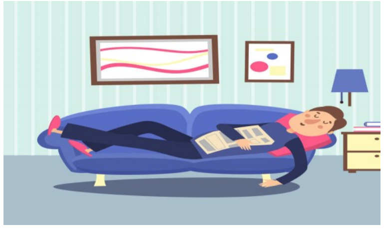
APPA NEWS

The Atlanta Post-Polio Association

Volume 37, Issue 3

FALL 2022

DO NOT READ THIS all in one sitting. There is only one proper way to read the APPA News, like this



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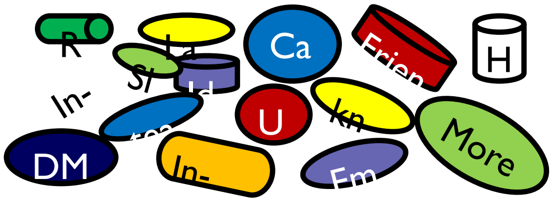

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Annual contributions help to educate the public and health care community concerning polio. We respond to the needs of individuals who suffer from post-polio syndrome through group meetings, educational programming, newsletters, and advocacy. APPA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

atlanta post-polio association

President's Message Rita Carlson

Our group continues to thrive as polio survivors. It has been my pleasure to continue to promote APPA's mission of support and education through Zoom. As the pandemic subsided we were also finally able to meet two places over the summer: At the Olive Garden for Lunch and Bogan Park for a picnic.

Under the planning leadership of Belinda Whitaker, our Christmas Party is to be held on December 3rd. By the time you receive this APPA News, hopefully you would have attended. If not. We will try to write a report with maybe some pictures in the Spring 2023 issue.

Rotary President, Jennifer Jones, announced there is a $150 million pledge to New York City, toward polio eradication for vaccinations and additional funding will go to the Global Polio Eradication Initiative for the start of a massive effort of the initiative's goal of US$4.8 billion funding goal.

On October 25th, Carol Crumby and I, along with Michael Yochelson, attended the Rotary meeting. I gave an overview of APPA and Carol gave a presentation about the timeline of polio and the post-polio sequelae.

Beth Petrunich, MBA, MSPO, COP(L), Assistant Clinical Professor & Orthotics, of the Department of Exercise Science and Sport Management has a need for models for a history and physical evaluation, under the supervision of their clinical faculty, for the research project. She invites our members to participate in the project. She will pay a modest amount of money to the participants. Please call her at (404)210-4238 if you desire to participate in the program which is held at Kennesaw State University, Kennesaw, Ga 30144-5591. Some other research participation options are on page 26.

Michael Yochelson, Chief Medical Officer at the Shepherd Center, with Carol & Rita.

Editor's Note

Support groups = making new friends, keeping in touch with old friends, having something in common to share life's journey. When APPA gathered in-person, back in the early years. Most members were still getting around and in the workforce. Now we might have a greater share at home, retired and not getting around so well. This is where covid has improved things for us by the Zoom gatherings. It is nice to see all our faces there, learn stuff together, and be able to chat as a group about things that are a shared concern.

Some folks in APPA have been a part of this support group since before 1985. They served on the board, and other volunteer functions, attended in-person meetings, and created some 60 yearlong friendships. Others of us came in later, lots of us transplants to the sunny south and others who decided PPS-denial was no longer working for them. The newer folks might wonder how to be more connected to APPA, I know I did, until 3 years ago.

After Alan Mitchell and Joe Drogan each had volunteered for many years to publish the APPA News, they retired, I volunteered. It has been my pleasure to follow in their templates. Besides getting to play with colors and pictures on the computer, and writing my thoughts; the best part is getting to know the folks who contribute their stories. All this done without leaving the house. The APPA news gets proofed by the contributors, my husband, my cousin and Barb Ruecksties, who correct all syntax, and we have fun doing it together over the phone. So this particular volunteer job is good for me, for now. However, APPA News could use an editorial team to research & write articles. Back to making friends: when you read someone's story and find a common experience, send them an email or find a time when you can both chat by phone, possibly even meet somewhere.

We are in this together. Climb aboard our roller-coaster and ride with us.

Let me repeat myself. APPA News could use an editorial team to research & write articles. In the last APPA News I put out the question: What Do we Want in a PPS Doctor? Joe Drogan rose to the task. See his answer on the following pages Aren't we glad to read Joe's writings again (and see his penguin)?

"Getting to Know Us" continues in this issue. Big thanks to Alan Oberdeck and Lili Guerry for sharing their stories.

Nancy Winter

What to Look For In a Post-Polio Doctor?

By Joe Drogan

A recent APPA NEWS posed the question "What to Look For in a Polio Doctor?" I will attempt to shed some light on this challenging issue. Challenging? You might ask. Simple, just ask your primary care physician for a referral. Easy peasy right? Not so much.

The first problem is most doctors know very little about polio in general. This is no reflection on them in any way. It's simply not taught in medical schools and hasn't been for many years. The reason is simply with all the information that must be addressed in the medical school there simply isn't time to devote much attention to Polio. In addition Polio is perceived to no longer be a threat to the general population here in the US.

