APPA NEWS

The Atlanta Post-Polio Association

Volume 39, Issue 1

Spring 2024

Please, when using the stairs
Stay to the right when going up,
stay to the left when going down.
This will keep people from
running into each other.

Open to read the contents

APPA Quiz

How do we know when we
have too many books
on our shelves?

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Annual contributions help to educate the public and health care community concerning polio. We respond to the needs of individuals who suffer from post-polio syndrome through group meetings, educational programming, newsletters, and advocacy. APPA is a 501(c)(3) nonprofit corporation. All contributions are tax deductible.

To contribute and join APPA, see back page.

atlanta post-polio association

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APPA Board

President's Message

In the Sunday, March 3, 2024 Atlanta Journal Constitution. They printed some information about the Long Covid studies at Emory. "Dr. Alex Truong is the pulmonologist who oversees the long Covid clinic at Emory. There were nine clinics chosen to study long Covid and were given about $5 million dollars from NIH for the research. Since there are no established therapies, doctors are relying on approaches which have worked for similar symptoms. Antihistamines are used to improve energy and focus. Albuterol is used to improve breathing and low dose naltrexone is used for brain fog and fatigue. One of the trials at this time is the use of Paxlovid for lingering symptoms and sleep studies will begin shortly."

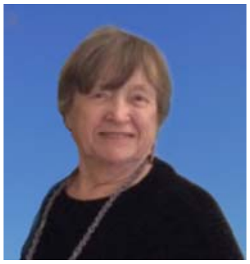
A few months ago Dr. Tiffany Walker, the lead investigator for the Covid clinic at Emory, gave a presentation about the Grant put together with a group, including Dr. Strasser. The Grant was awarded. She recently testified before Congress about post polio and long Covid and asked for additional money for clinic research. The idea of including the experience from Post-Polio in this research has to do with the hope that treatment of Long Covid or Post-Polio might have similarities.

About 18% of adults who have suffered from post Covid-19 have symptoms that last about three months." The Grady clinic is accepting only internal referrals but will open it up to patients outside the hospital system and self-referrals later this year. At Emory call the central scheduling number at (404)686-2505 and ask for an appointment with the Long Covid clinic at Emory University Hospital Midtown. There is currently a waiting list of about three months". Joe Drogan is the APPA liaison to these studies.

We have planned for APPA 3 in-person meetings: The dates selected are April 9 at the Olive Garden near the Gwinnett Mall, August 8, location to be determined and September 16 at the Shepherd Center for a picnic. December 4 would be the group's Christmas party. A party during the week will be cheaper and hopefully, more members can attend.

Please contact me for any suggestions for programs or issues of importance to you I am grateful to be serving as APPA President and find it to be a wonderful experience to affect social change.

Rita Carlson,
President



Welcome to new members.

Janice Irwin in Kennesaw
John Swett in Smyrna
Laine King in Stone Mountain
Everado Carbonell in Atlanta.

Soon we hope to be publishing a new APPA Directory for 2024-2025.
We also hope you can meet old & new friends at the APPA events.
Watch your email for those announcements.

Are Polio Survivors (and PPS'ers) Becoming extinct?

In the USA most people got the polio vaccine in the 1950's. This was not so for many other countries. In Australia, for example, it has been estimated that up to 40,000 people had paralytic polio between 1930 and 1988. From an article in the Australia Post Polio news: ***"we know that there are thousands of people with polio-related issues across Australia from as young as 30 years old. Hospitals will be seeing polio survivors for at least the next six decades."*** In other countries polio was still doing damage until very recently. What does this have to do with the Atlanta Post-Polio Association (APPA)?

We have the happy fact of living in the South, which is a pretty popular location these days, especially for those who no-longer want to tolerate the cold. Our support groups have a responsibility of educating ourselves and the medical community as to the best practices for managing PPS. Now it has been discovered that many people contracted polio, but did not know it or have problems until PPS symptoms occurred. This can mystify the clinicians who still don't know to diagnose PPS, after excluding other reasons for such symptoms. Some Polio-survivor support groups faded out due to age and lack of energy to maintain a group; but thanks to the internet a small group can just join another group. My hope is that APPA will continue it's mission and that enough of the younger/stronger among us will volunteer to keep it going.

From the Editor

The fun of being the APPA News Editor is laying out contributions from our own members. Big thanks to Joe Drogan who used to be APPA News Editor and APPA President, and continues to do a lot for APPA. This time I asked if he could write something else for this issue and he did. See page 15 on SLEEP and FATIGUE, and the mystery of what one has to do with the other.

Alan M. Oberdeck has always come through with fun thoughts to write up for us. He also is making calls and encouraging members to tell their own "polio-and-beyond" stories in the "Getting to Know Us" series. Last Fall Alan started boasting about the new light-weight power chair he had. His article will tell you all about it, starting on page 10.

My latest news is that I now also have this Chair and today powered around the doctors office and then to a restaurant. Some of the people around us were quite amazed that I had a foldable power-chair coming out from behind my driver's seat. So now I say: "Have-powerchair-can go places!" The chair and I might manage a few of the APPA in-person events this year.

My other comments are found here and there in this issue. APPA Event Highlights and other borrowed thoughts which I hope will be of interest to you. Thanks for reading the APPA News.

Nancy Winter

My own answer to the APPA Quiz: We keep books to be there for us at the right time and to suit the right mood.

What's your answer?

Highlights of APPA Events

December 2023—March 2024

December traditionally would have been the Annual Christmas Party. But plans had to change and the proposed party was cancelled. For in-person events we hope to have coming up in 2024, see the President's Message, page 3

January

January is usually our time to not have a First-Saturday-of-the-Month Zoom meeting. Only the APPA Board meets to wrap up the previous year and plan for the next. The APPA Board members are listed on page 2. However, some terms will end and we would love to have volunteers to give us input and consider serving on the Board in forthcoming years. It's generally fun to do because we are such a talented and friendly group. However we are mere volunteers, getting older and PPS has it's own challenges. Nevertheless, we hope to steward your membership donations to best serve you and the post-polio community. Speaking of membership donation, return to page 5

February — Red Light Therapy

February 3, 2024 . Dr. David Nguyen introduced us the treatments they use at Mercy Laser Therapy. One is red and near infrared light to treat injuries and reduce pain. The therapy treats the source of pain and improves muscle performance. Dr. Nguyen's practice is located at 3775 Venture Drive in Duluth. For more information call (404)350-7631 or see many videos on https://www.mercylasertherapy.com/

Mercy Laser uses the NovoTHOR® machine as a full-body red light therapy bed, using red and near-infrared light to treat injuries, relieve pain, relax muscles / joints, and increase blood circulation.

