV-D68 in 2016?

The CDC is aware of limited sporadic EV-D68 detections in the U.S. in 2016. There is no indication of unusual activity. Enteroviruses are ever-present in the community, and each year we expect to detect cases. As in previous years, CDC will continue to work in 2016 with states by testing specimens to determine virus type, supporting the identification and investigation of outbreaks, and monitoring seasonal activity.

Thoughts On Freeing A Stranded Swallow *by George Allan*

What a marvelous little bird is a swallow.
in flight, so agile and acrobatic and yet so graceful
but he was helpless when I found him stranded in that hollow
there, without a helping hand, his fate would have been so awful
with outstretched wings flattened against the deck and all forlorn
there was not a chance he could ever get himself airborne
raising him from the floor to hold him aloft
I sensed I had ne'er caressed anything so incredibly soft
as he nestled quietly, I sensed that he might linger
till feeling the wind filtered past each supporting finger
from my gentle cupped hands, he launched himself to the freedom of the air
having saved him from his dreadful plight, I could not help, with his, compare
the lives of my fellow survivors in these and other lands
who have been freed from Polio's grip by so many gentle helping hands.
(in honor of World Polio Day, October 24)

Round 'em Up, Move 'em Out

by Millie Malone Lill

Last month, my building was struck by lightning. I don't think it was personal vengeance from a Higher Power, although one never knows. I have tried to behave but it isn't easy for me. As a result of this strike, our elevator was out of service for about 2 weeks while parts were ordered to repair it. That wasn't the entire damage, though. The lightning also wiped out several telephones, a washer/dyer set belonging to one of the residents, some TV sets and our entry system. Before lightning, visitors used a phone in the outer lobby to call whomever they wished to visit and then were buzzed in. Not anymore. Until it is repaired, residents must physically go to the entry door and open it for visitors. Not an impossible task, you say. No, not if you are not on the second floor with no elevator and no way to get downstairs to the door. Thank heaven, the elevator is now working.

In the two weeks I had to ponder the situation, I decided that I needed to move to a downstairs apartment. I wasn't terribly interested in the one that was available, so I told our Resident Service Director that if the apartment belonging to Mary P. should become available at any time, I'd like to sell my apartment and buy that one. Mary was, at that time, in a nursing home recovering from a fall. The next morning our RSD knocked on my door to tell me that Mary had died from severe pneumonia. Wow. That was quick.

While visiting with one of our new residents, I mentioned my upcoming move and she immediately called her best friend to come and look at my apartment. The friend loved my big open kitchen and large airy living room and as soon as she was able, she put down her earnest money. So my apartment was sold before it was technically on the market. Not complaining, that's for sure!

So here I am, packing up, trying to downsize, wondering who to ask to help me with this truly monumental task, swearing at myself for being a pack rat. The new apartment has two bedrooms, so that will give me an office again. However, the kitchen and living room are not quite as big as what I have now. It does have more storage space than this apartment, though.

I also have to mortgage my farm for a period of about 3 months or maybe even less. My bank does not do bridge financing. That means bringing my abstract up to date, getting a title search done, and lots of paperwork to sign. Reams of paperwork, it seems like. Lots of trips to the bank, also.

Meanwhile my normally hectic life has not slowed down a whit. Do you see where this is headed? Can you see that Polio Wall looming menacingly in the near distance? Does that look like a sneer on its face or is it just me? I can't exactly take my time getting stuff moved, because the woman who bought my apartment is anxious to get in here and I'm, frankly, anxious to get her check so I can pay for my new digs. So I'm lurching around here between cardboard boxes and plastic totes, and slowly dismantling my six years worth of accumulation.

You know how I hate to ask for help, but if one of you or several of you could maybe put some chocks between me and that cursed Polio Wall, slow its progress down at least a little bit, I'd be eternally grateful. Thanks. I knew I could count on you.

Web Corner

A list of good doctors around the country

<https://www.facebook.com/groups/PostPolioCoffeeHouse/files/>

Kevin's Trip to Jamaica...a Brett approved article about accessible travel

<https://www.brettapproved.com/blog/kevins-review-of-secrets-at-st-james-montego-bay-jamaica/#more-485>

Rules are there to be improved

<https://medium.com/@martynsibley/rules-are-there-to-be-improved-943b12c790ab#.o18hu36o2>

Amigo Mobility webpage

<https://www.facebook.com/amigomobility/>

Mysterious Polio-like Disease

http://www.nbcnews.com/health/health-news/mysterious-polio-illness-paralyzing-u-s-children-n658766?cid=sm_tw

Hints on finding an accessible apartment

<http://www.transfermaster.com/blog/view-post/How-to-Find-an-Accessible-Apartment-Online>

New Apple watch designed for wheelchair users

<http://www.transfermaster.com/blog/view-post/Apple-Watch-Is-Wheelchair-Inclusive>

Polio Survivors Face New Disability

<http://www.scidev.net/asia-pacific/disease/news/disabilities-polio-survivors-treatment.html>

A Balanced Way of Living

<https://www.facebook.com/BALANCEDWAYofLIVING/>

End Polio Now

<https://www.facebook.com/groups/Pa.PolioNetwork/permalink/638308646329556/>

Other Polio Newsletters

<http://www.papolionetwork.org/support-group-information.html>

<http://www.papolionetwork.org/>

<http://post-polio.org/>

<https://www.polioaustralia.org.au/>

<http://www.poliosurvivorsnetwork.org.uk/>

A Little Bit of Humor

MAGIC LAMP

A man found a magic lamp on the beach. He rubbed it and out popped a genie, who gave the man three wishes.

The man wished for a million dollars and ***POOF***! There was a million dollars.

Then he wished for a convertible and ***POOF***! There was a convertible.

Lastly, he wished he could be irresistible to all women and ***POOF***! He turned into a box of chocolates.