That may be changing with the polio event up in Rockland county N.Y. just north of New York City. How's this for a surreal event? While I'm writing this article I hear a story on Fox News about polio being found in the waste water IN New York City! I would have never thought in a million years that would ever happen. That would mean there are polio cases in New York City. That's the only way it can end up in the waste water system.

I've always hoped there would be a little more attention paid to polio but I sure didn't want this to be the way that happened.

There are an estimated 300,000 polio survivors in the US and of those approximately 20-40% have Post-Polio-Syndrome (PPS). (60,000 - 120,000). Medicine like other for profit businesses tend to spend money where it is needed most and will generate the best return on the dollars spent. With the US population at 332,403,650 and the number of polio survivors at 300,000 that's only .09% of the population. So the odds of a doctor encountering a PPS patient are pretty slim. You don't see a lot of Studebaker service facilities around these days.

Continued on next page

Post-Polio Doctor, continued

Literally all of the polio doctors have taken it upon themselves to get trained on polio and PPS. Most of these doctors did so years ago when there were more potential polio patients out there. As our numbers declined so have the number of doctors with this knowledge. Most of us have retired, quelle surprise, so have the PPS doctors. So the question "What to look for in a polio doctor?" certainly includes where do you even find a PPS doctor?

What do we look for in a polio doctor? Typically we have sought out doctors that are physiatrists. This branch of medicine concentrates on physical medicine and rehabilitation.

From Wikipedia:
"Physical medicine and rehabilitation, also known as physiatry, is a branch of medicine that aims to enhance and restore functional ability and quality of life to people with physical impairments or disabilities. This can include conditions such as spinal cord injuries, brain injuries, strokes, as well as pain or disability due to muscle, ligament or nerve damage. A physician having completed training in this field may be referred to as a physiatrist."

Other things to look for in a PPS doctor.

1. Knowledge of how PPS means overuse of any of our muscles causes irreversible damage (the opposite of "No pain no gain" a mantra fostered by physical therapists and trainers).
2. The ability to evaluate the following:
   - A. Muscle strength. Are we are getting weaker and by how much?
   - B. Checking on our ability to swallow. Some PPS patients have difficulty with this.
   - C. Our breathing.
   - D. Our gait, if ambulatory, changes could be due to increased muscle weakness.
   - E. Our shoulders, rotator cuffs etc. especially if crutches or manual wheel chairs have been used.
   - F. Fatigue level.
   - G. Sleep issues including Sleep Apnea caused by Central Nervous System issues present in polio survivors. This as opposed to the usual obstruction of the airway which is much more frequently a cause for Sleep Apnea.
   - H. Blood pressure issues due to reduced ability to exercise.
   - I. Weight gains due to reduced ability to exercise.

Continued on next page

Post-Polio Doctor, continued

3. Knowledge of the Medicare and insurance systems to facilitate the acquisition of medical equipment including power chairs. Also the ability to fill out various forms required by insurance companies as to the state of the patients disability. Some insurance companies don't seem to understand that a polio disability is permanent and require paper work to be completed repeatedly.
4. Knowing what health concerns are not related to polio, including vision, hearing, taste, smell, seizures, allergies, dizziness, abdominal pain or diarrhea, cancer, liver and kidney disease.

Finding a physiatrist greatly increases your chances of finding a doctor with some knowledge of PPS. It's a great place to start.

It may just be that now it'll take a team of doctors to serve collectively as our polio doctor. This may include a orthopedic, neurology, pulmonary, and an internist.

That said, where to find an actual PPS doctor is a whole separate issue nowadays. In looking it would appear that with the retirement of Dr. Strasser there aren't many choices left. Dr. Beninga at Shepherd Center has been treating some APPA members. She is a physiatrist specializing in spinal cord injuries. Problem is she is not accepting any new patients. It would appear from the map on Post-polio.org's website there aren't any post-polio clinics anywhere in Georgia at all. So at best we are going out of state to find a clinic. I guess the good news, if there is any here, is that once you get established with an out of state doctor most of your visits could be telemedicine.

In the meantime it seems to be more important than ever to become as knowledgeable about post-polio as you can. You become a member of the team I mentioned above. There is a huge amount of information out there from books to support group publications like APPA News. Read our old issues available on our website. Many books have been written too. Just to get you started here is a link to a resource book from the Colorado Post-Polio group. Colorado Post Polio and Easter Seals Resource Book Post-Polio Health International has a resource locator here is the link
https://post-polio.org/networking/directory/

I wish I had better news for you. It does seem as things evolve even though polio support groups are declining it may well be that they are more important than ever.

END

Other Bits & Pieces and assignment for the next issue.

Joe Drogan answered that question completely. Coincidently the California San Gabriel PPS group showed the following in a recent Zoom meeting. This Chicago clinic offers the kind of multidisciplinary follow-up care for chronic conditions.