As usual our Zoom meetings are full of new information. Not only from the presenters but from our fellow PPS'ers (post-polio-survivors).

See next page for pictures and go to their website for more explanation and videos of this light therapy.

From https://www.mercylasertherapy.com/

Mercy Laser Therapy is a clinic established in June 2020 in Atlanta, Georgia. Theclinic is focused to bring health and joy to everyone. Through years of research and learning, our clinic has learned the use, and seen the results, of Laser Therapy. Our offices are equipped with NovoTHOR, a whole red light therapy bed that uses red and near-infrared light to treat injuries, reduce pain, relax muscles/joints, and increase blood circulation - all approved by the FDA

March — MUSIC

March 2, 2024.

Our guest presenter was Eileen Sterns who had some bits to share about being the younger sister of APPA member, Barbara Mayer. On the topic of being a sibling to a polio survivor, her comments were typical, in that the PERSON far outweighs the effects of polio.

Eileen for income is a court reporter. But her passion is as a musician and, most recently, the benefits of music as a non-pharmacological intervention for treatment of pain, brain maladies, and the process of death. During her talk I thought the term Thanatologist referred to harp players because she was a harpist. But a thanatologyist is someone trained in the process of death, like Hospice people. (in case you didn't know that word; I didn't and had to look it up).

Eileen is currently in the program to become a Certified Music Practitioner (CMP). Eileen will be able to use her musical talent to help in Hospice, nursing homes etc. She plays the harp (a travel-sized model) and gave us a demonstration of the various modes from music theory. Major, Minor, Dorian, Aeolian Phrygian, etc which evoke different feelings. Here are a few of the really cool concepts she shared with us.

An amazing fact about tempo and what music does to our nervous system even if patients are comatose.

A non-pharmacological approach to pain uses a concept "Gateway Management." There is a highway to the brain, but only some stimuli might make it. If one can crowd out the stimulae from the pain,

Continued on next page

Highlights from March: MUSIC Continued

i.e. with music or thoughts that come with it, it can crowd out the pain.

Synchrony: This is so cool. Our heartrate can be adjusted to match a rhythm of the music in the same way that metronomes will synchronize with each other. Eileen is right! Go on YouTube and look up "metronome synchronization " Wow, and this concept is spawning exciting research in about every subject, astronomy, chemistry, and cardiology.

The opposite of the "Fight or Flight Response is the "Relaxation Response". Obvious then to have music to evoke the positive response.

Memory Music. Playing something that the patient associates with a positive time.

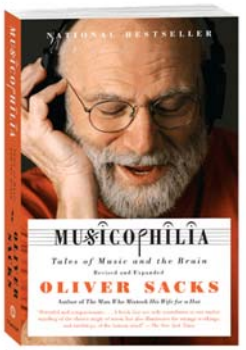
Prescriptive Delivery. Is knowing the patient to design the best musical therapy, i.e. don't play some song that they hate.

Holding Space. Setting the tone in a room before and after playing a song to let the music play without distraction and allow it to hold the space after the performance stops.

Transparency. In treating patients the CMP is not there to perform for her own satisfaction but to stay in the background and let the music flow.

A motto Eileen shared from a Hospice: "Healing beyond Cure". Eileen plays many instruments. She performed her own song on the harp. Beautiful!

Last week the Boca Area polio group was entertained and educated by Diane Wall, a polio survivor and music therapist. Her focus was more toward music for mental health. She demonstrated samples of the many music genres that can be used. Her first sample was "I love Rock n Roll" She recommended reading more from Oliver Sacks. https://www.oliversacks.com/oliver-sacks-books/musicophilia-oliver-sacks/ — check this out, but not before you finish reading this APPA News.



If you like the old rock sound but prefer lyrics of faith rather than youthful lust, check out WinterBand on YouTube.

My wonderful, new Journey Chair and the Journey it took to find it.

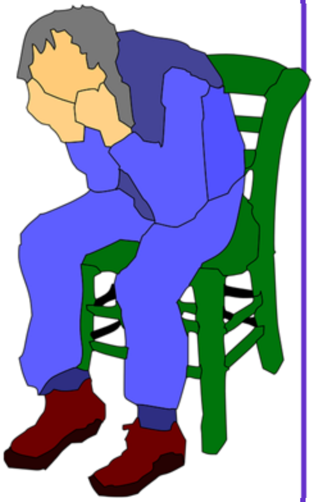
By Alan M. Oberdeck

When I recovered from polio in 1953 I progressed from wheel chair to "Kenny Sticks" (Crutches that had the top portion cut off about 5 inches above the handle and at that point a leather circle was riveted to each of them.) I used them until I was strong enough to walk on my own and not fall down.

Then I put them aside. I continued to gain strength. I began to try to fit in and not become a "cripple" and look like a normal person. That attitude continued for the rest of my working life. When I became tired I would develop a slight limp.

28 years ago I fell and shattered my tibia plateau, ("How I got run over by a waitress and survived", article in APPA NEWS Winter to Spring 2023). After I mended I had to use a cane which continued well into my retirement. I was still as independent as an 80 year old could be.

I was able to go anywhere. About 3 years ago I fell and began using a walker. At that point I was as independent as one using a walker could be, but the distance I could go before getting tired became shorter and shorter. Eventually I was unable to climb steps. It got so bad, I began using an electric wheelchair with my walker to get around in the house. It became challenge to use the walker to go to church and Walmart was out of the question! During that period my legs became so weak that I was finally unable to get up from a normal chair. I could get up from a chair if it had arms.



Then my weakness progressed so I had to use a 4 inch foam pillow in the seat of the armchair to give me enough height to get up out of the armchair. Then I crafted a 6 inch pillow, which I carried around with me when out of the house, made from Styrofoam to be able to easily get up from the armchair. I chose Styrofoam because the pillow had to be light enough to carry with me when I visited places. I had to even change my car to one I could get out of. Except for going to church, essentially I was housebound. I could only go places that had armchairs.