A presentation from a Post-Polio Syndrome Advocacy Meeting Hosted by the Rotary Disability Advisers. The presenter is James Sliwa, DO, Chief Medical Officer & Senior Vice President of Medical Affairs, Chief Quality and Safety Office at the Shirley Ryan Ability Lab in Chicago, IL. Here's the link. https://youtu.be/H4kZOPA9-TU

There is good information from Dr. Sliwa, basically we need from the medical community help for: Symptomatic Management and Maintain Functionality.

The other thing mentioned was the Spoon Theory about good & bad days. Also on YouTube. Search for "But you Don't Look Sick". This is useful for anyone who feels frustrated when the well-meaning strangers & friends want to give their advice of how to fix you because you hesitate to make commitments, or you say you will do something but then that PPS fatigue hits you again and you really just cannot.

Assignment for next issue of APPA News: Sorting Clutter, Memories, Downsizing & Moving. How you do it?

APPA News needs your expert advice. It alleviates stress if we have an idea of what all it takes to face a PPS future, i.e what if I have to move to a more accessible location as I face a decline in functionality?

As some of you APPA readers are already experts in this, please share your expertise. What did you do? What did you wish you had done? Anything will help. Give me a call, email or snail-mail. I'm in the Directory. *Nancy Winter*

Picture from Creative Commons

APPA Activities

Since our last APPA News, there have been good opportunities for fellowship and education. There was a lunch at Olive Garden and a picnic at Brogan Park. APPA needs volunteers to arrange in-person visits closer to where you live. Just use the APPA Directory to see who all lives in your area, and speak with us about setting something up. Thankfully, we also enjoy our Zoom meetings.

August featured Michael Kossove, September featured Barbara Mayer. October featured Shirley Thomas. For the November meeting we met at FODAC. Thanks to Allison Stockton and Leslie Schulgen most of our Zoom meetings are archived on our website. I did write up highlights for three of the meetings starting on page 21.

The discussions following the presentations on Zoom is often also very informative. For example October 1st Zoom meeting, Linda Priest gave us a glimpse of the ordeal that followed her van accident earlier this year. Her experience from the hospital to the rehab facility to the nursing home, back to the hospital and finally to her son's home is a wake-up call for us. At time of this writing it is hoped that Linda can present her experience at a meeting. For this issue, I wanted to present some things that came up from that discussion. See the next page about the **Ombudsman Program** available to residents in skilled nursing facilities and assisted living. If you ever find yourself in one of these facilities, make sure you and your family know your rights and who to contact, if you are ever in doubt that the facility's management is not protecting your resident-rights The Ombudsman Program is here to work for you. It can also be a wonderful **VOLUNTEER OPPORTUNITY:** Anyone who is able might want to consider volunteering for this program. You work with the regional ombudsman to make authorized but unannounced visits to speak with the residents about their care in these facilities.

Also what came into discussion is our fearsome future. It alleviates stress to know what to do to face the future, especially when we experience diminishing capabilities. I wanted to research this a bit more for my own sake and for us and decided it will be better to assign it to you. See page 8.

ARE WE GOING NUTS?

Some years ago I took a course to become a "Certified Senior Advisor". I had learned so much from that course and now happy to see the Society of Certified Senior Advisors has grown and has wonderful online resources. Www.CSA.us. Among the useful things I learned from CSA was that dementia in seniors can have many causes, a common one is a UTI. which is treatable by antibiotics. UTI's don't show up painfully in seniors like when we were younger., but it can cause an acute onset of dementia. This knowledge came in handy with 3 families I knew, when it turned out their senior was not permanently demented. Much information online, about that. Search: "UTI and dementia".

The Georgia LongTerm Care Ombudsman Program

Ombudsman
LONG TERM CARE
RESIDENTS' ADVOCATE

How many people are in long-term care facilities in Georgia? Answer: The number of licensed facilities is approximately 370 nursing facilities and 2,600 board and care/personal care homes/assisted living communities with the capacity to serve 80,000 residents.

Resident Rights (posted at every facility)

- Right to be informed about and exercise their rights
- Right to know about services and financial charges
- Right to participate in planning their care and treatment
- Right to refuse treatment
- Right to confidentiality of records
- Right to privacy
- Right to control their finances
- Right to freedom from abuse, neglect, and exploitation
- Right to freedom from chemical and physical restraints
- Right to express grievances without fear of retaliation
- Rights pertaining to admissions, transfers, and discharges, including the right to appeal
- Right to communicate freely with persons of their choice

Volunteering through the Ombudsman Program. See the Q&A at this link. https://www.georgiaombudsman.org/wp-content/uploads/Volunteer-FAQs-Revised.pdf

To reach an Ombudsman Representative please call 866-552-4464 and choose option 5.
[Georgia Long Term Care Ombudsman Program (georgiaombudsman.org)](https://www.georgiaombudsman.org)

Ride of a Lifetime

For the past few weeks I have been in a sort of malaise. Better to get lost in a long book and out of my own head. Tonight (9/19) I happened to peek into the Polio Friends Group on Facebook and found I am not alone in this feeling and that some people have phrased well the ups & downs, good and bad days of PPS. Then one regular participant Ken Allen mentioned "Ride of a Lifetime".

The vision of a roller coaster ride came to my head. Suddenly, the thrill is back! I'm not a depressed-can't-do-much-post-polio, I am on an amazing roller coaster ride with some wonderful friends (you). So looking at the ups and downs, unforeseeable turns —perhaps screaming in fear with the friend next to us — We are not just PPSers getting older we are, we can, we may as well enjoy this <u>ride of a lifetime</u>.

And that brings us to the **"Getting to Know Us" Series.** Alan Oberdeck was kind to just submit his story and, being the author that he is, it didn't need any editing on my part. Lili Gentle Guerry probably never would have told us her story, except we got to talking one day and she mentioned being in some films. I told her that *Carousel* was my favorite-of-all-time musical, and Lili was in it!

Alan M. Oberdeck Polio Graduate 1953

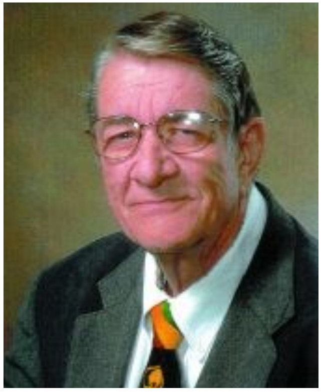
I am Alan M. Oberdeck an APPA member since the 80’s when we met at Emory. I was born in Edgerton, Wisconsin Feb. 1940. I grew up on a dairy farm 4 miles west of Edgerton. In addition to the cows we raised tobacco. I attended a one room 8 grade country school.

In 1952 I had “plans’! Puberty had really hit me that spring and I was attracted to a special girl, I was bored with farm life and when I became 16, I was going to get a motorcycle and head for California. While working in the fields that summer I had the time to think about and plan my escape. School started the day after Labor Day and I couldn’t wait to get back.

The Sunday of Labor Day weekend we were working in the tobacco field after we got home from church. I felt dizzy and sick so dad sent me to the house. The next day (Labor Day) I had to sit on the potty and I was so weak I had to call for mom to get me back to bed. Instead of going to school the next day my dad carried me into the doctor’s office. I had a spinal tap after which I was too dizzy to even sit up. It showed I had polio.

JANESVILLE, WIS.

Edgerton Boy Almost Fully Recovered from Polio After Kenney Treatment



I was hospitalized in Janesville, Wisconsin. I was devastated! So much for the plans I had made for school that year. I spent three weeks in the Janesville hospital and was treated by a bone doctor who measured me for full body braces. At that time I could only use my left hand as the rest of my body was so weak. I didn’t know it, but I had what at that time was called spinal polio and bulbar polio, but no iron lungs were open so I never was placed in a lung.

My dad, through some 4-H acquaintances was put in contact with a person who knew of the Sister Kenny Institute In Minneapolis, Minnesota, a polio treatment center. I was taken there and spent six months in recovery.

When I was discharged I was able to walk with shortened wood crutches called “Kenny Sticks”. My body was very weak, the right leg developed 1 inch shorter than my left and my right knee developed two joints, I had to be careful when I walked and my right ankle wore a brace inside my shoe. At The Sister Kenny Institute, it was drummed into us that it was a competitive world and if we were to succeed we had to be better than our competition to cover our disabilities.

Continued on next page

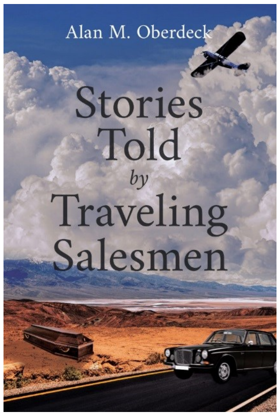
Alan M. Oberdeck, continued

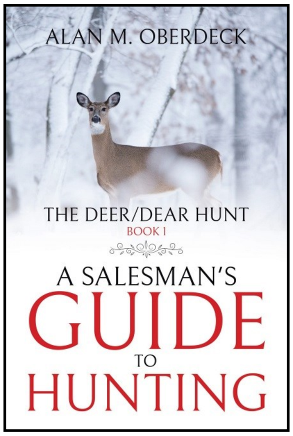
I could not farm, I got an Associate Degree in Metallurgy, worked in a lab, worked as a draftsman and a Design Engineer. I went back to school and earned a Bachelor of Arts Degree and spent 35 years as a traveling Salesman, most of the time covering 17 states although for a period of time I covered the whole U. S. Canada and some of Mexico.

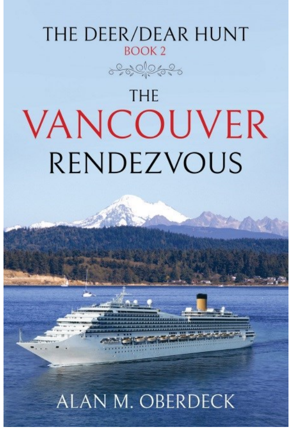
The travel was exhausting, but I was able to rest between sales calls. To the company I denied any problems and put on a great show. I retired at age 66 and became an author with six books in print.