At that point going to the doctor required my wife to go into the doctor's office to get a wheelchair out to the car to wheel me into the office. I found that placing the Styrofoam pillow on the seat of the wheelchair gave me enough height to let me get up from the wheelchair without help. Now all I had to do was find a wheelchair that was light enough so my wife could lift it into the trunk of my car and we could go places together again.

It had to be able to go by itself as my shoulders wouldn't cooperate with me propelling it by hands with the rings on the wheels. I didn't want to have to have my wife, or a care giver, have to push me everywhere. I went on the internet and found many ways to cart around a wheelchair on the back of the car. None of them seemed practical in my case as they, in themselves, seemed to have more restrictions on my freedom to go where I wanted to.

I looked, on the internet, at portable light electric wheel chairs that fit in the trunk of a car. There were several offerings, but they all weighted over 50 pounds and I would have to have a strong caregiver to help me go anyplace.

Then in one of the magazines I subscribe to I came across an advertisement. It was for an electric wheelchair that was light, folded to fit in a car and weighted only 37 pounds. My 80 year old wife lifts 40 pound bags of dirt out of the trunk of her car. I showed the advertisement to her.

We called the number and after talking to the salesman on the phone I ordered it. It arrived in 10 days and was easy to set up.

When I had inspected it and read the directions, and there are a long list of do's and don'ts, I placed my Styrofoam pillow on the seat and tested whether I could stand up from the chair with no help. I passed that test. I then plugged it in to charge it. It came with a charge that was good enough for the first tests, but I wanted to make sure it was well charged before I used it.

A day later I used it around the inside of the house. It is less than 18 inches wide and can go almost anywhere in the house. It was slower than my Invocare Pronto M 41, but was very maneuverable and easy to use. The way the arms fold up I could wheel right up to a desk or table and sit as though I were sitting in a regular chair. We drove it into the garage and to the car. It fit nicely into the trunk of the car. It was easy enough for my wife to lift in and out of the trunk.

I tested the chair out onto the driveway and it took the slight hill with ease. I drove it on the gravel part of the driveway and it handled it well. Because the instructions said "don't use on grass", I didn't try it on grass. I was able to drive it into the back door of the house with a makeshift ramp. Our first outing was to Lowes lumber store in Milledgeville to by a proper ramp. That was a success.

Our second outing was to Walmart in Milledgeville to go grocery shopping. I annoyed my wife by following her around!
Our third outing was to Walmart in Eatonton where I ran it for a long time to run down the battery.

It works well at church. It handles parking lots rather well. We went to the doctor.'s office in 18 degree weather and it worked well. It lives in the car trunk to be used when we go out.

I finely, after running it for a long time, brought it in the house to charge the battery. I had planned to use the walker to go to the car, in the garage, and ride it into the house using the proper ramp we had bought at Lowes. My wife would bring the walker when she followed. That was the plan. So when I told her that I thought it was time to recharge the battery she immediately went out to the car and, it being so light, wheeled it into the house and parked it where we charged it. It is that light and handy!

It is not as flexible as the walker in getting around in the stores, "people get in the way". But, at least I can get out of the house and go to the store now. I hadn't been in a Walmart in 2 years!
The way the arms fold up I can eat at a regular table in a restaurant! So that gives us more flexibility in places we can go out to eat.

So if you are still walking with a cane or a walker, but you are reluctant to go places that are very tiring and you are avoiding them. If you have come to that point, there is an answer and it will ride in the trunk of your car.

It is made with "space age materials" which ate mostly carbon fiber filaments molded with a resin to form the parts. It has a removable battery which weighs about 10 pounds. Funny thing, though, the battery is not connected to the wheelchair with wires; it is up against a sensor which conducts the energy from the battery without any physical connection! Amazing!

My experiences so far:

- In cold weather it runs slower from the car to the store.
- The controller stalk slips into the handle and is held by a knob that screws in to make it tight. The purpose of this is so you can turn it upside down out of the way when it is in the trunk of the car.
- The push handles at the back of the chair seat fold out of the way for it to fit into the trunk.
- It readily goes over 1 inch door thresholds.
- So far I have not run the battery down into the yellow range as the green range has been sufficient for all of my ramblings and I have charged it before it got to the yellow range.
- When the battery needs to be charged it can be easily removed from the chair in the trunk of the car and brought into the house as there is a charging port in the side of the battery.
- The one drawback is that it can't be run outside in the rain. It is not waterproofed and water would short out the electrical.

Places I have been using my wheelchair (All on the initial charge of the battery)

- Lowes.
- When going to church I can now park in the parking lot.
- I have been to Walmart several times and it handles that parking lot rather well.
- I have used it to go to the Doctor's office on several occasions.
- It works well at Cracker Barrel Restaurant as I can easily sit at a table.
- It worked equally well at Waffle House even with the narrow aisles.
- I used it to vote.
- I was able, with a portable ramp, to get over the three inch thresholds in my daughter's house. (A 2 foot by 27 inch piece of 3/8 thick plywood will fit in the trunk under the wheel chair and is long enough to get over a high threshold.)
- I visited AutoZone and bought car parts.

Want to get a Journey Chair?

Note from the editor

After I read this and listened to Alan boast about his new Journey Air Elite Chair, I realized this could be the chair that would work for me. Then we found a way to make it easier for other polio survivors, especially APPA Members and veterans. Our home business, Sellcom Inc, received permission to sell these chairs and offer special discounts.

Please call me if you want more information. As a fellow PPS'er, you might be afraid to disturb me by a call. This phone number stays off when I'm sleeping. So be assured, anytime is fine and I will be most pleased to speak with you about this chair (or anything else).

If you would like to try the Air Elite, you can come over to test mine, or, now that I am finally more mobile, we can meet at some mutually convenient and accessible location, like a parking lot.

This chair is to be a life-changer for us. Among its advantages, it weights only 29 lbs, and folds flat enough to fit into our car, even behind my driver seat. And it will fit into any sized car for the times my friends or grandchildren want to take me and the chair on an adventure.

See below, Steve Winter can lift the chair with one finger. As long as I'm holding onto something, my arm strength is enough to leverage it in and out of my car. We have other Journey powerchairs on our webpage: which I will continue to work on—when I get done with this issue.

www.USAPowerChair.com

Hope to see you there.