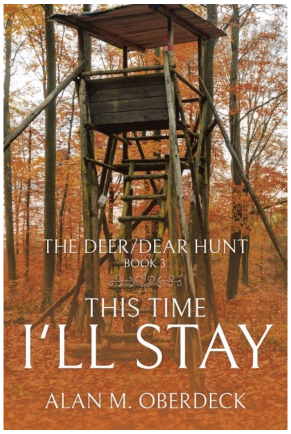
I married my sweetheart in 1962 and we celebrated our 60th this year. We have four children, 13 grandchildren and 16 great-grandchildren. I now walk with a walker and don't go many places. If you wish to know more about me, go to my website

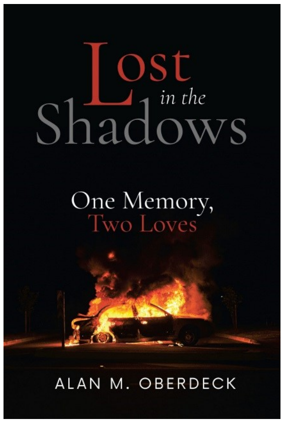
www.alanmoberdeckauthor.com

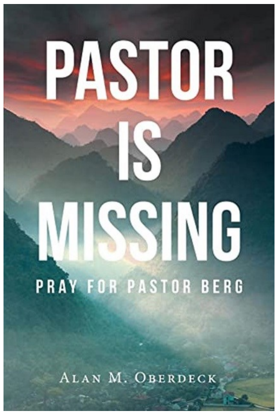








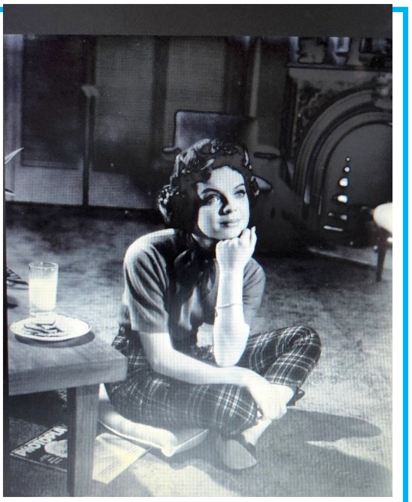




Editor's note to our many Book Readers in APPA. Go to Alan's website to see a summary of each of these books and purchase directly from the site. Also, check out his autobiography and other good stories there.

Lili Gentle Guerry Polio Graduate 1946

Looking back, I might have just as well stayed in Alabama and married a farmer. But life took different turns and now I am in Dallas Georgia. I have been in APPA for a good number of years. Until now, hadn't shared this part of my life.



From: Will Success Spoil Rock Hunter

I was one of three kids in Franklin County, Alabama. We went swimming in Bear Creek, in the woods behind our house, and that probably is where my sister and I picked up polio, in1946. We were in Florence Hospital and Dr. Leslie did his internship there. Later we went to Warm Springs. My sister was in an Iron Lung. I was left with a weak left leg and back. I had the Sister Kenny therapy with the hot wool. It was such a comfort to me that I still love that smell, like winter clothes drying on the radiators.

Back then a lot of kids wore flour sacs for play clothes. To change the stigma of wearing plain flour sacs some smart company sold them with flowers and other decorations, I remember wearing those. But there was that other stigma attached to polio so kids were discouraged from playing with me and no one sat near me at church, even with my grandmother playing the music.

I took ballet lessons and that helped me learn to walk better. Early on I realized that I needed ten hours a night of sleep so I wouldn't hurt. Got off brace full time, still used it sometimes. Left leg always weak.

At age 15, I was involved in the Miss Alabama contests. From there I fell into a group of people doing different plays. We would read lines for each other, and we did some plays. In the interim, I did coffee commercials, live, once each week. My face ended up on the billboard, for Red Diamond Coffee & Tea.

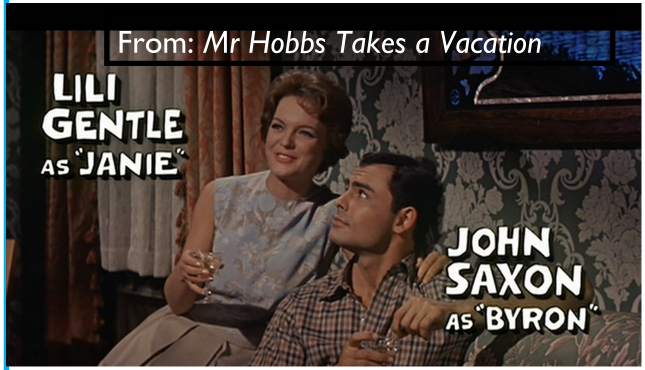
I won a gift to do tryouts in New York and was signed under contract with 20th Century Fox. I still had to finish school. My Mom and my sister moved with me to California. The National Guard helped to transport my sister in the iron lung. I was in films and TV, my acting career is online under my maiden name Lili Gentle.

My debut in film was in Carousel. (The credits called me "young girl #1") Pictured here singing: *You'll Never Walk Alone.*

Continued on next page

Lili Gentle Guerry, continued

I met Dick Zanuck and married him when I was 17, he was about 25. Our first baby was born when I was 18. I was pregnant with our second baby when I played Janie, Jimmy Stewarts, pregnant daughter in the film *Mr. Hobbs Takes a Vacation.*


From: *Mr Hobbs Takes a Vacation*

I had to leave the house at 6:30, AM. I would worry about my daughter at work every day. I'd call in during lunch breaks. But I got the bedtime bath routine. Being in film, I was completely controlled by the studio; they controlled where I went and how I looked. I'd get chewed out for too much sun, or too much or too little weight. It was a lonely, isolating life. I was well supervised and kept busy . I didn't really go for the glitz & glamor, though we wore magnificent gowns.

Later, Dick (as a movie producer) and I were always traveling. The flair and the glamor were appealing. I was never pleased with what I did—especially mixing mothering and career.

We met a lot of film people that were "upper class" in their own head, but I also met down-to-earth people, like the Stewarts. Jimmy Stewart and his wife became our friends and were lovely people. I was very close to Dick's mother we would travel together Hawaii, Mexico. I went with them in Paris when they were making the WWII movie: *The Longest Day.* It was astounding how they could take different shots, fade in & out and make it appear altogether different. I would have enjoyed the cutting and the photography end of the business. I would have been interested in studying that.

Once I was invited to see Howard Hughes. Evidently, he had seen me in a March of Dimes poster. I was holding the poster in a photo, between Jane Russell and Dick Eagan. My agent Dick Clayton, told me if we sign with him, you have a contract for life, on the other hand you will be restricted on everything you do. They sent around a limousine for us and from there we went to another limo and then into a photo studio. Mr. Hughes came in a wheelchair, asked about me, that I had polio as well. He said he had polio as a child that his mother had told him that. He was very nice, very small, not goofy, soft spoken. He thought I was too young for his stuff. He took Jane Russell. He thanked us for coming offered us the use of his plane to travel back & forth to Alabama. I never did use his plane, but my mother did.

Continued on next page

Lili Gentle Guerry, continued

Movie business is not what people expect. I was shy and could cover it up with comedy, the only way I could perform; I had to do it, my sister needed me to help support her. Lillie Mae Caldwell was entertainment editor back in Alabama, and wrote about me constantly. I wanted to go home and do radio, morning shows and talk about current things. It was where I knew people and I loved the farm land. I love Georgia woods and this whole state. I still have a few relatives in Alabama. I've met people here who are wonderful and have had such interesting careers.

My grandfather was in agriculture before he became a doctor. We lived in "the sticks" in Alabama He was in charge of the crushed rock for agriculture, rocks in Alabama were sent to Hawaii to improve Pineapple growth. As years have gone by, I've been interested in nature, growing things, having a garden, I liked being able to give away tomatoes.

I was never in awe of film stars but I loved Roy Rogers & Dale and belonged to the Happy Trails Club in Alabama

I Married Timothy W. Guerry, in 1975 and were together 43 years, until his death in 2018. He was in the photo business. We did a lot of work. It was a fascinating life, probably boring to others, all we talked about was photography. We moved first to Chicago but I wanted to come back to the South. We thought of Alabama or Florida. As it happened, something went wrong with the car near Marietta and we've been in this area ever since. We set up our own studio and sold the shots to manufacturers for ads and catalogs. It was a feast and famine type if business. Weekends I would love to chop firewood.

Timothy was my caregiver. In 2018, he dropped dead in the driveway. Since then I've had to come to terms with a lot of things. I'm only 82, I know that's elderly, but not in my head.

Somewhere in these years, I joined APPA. I first learned of it via Gini Laurie (Founder of Post-Polio Health International). Joan Hedley there told me how

Continued on next page

Lili Gentle Guerry, continued

to understand PPS: start living your day with 10 pennies in the basket. Every time you do things, that might be 1-2 more pennies, when you run out, you have to rest.

Silvia Gray was in APPA outreach, and She told me we are healing our brains by letting our thoughts just flow – restful. The less meds the better. So now I rest and nap a lot. Fatigue is so great.

I didn't think PPS applied to me. But, like most of us, the legs gave out and I couldn't mow the lawn anymore. Then things that I used to lift easily seemed too heavy. I'm glad that my family that went through the polio with us are deceased and do not have to go through it again with me.

Happy to still be around. I find interesting people here in this senior community. Staff here are terrific. We went through covid, shut down twice, people were dying – staff give you sense of caring and it's real. Like living in a house with a lot of people only you can close the door.

We have our own apartments and there is a dining room for 3 meals and we can go down anytime to get food and coffee until the end of the day. We have microwave and dishwasher in our apartment. Food shortage is hitting us. Food in bulk, no one wants to pay the cost. Hamburger is smaller than the tomato. Quiet life, I face pretty woods, I can see the birds, humming birds, We have activities, committee meetings, some even go fishing.

Imagination gets us through a lot. It's hard where we live and residents die. We get to know residents and and their families. Eye opener for survival. When you decide and make acceptance of death, then you eliminate a lot of stress. I have some wonderful friends here and there. And I'm glad to be in the south as I cannot tolerate cold.