The Journey Chair is not a Medicare item. But this new Journey is the lightest power chair being sold. It is the best option until they come up with the flying carpet.

Nancy Winter
919-612-7841
www.USApowerchair.com

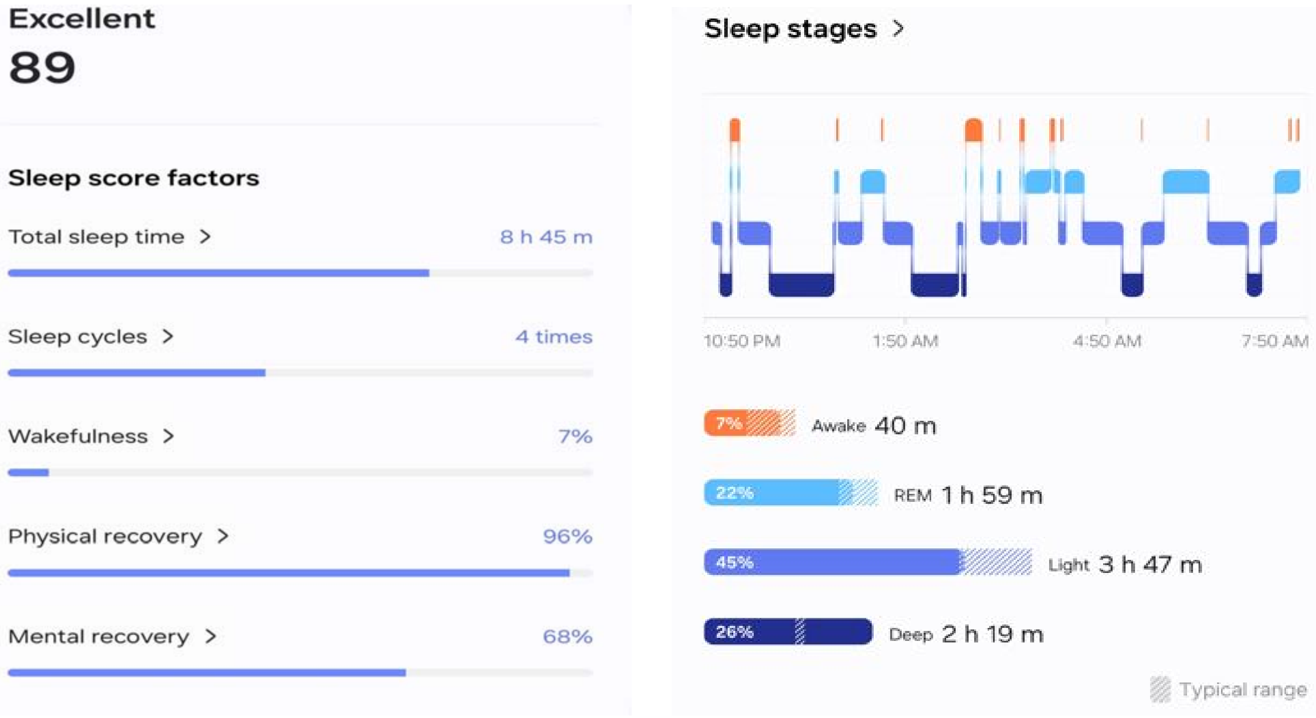
Post-Polio Syndrome Fatigue and Sleep

By Joe Drogan

This article could also be titled: “Adventures in Science and Writing.” That is what happens when you have an idea or premise for an article that fails to play out as anticipated. My theory was that Post-Polio Fatigue could be alleviated or at least improved by better quality sleep. Makes sense doesn’t it? Quality sleep improves fatigue for non polio people so shouldn’t it follow that it would help with Post-Polio Fatigue as well? I’ve been studying my sleep for many years now, since I was diagnosed with Central Nervous System Sleep Apnea and prescribed a CPAP machine.

This whole latest sleep adventure started a few months ago. I was interested in improving my energy levels and improving my PPS fatigue days. When they occur they completely ruin my entire day. There seems to be no rationale for when they occur. Others have told me the same thing. One thing that does seem to happen for a lot of us is that there seems to be a delayed reaction to an extra busy day. For example if we overdo it on say Monday we’d expect to have a fatigue day Tuesday. What often happens is that we are fine Tuesday but have a severe fatigue day on Wednesday. It’s like it skips a day then caves in on us. Why?

Reports generated by the Smart Watch and shown on the phone.



Excellent
89

Sleep score factors

Total sleep time >	8 h 45 m
Sleep cycles >	4 times
Wakefulness >	7%
Physical recovery >	96%
Mental recovery >	68%

Sleep stages >

7%	Awake	40 m
22%	REM	1 h 59 m
45%	Light	3 h 47 m
26%	Deep	2 h 19 m

▨ Typical range

Sometimes we get an afternoon crash too. When that happens there is no avoiding it we are simply "done for the day."

There are also the brain fog events. They feel like when I used to be on a 14 hour day programming computers. Your brain simply says "no more" I'm done and refuses to think anymore. Sometimes a break will help but not always.

Nobody seems to know why the fatigue days occur anyway so I set out to see if sleep played a part in it. In order to do this I needed to analyze my sleep. I have a new "toy" called a smartwatch. Mine is a Samsung Galaxy6. Apple also makes one and Oura makes a ring you can buy that is similar. I love the watch, it does a lot more than just analyze sleep. It is an extension of my smart phone.

It reminds me of calendar events, track my steps to ensure I don't overdo walking, shows the weather, it can measure my electrocardiogram (ECG), and body composition. It even has a timer (so when I let my kitty Spooky out onto the screened porch I don't forget to let him back in!) Disclaimer…these devices aren't medical grade instruments and are only for an indication of various medical readings. That being said, between my CPAP machine and the watch I get a pretty good reading on my sleep. It even measures my oxygen levels overnight and seems pretty accurate as compared to the fingertip pulse oximeters I have.

The bad news is that, at least for me, my quality of sleep doesn't seem to affect my PPS fatigue days. When they occur they just do. Is the fatigue lessened? It's hard to say for sure. Is there a way to accurately measure fatigue? The CPAP machine measures sleep apneas both blocked airway and clear airway hypopneas which can cause fatigue.

I had no idea going into this how important and complicated sleep is. Last week was National Sleep Awareness Week, coinciding with Daylight Saving Time (DST.) DST is a whole subject in itself. A one hour time adjustment seems to cause all sorts of problems as people adjust to it as evidenced by an increase in car wreaks during the next days commute. There is a lot to unpack here. The smartwatch has sleep coaching on it. When you run it you are walked through a routine designed to improve your sleep. There are tips that are meant to improve your sleep score. Most make sense but there are caveats. For example they say to avoid screens like TV, your cell phone, and tablet for an hour before bedtime because they emit blue light that interferes with your being ready to sleep. But if that's true why do we sometimes fall asleep while watching TV? Some people tell me they can only fall asleep with the TV on in the bedroom.

Caffeine can affect sleep. When I was an IT guy we worked 60+ hours a week sometimes more when disasters occurred. We lived on caffeine. Now any caffeine after 10AM will sometimes prevent me from falling asleep 12 hours later at bedtime. But why then do I nod off around 7PM watching TV then have trouble sleeping at 10PM? One time I couldn't sleep all night so around 3AM I gave up and got up. I drank two 20 oz mugs of strong coffee and around 9AM was falling asleep at my desk! Is the caffeine thing all in my head? Sleep is tricky.

A while ago I found I was waking up every morning at 3AM. It wasn't to use the bathroom, I just was waking up. It drove me nuts until I gave up and decided it just is what it is and decided to stop worrying about it. That very night I quit waking up at 3AM. I think I was programming my brain to wake up at 3AM to check and see if I was going to wake up at 3AM! Like I said this sleep thing is tricky.

Here is a list of sleep tips. If your sleep is a big issue I'd suggest you incorporate as many of there as you can and see if there is an improvement. Then you can one by one eliminate one at a time to see what works for you.

Stop late-night screen use. Maybe stop taking your phone or tablet into bed with you. Even with the blue light filter some devices have the content, bright screen, and mental stimulation tells your brain you aren't ready to sleep yet.

Try meditating for a few minutes or so before bed to relax your mind.

Try reading a book, just not on a electronic device, and nothing too stimulating.

Try and maintain a consistent sleep schedule, as in going to bed and getting up at the same time. I have trouble with this one as I love to stay in bed in the morning, snuggle with my kitty Spooky and check on current events, the stock market futures etc.

Try and only be in bed for sleeping so your body learns to associate being in the bed with sleeping. Make your bedroom as dark as possible. No late TV drama/politics/news.

One thing I'm doing that has helped a lot and isn't mentioned anywhere in the research I've done is to try and get all ready for bed at least a half hour before bedtime. By that I mean check the house, doors locked, cuckoo clock wound, teeth brushed, prayers said, Spooky has food and water, lights are mostly off, morning coffee setup done, phone is on it's charger, and overnight glass of water is on the nightstand. When all that's done it's a little light TV like old Cheers reruns and then it's just a quick and easy trip into bed!

It's also important to find what works for you as an individual. I have a little trouble with acid reflux that was making me be congested overnight and in the morning. I found an easy solution for it. I try and eat dinner early. Is that why the Senior Special in restaurants is at 4PM? I also avoid evening TV snacking which also helps with weight maintenance.

I discovered that using a wedge shaped pillow to elevate my upper body a bit made a huge improvement in that congestion. My doctor says the acid irritates my esophagus and my system produces mucus to alleviate that. Also as an added unanticipated result my lower back pain is very much improved with the wedge pillow. I did not see that coming!

My doctor says I need 60oz of liquids a day (decaf coffee counts). Any time of day is ok so I try and drink them all in the morning and very little after 5PM. If I do that I'm less inclined to need to use the bathroom overnight.

We love our pets, there is no denying it. Do they interfere with our sleep? Maybe but most, if not all, declare without hesitation it's worth having their sleep interrupted by a pet that wants a little middle of the night snugglin'. When I first adopted my kitty Spooky he kept me awake all night "checking on" me every 20 minutes or so. I had to close the door to keep him out which he was ok with but now he's 4 years old and he comes to "tuck me in" and then only checks on me once or twice a night and wants a few minutes of cuddlin'. In analyzing my sleep data it doesn't seem to affect my sleep scores so the door stays open.


"Spooky"

All of this being said where does that leave us? Well it seems to me that all of this "sleep science" is fuzzy science. By that I mean there are all sorts of sleep gauges, indicators and rules pertaining to sleep but they don't appear to be hard and fast in nature. I can follow all of the so called steps, tricks and get a so-so nights sleep. Conversely I can break all of the rules and sleep great.

A lot of it is sleep pressure. Have you ever had a big day planned for tomorrow and said to yourself "I really need a great nights sleep tonight" only to find yourself wide awake at 3AM saying this is gonna be a disaster tomorrow. Have you ever gotten to sleep too late and said "I need to sleep fast?" Have you ever said "I really need to stay awake until midnight" maybe to see a comet or the ball drop on New Years Eve only to wake up at 3AM to realize you missed it.

I once nodded off driving home from a beach party (there might have been alcohol involved) for a second I dreamt I was driving down the road just fine. Apparently one of the ways to get killed in a car. Also one of the many times God felt He wasn't quite done with me here yet. The feeling of the road getting rough as I left the pavement woke me up.

One thing I realized long ago that really helps me is that if I am awake for what feels like all night I'm fine the next day and will sleep like a baby the next night. The less I worry about sleep the better it is. My sleep isn't as good when I wear the pulse oximeter on my finger overnight to test my oxygen levels. Has anyone ever slept great at the hospital during a sleep study? It seems like what works is to follow as many of the "rules" as I can and it almost always works out pretty well.

There will be exceptions and what works for one may not always work for someone else. I've been working on and interested in my sleep for a long time starting way back when I was prescribed the CPAP machine. I review my CPAP data and pay attention to what it tells me. The last time I saw my neurologist he said he's only ever seen one patient with better CPAP "numbers" than mine. Did somebody say "challenge?" My numbers have improved ever since. One measure is called AHI (Apnea Hypopnea Index). A reading of 5.0 or less is considered normal. My readings have improved to an average of .4 for many months now. Last night my number hit zero for the first time ever! It appears that all this work on my sleep has vastly improved my CPAP numbers.