END

Sneak Preview.

What do the tops of trees have to do with one of our long time APPA members?

We are planning to answer that in the issue for Spring 2023

Wheelchair life:
Visit to the FDR home and Presidential Library

Nancy Winter

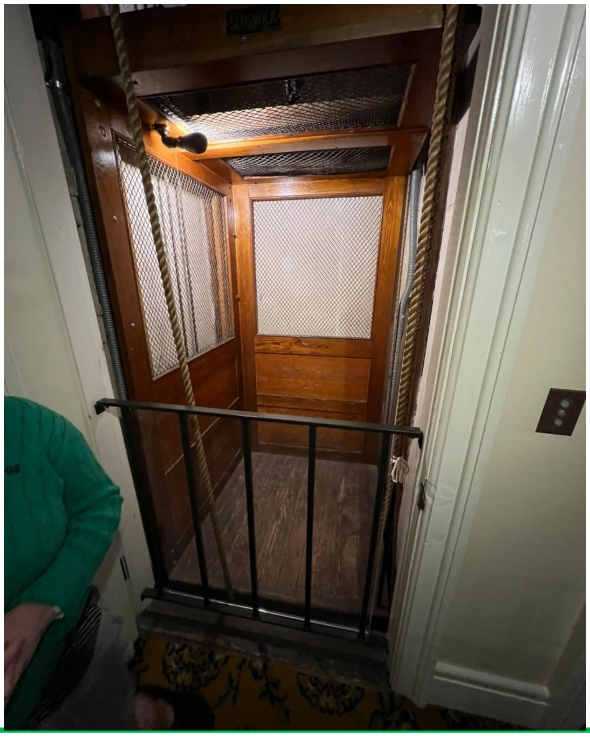
In the first week of September, my wonderful, pregnant daughter and her husband made arrangements for me to visit them in New York including the Lyft to the airport, the "pushers" at the airport to put me on the plane, and then a week of historical explorations in the city and along the Hudson. For now I will skip the details of the wheelchair they used to push me around, the ride around the harbor on a 1929 sailboat, the Russian Tea Room, Central Park, 9/11 Reflecting Pools, West Point Labor Day outdoor concert, with cannons and fireworks, The military museum, The "76 House, etc. etc.

Amazing all the things I can do when someone else is driving and pushing the wheelchair. We had a lot of discussion about accessibility and the ideal living structures for wheelchair folks.

So we decided to drive up to Hyde Park and view the home of Franklin D Roosevelt and find out how he got around in a wheelchair. Their home was a family home of several generations. When polio stole FDR's walking ability, The Sedgwick Company (makers of dumbwaiters) constructed an elevator of pulleys & rachets. He was strong enough to lift his own weight. Here is a picture. ⟹

Sadly this invention was not for me to use as a tourist. Instead they had recently created a small electric elevator so we can view the bedrooms on the second floor.

As we know, FDR went to great lengths to hide the fact that he couldn't walk. His home library and office, was 7-steps down. For us tourists we could walk across a plexiglass floor and view the ramp that he used. This wooden ramp would be tucked out of site for dignitaries. When they came to see FDR he would stay seated at his desk in the library. The visitors would use the normal stairs and he would speak to him from his desk. They had no idea.



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Visit, continued

I had always just associated FDR with the depression and the war and later learned his connection to polio and Warm Springs, I did not realize that he was Secretary of the Navy and Governor of NY before being President and before polio. From the home, we toured the vegetable garden with an ingenious wheelchair accessible plant container & composter. Here is a picture of that ⇒

While on the subject of hiding our **vulnerabilities and adapting to disabilities,** I wanted to share this quote from a WWII book recently discovered through my reading group. By Erik Larson: *The Splendid and the Vile*. Until war was declared Churchill had not met FDR in person. But on the first night of Churchill's secret trip to the White House, this episode page 488.

> *The first night Churchill and members of his party spent in the White House, Inspector Thompson—also one of the houseguests— was with Churchill in his room, scouting various points of danger, when someone knocked at the door. At Churchill's direction, Thompson answered and found the president outside in his wheelchair, alone in the hall. Thompson opened the door wide, then saw an odd expression come over the president's face as he looked into the room behind the detective. "I turned," Thomson wrote. "Winston Churchill was stark naked, a drink in one hand, a cigar in the other.":" The president prepared to wheel himself out. "Come on in, Franklin,," Churchill said. "We're quite alone."*

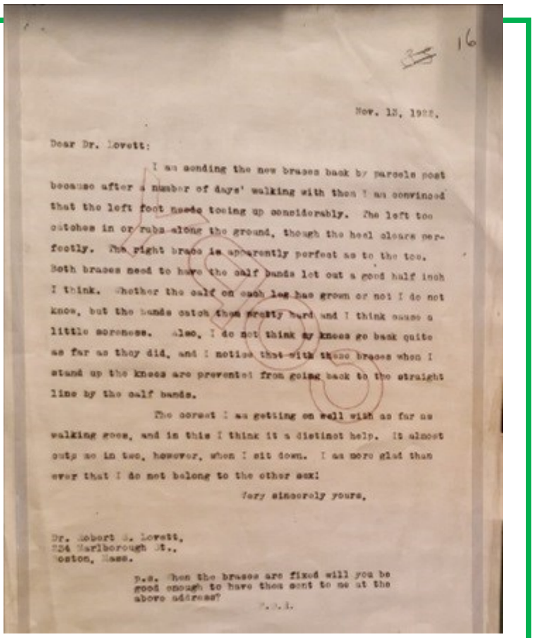
Continued on next page

Visit, continued

The Franklin D. Roosevelt Presidential Library and Museum was a huge education and one could spend many more days there. We did take a few photos, not easily shared here.