Bottom line is when my sleep is better it doesn't seem to improve PPS fatigue days. I need to keep better track of when they occur but it does to be subjective to some degree. Am I having a fatigue afternoon or just being lazy? A friend calls to say "Hey that pretty girl you said you are interested in wants to meet for coffee" and I'm too fatigued to want to go. *That's a fatigue day*. The good news is that if I improve my sleeping my non-fatigue days are better than ever and I can somewhat make up for the days I'm fatigued. In other words my good days are even better and who doesn't want that!

Now if I could just convince Spooky to be diurnal instead of nocturnal things would be even better. As I write this at 4PM he's fast asleep in "our" bed.

Hope you learned a little bit about sleep. I need to wrap this up and go meet somebody for coffee. At 4PM you can bet it'll be decaf!

Spooky—after being told he'd be on the cover of the Spring 2024 issue of APPA News!

Update on the Long Covid Project : Excerpt of email from Dr. Strasser

...The Long Covid Project is just getting ramped up. The program director, Dr Tiffany Walker, sees commonalities with Long Covid and other post viral syndromes like PPS, and longer term, she would like to include individuals with such conditions. Part of the issue now seems to be that Dr. Walker can't figure out how to involve polio survivors, partially because of the funding restrictions of the grant. …..

Here are a few suggestions if APPA members are still interested in helping with this project. ….Brainstorm among yourselves on how you as a group or as individuals could help, and offer some suggestions. Perhaps ask her to provide an update to APPA in a future meeting. She could even pose questions to the group on how to manage certain situations.

Again, I believe polio survivors have unique insights into the plight of Long Covid patients which could be helpful. The issues of "brain fog", fatigue, difficulty being taken seriously, and adapting to loss seem quite similar between PPS and LC.

Please, when using the stairs
Stay to the right when going up,
stay to the left when going down.
This will keep people from
running into each other.

This picture came from a miscellaneous site on Facebook. It illustrates the sort of thing that happens when bureaucrats make decisions and post rules without the full understanding.

Speaking of Advocacy:

APPA Member, Leslie Schulgen recently ran into this ("bureaucratic nonsense") when the door that many people use to get to the swimming pool, was locked. People could exit, but no longer enter, from the parking lot. This created much difficulty to get to the pool area without an arduous walk. Evidently, it was felt that outside access to this door presented a security problem. Since then Leslie has been advocating for those who want/need this door. This has not been an easy task. There are likely other ways to solve one problem, like security, and still maintain the access people enjoy, in this example, to get into pool therapy sessions.

The history of the post-polio movement included advocating for accessibility. The result was the *American Disability Act*. Some of our APPA Founders were involved in that Act, including Linda Priest. Who will be presenting to APPA on Zoom in April It is thanks to such advocacy that we have ramps on sidewalks and into places of business. But access still requires effort and awareness of problems when they exist. Two examples I've noticed are heavy doors that are hard to use. Or grocery stores that have the handicap parking on the door farther from where they provide the powerchairs. We can advocate for better solutions than people "running into each other on a stairway."

Bruno Bytes: Constipation Nation?

Excerpt from October 1, 2018
https://polionetwork.org/bruno-bytes

CONSTIPATION NATION?

Polio survivors have slow guts thanks to poliovirus-damage to the vagus nerve (see above) that should provide stimulation to move food from your mouth all the way through to the other end (see articles in The Encyclopedia of Polio and PPS).

Here are some things about constipation you may not know:

1. Constipation isn't one thing. Sometimes poo gets stuck in the ascending colon on the right side of your belly, sometimes in the transverse colon across the top of your belly, sometimes in the descending colon on your left side or in the rectum. So, you have to focus treatment where constipation occurs.

2. Not all laxatives work in the same way or in the same place.
- Roughage and Senna irritate the whole colon to make it move;
- Miralax and Colace add water to your poo to "lubricate" the colon;
- Dulcolax stimulates the ASCENDING colon if you get plugged there;
- Psyllium absorbs water and expands to stop diarrhea but also combines with sludge to make one single poo (and not lots of little "rocks") that itself stimulates the colon naturally to make things move. (You should plan to sit on the throne after eating to take advantage of the natural stimulation caused by food in the colon);

- Magnesium supplement may help with moving things along.
- Suppositories and enemas are for rocks in the lower colon and rectum.

3. If nothing is moving, your stomach isn't emptying or the colon won't respond to the above treatments, there is a great drug -- domperidone (sadly NOT Dom Perignon) -- that directly turns on the muscles that empty the stomach and move the colon.

Domperidone has no side effects and doesn't enter the brain (as does Reglan, which can cause Parkinson's-like shaking and should not be used by polio survivors). Of course, the FDA hasn't approved domperidone even though it's been sold over the counter for 20+ years in Europe for nausea during pregnancy!

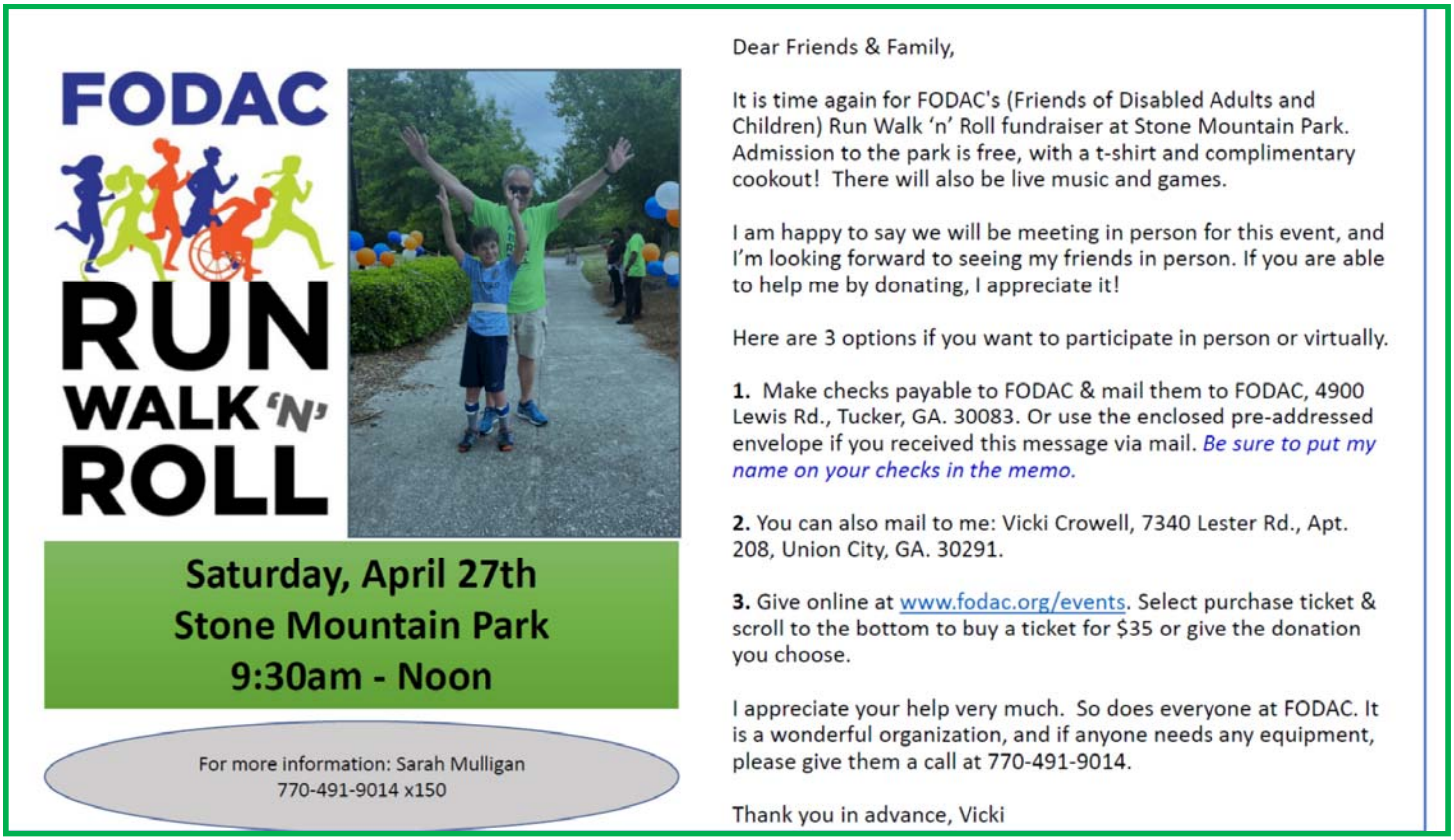
Bruno Bytes: Constipation Nation, Continued

So, there's a short course on pushing poo. You may need a combination of treatments or different treatments at different times for different types of constipation. Keeping a poo diary (quantity, quality and time of day) that includes symptoms and what laxatives you've taken is vital so that you can identify your natural rhythm, where things get stuck and what you need to take to make things work.

Happy eating (and the other thing).

Acting a bit strange lately? (from the editor)

Sudden onset dementia or delirium. Caution to old folks and their family members. A sudden change in personality can sometimes be caused by an infection. UTI’s do not manifest in elderly like they do in the younger folks. This is something I learned years ago through Certified Senior Advisory (CSA.us). Since then this one small piece of knowledge has been helpful to 5 families, so I’m sharing it here. When we hear so many stories about Alzheimer's, and our kids might be anxiously watching for those symptoms in us, it is good to know that dementia has many treatable causes. There are now more studies and discussion about this by just searching “acute onset dementia and UTI’s” . In looking around for appropriate clip art to dress up this page, I discovered this website: www.betterhealthwhileaging.net. Don’t get lost in there be-



FODAC

RUN WALK 'N' ROLL

Saturday, April 27th
Stone Mountain Park
9:30am - Noon

For more information: Sarah Mulligan
770-491-9014 x150

Dear Friends & Family,

It is time again for FODAC's (Friends of Disabled Adults and Children) Run Walk 'n' Roll fundraiser at Stone Mountain Park. Admission to the park is free, with a t-shirt and complimentary cookout! There will also be live music and games.

I am happy to say we will be meeting in person for this event, and I'm looking forward to seeing my friends in person. If you are able to help me by donating, I appreciate it!

Here are 3 options if you want to participate in person or virtually.

1. Make checks payable to FODAC & mail them to FODAC, 4900 Lewis Rd., Tucker, GA. 30083. Or use the enclosed pre-addressed envelope if you received this message via mail. *Be sure to put my name on your checks in the memo.*

2. You can also mail to me: Vicki Crowell, 7340 Lester Rd., Apt. 208, Union City, GA. 30291.

3. Give online at www.fodac.org/events. Select purchase ticket & scroll to the bottom to buy a ticket for $35 or give the donation you choose.

I appreciate your help very much. So does everyone at FODAC. It is a wonderful organization, and if anyone needs any equipment, please give them a call at 770-491-9014.

Thank you in advance, Vicki

APPA has a close relationship with FODAC. Through the APPA Special Needs Assistant Funds (SNAF) we can contact FODAC and let them know if we are in need of some sort of equipment. They accept donations of medical equipment and often have refurbished items available. APPA pays our $25 membership to FODAC and our SNAF funds are there to help us pay for particular items. For example, I had a rollator that was too big for me. FODAC had a smaller one and we made the trade. Then the bearings in the another rollator had broken. FODAC couldn't replace the wheels at the time, but did have a replacement rollator on hand. Then I needed a powerchair to use in my home. They had a used one that has served me well thesepast few years, if you read the APPA News you would have heard me boasting about that.

FODAC raises funds through the annual **Run Walk'n'Roll at Stone Mountain** and APPA Member Vicki Crowell has often made headlines as the winner in the race.. Let's help her do it again this year. FODAC has a marvelous **Thrift Store.** At least one of our members was able to downsize and donate really nice furniture to their Thrift Store. I was able to go and buy some really fine clothes and other items. The following two pages explain this program. If FODAC doesn't have what you need, there is an application for access our Special Needs Assistance Funds. These will pay directly to vendors to purchase custom medical devices. This year Georgia Gives raised about $1,800 which continues to support our SNAF Program.

SPECIAL NEEDS ASSISTANCE FUND (SNAF)

SNAF PURPOSE: To give financial support to our APPA polio survivor members who need assistance in purchasing, refurbishing, repairing or installing needed medical devices.

APPA, in partnership with FODAC (Friends of Disabled Adults and Children), will help ease the financial burden by using the following guidelines to make efficient use of our available funds in accomplishing this purpose.

GUIDELINES for using FODAC:

1. Any post-polio survivor member with two years of uninterrupted dues payment and eligible 24 months from 1st payment can apply for up to $1000 per year with a lifetime limit of $3000.
2. APPA's SNAF funds will pay:
    a) One time $25 FODAC membership fee
    b) FODAC's cost for parts, all repairs and refurbishing of devices.
    c) A $25 contribution to FODAC for each repair/refurbishing service
3. An item can be secured or refurbished from the FODAC facility near Stone Mountain, GA. Equipment may be secured at any of the FODAC facilities in Georgia, when available. It will be necessary to call FODAC (866-977-1204) and explore the availability of equipment* or repairs/refurbishing and installation service requests for a specific devices (lifts, hand controls etc).
4. APPA will cover all expenses for APPA polio survivor members involved in using FODAC services up to the previously stated limits (#1,2). The SNAF Application for Custom Medical Devices is only need for items that are not on the attached price list.
5. If, or when, the medical device is no longer being used, it should be returned to FODAC.

* FODAC requires a detailed doctors **prescription on very costly items** (scooters, etc)

***Questions**? Contact the SNAF committee at*
appasnaf2020@gmail.com

SNAF APPLICATION for CUSTOM Medical Devices

(Devices to be purchased from Vendors <u>other than FODAC</u>)

Do not make a purchase without preapproval. **Check for approved funds will be made out to the vendor. COSTS will NOT BE REIMBURSED to any member.**

An applicant who is a Post-Polio Survivor must be an active APPA dues paying member with two years of uninterrupted dues payment and eligible 24 months from 1st payment before submitting request. The member can apply for up to **$1000 per year** with a lifetime limit of **$3000.**

APPA members requiring a device with highly specific custom requirements, should consult with a medical provider and request a prescription. For other custom needs, appropriately documented price quotes MUST be included with the application when the request for funds is submitted for approval.

1.	Last Name: First Name
2.	Device and or Service requested (be specific)
3.	Cost and description for any custom medical device (not currently available at FODAC). Cost ____________________ Description of medical device or equipment needed (Attach any documented quotes)
4.	Medical Needs verification—Doctor prescription (please attach copy)
5.	Vendor (name, address, phone)
6.	Approximate date needed

Mail application with attachments to: APPA SNAF Program
2627 Glenrose Hill, Atlanta GA 30341

Please contact us to confirm we received your application.
Contact the SNAF committee at appasnaf2020@gmail.com

The APPA Cure — Only $25/year.

Guaranteed to ease any drudgery from PPS. Absolutely no adverse side effects.

Remember your annual donation to APPA. Paid membership gives you invitations to special events, the e-version, the printed version of APPA News, and more. When you have two years of consecutive paid memberships you are eligible to receive the SNAF benefits of APPA.

Special Thanks to Pat Harris and her Member Services Committee

Over the past 5-6 years Pat Harris and the APPA Outreach Team have mailed hundreds of Birthday, Anniversary, and other cards to APPA Members. They also make phone calls to check on members who are homebound and/or not able to join us on virtual events. It is through Pat's efforts that APPA tries to assure that all members have the personal support they need, especially when going through a particularly tough time.

Our Sympathy to
Leslie over the
sudden loss of her son Dale.

Also this year we note the passing of
APPA Members:

Mary Ann Henderson
James Harrison

THE APPA VISION: The Atlanta Post-Polio Association (APPA), for nearly 40 years, has helped to educate the public and the health care community concerning the late effects of polio. We respond to the needs of individuals who suffer from post-polio syndrome through group meetings, educational programs, newsletters, website, online discussion, and advocacy. APPA has a Special Needs Assistance Fund (SNAF) to help members who need to be financially assisted with devices that increase stability and mobility.

THE APPA MISSION: Provide a supportive and educational environment to exchange accurate information and resources about Post-Polio issues among our Polio survivors, families, friends, and caregivers.
Provide awareness, social, and spiritual needs of polio survivors. Assist Polio survivors and their caregivers in managing and coping with the effects of Post-Polio Syndrome.
Encourage the participation of APPA Members to share their skills and insights with APPA.

JOIN APPA

☐ Individual	$25	☐ **Gold**	$100
☐ Family	$45	☐ **Platinum**	$150
☐ **Bronze**	$50	☐ **Corporate**	$250
☐ **Silver**	$75	☐ **Lifetime**	$500

Additional Contribution $__________

Atlanta Post-Polio Association
1036 Parkway Court
Buford, GA 30518
Make checks payable to: **APPA**

APPA is a 501(c)(3) nonprofit corporation. All contributions are tax deductible

Please **CHECK** all that apply.

◊ I am a new member.
◊ I am renewing my membership.
◊ Please update my contact information as shown below.
◊ I am unable to contribute at this time but would like to receive the APPA NEWS.
◊ If I have an extra printed copy of APPA NEWS I can share it with a friend or leave it in the reading area of my doctor's office. Many PPSers are moving to Georgia, this way they might learn about APPA.

We need you! Would you be willing to serve APPA in any of the following areas?

◊ Membership outreach (phone calls to shut-ins)
◊ Public relations
◊ APPA phone tree
◊ Fundraising
◊ Programs
◊ APPA NEWS (write articles, proofread)
◊ Database assistance
◊ Assist at social events
◊ Assist with APPA phone line
◊ SNAF Committee
◊ Story tellers

Name(s) ____ DATE __________
Address ____
City State Zip ____
Telephone _____________________
Email Address ____

The information provided herein represents what the authors believe they heard during **APPA** presentations. The authors are neither legally or medically trained and their opinions are their own. **APPA** does not assume any responsibility for the accuracy of the information provided. APPA NEWS is for fun, outreach and support and sometimes useful information. The Editor will be most pleased to hear from APPA NEWS Readers.

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1036 Parkway Court
Buford, GA 30518
(404) 350-7631

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THE BLIND OR
HANDICAPPED
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Look for us…..we're on the web.
www.atlantapostpolio.com

APPA NEWS

Atlanta Post-Polio Association

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Nancy Winter - Editor

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