This is a letter written to Dr. Lovett expressing that the leg braces are helping some, but he is returning them by Parcel Post. He lists the specific adjustments that he would require. Written in November 1922. He hadn't walked since August 1921.

See FDRLibrary.org for connections to written and recorded archives.



~~3~~ 16

Nov. 13, 1922.

Dear Dr. Lovett:

I am sending the new braces back by parcels post because after a number of days' walking with them I am convinced that the left foot needs toeing up considerably. The left toe catches in or rubs along the ground, though the heel clears perfectly. The right brace is apparently perfect as to the toe. Both braces need to have the calf bands let out a good half inch I think. Whether the calf on each leg has grown or not I do not know, but the bands catch them pretty hard and I think cause a little soreness. Also, I do not think my knees go back quite as far as they did, and I notice that with these braces when I stand up the knees are prevented from going back to the straight line by the calf bands.

The corset I am getting on well with as far as walking goes, and in this I think it a distinct help. It almost cuts me in two, however, when I sit down. I am more glad than ever that I do not belong to the other sex!

Very sincerely yours,

Dr. Robert W. Lovett,
234 Marlborough St.,
Boston, Mass.

P.S. When the braces are fixed will you be good enough to have them sent to me at the above address?
F.D.R.

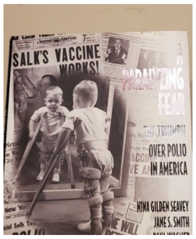
After this visit I went online to see what improvements have been made to home elevator devices since the modified dumb-waiters. There are some really cool options and many companies getting into the market. I note that many old and new homes are still being designed with stairs. So when the time comes, I would like one of these lifts that work by variations in the air pressure. This picture illustrates solar power possibilities. See online more about pneumatic vacuum elevators for videos and designs how these can be built into homes for us. I'm glad I will not have to lift my own weight by ropes & pulleys.

APPA Zoom Meeting Highlights

Saturday August 6, 2022. Michael Kossove is a Microbiologist, and a polio survivor. He is Professor Emeritus, and Adjunct Professor of Microbiology at Touro University, School of Health & Sciences in New York. Prof. Kossove has been researching polio and PPS for over 30 years. He has spoken, in person, to support groups, and at conferences across the US. Now he is doing his presentations by Zoom. He has recently Zoomed in Beijing, China, and London, England. The following **Highlights are from my scribbled notes**: Because of polio, the March of Dimes was once the largest charity in the world, with idea that anyone could at least contribute a dime. Polio virus lives in feces so it spreads by contaminated food or water, e.g. flies can carry it from discarded diapers. The virus only infected the nerves to the motor muscles, not sensory nerves. The bulbar form hits autonomic nerves to heart and lungs. Paralysis occurred in only a small percentage of cases which means millions of others had the virus. Many had polio virus but no symptoms until PPS. Polio virus needs cells to replicate, it does not reproduce on its own. Virus multiplies in the intestine, then to the blood stream and to the nerves. The only receptor sites are in the nerves; it does not attach and damage other organs. The loss of functions in PPS reflects the real damage of polio before the nerves sprouted to assist the damaged nerves. More energy is required to serve muscles via the sprouts.

The polio strain found in New York this year is same is that in Israel and UK. Sewage to detect presence of polio and covid is being tested daily, but not in all counties. If you had polio but not the vaccine, you could still catch one of the three serotypes. You can get your titers tested to see if you are fully immunized. PPSers do well with a interdisciplinary team of physicians, PT, OT, physiatry etc. Such teams are available in Florida, but evidently not in Georgia.

Saturday September 10, 2022. APPA Member & Secretary Barbara Mayer on a review of book "A Paralyzing Fear: The Triumph Over Polio in America. Seavey, Smith, & Wagner. Barbara had such interesting stuff to share in her book review, so I bought my own copy from ABEbooks.com. There is a movie of this same title available on YouTube. Barb's Book review is archived on our APPA website, under past events.



Barbara Mayer retires this year from the APPA Board
Her 9 year term, as our most excellent Secretary, ends this Year. Thank you Barbara!

APPA Zoom Meeting Highlights, continued

Saturday, October 1, 2022. Shirley Thomas with the updates on Medicare for 2023. As usual, her presentation had a lot of information. Please watch it via the Events page on our website
https://www.atlantapostpolio.com/upcoming-events
Also look at other past events.

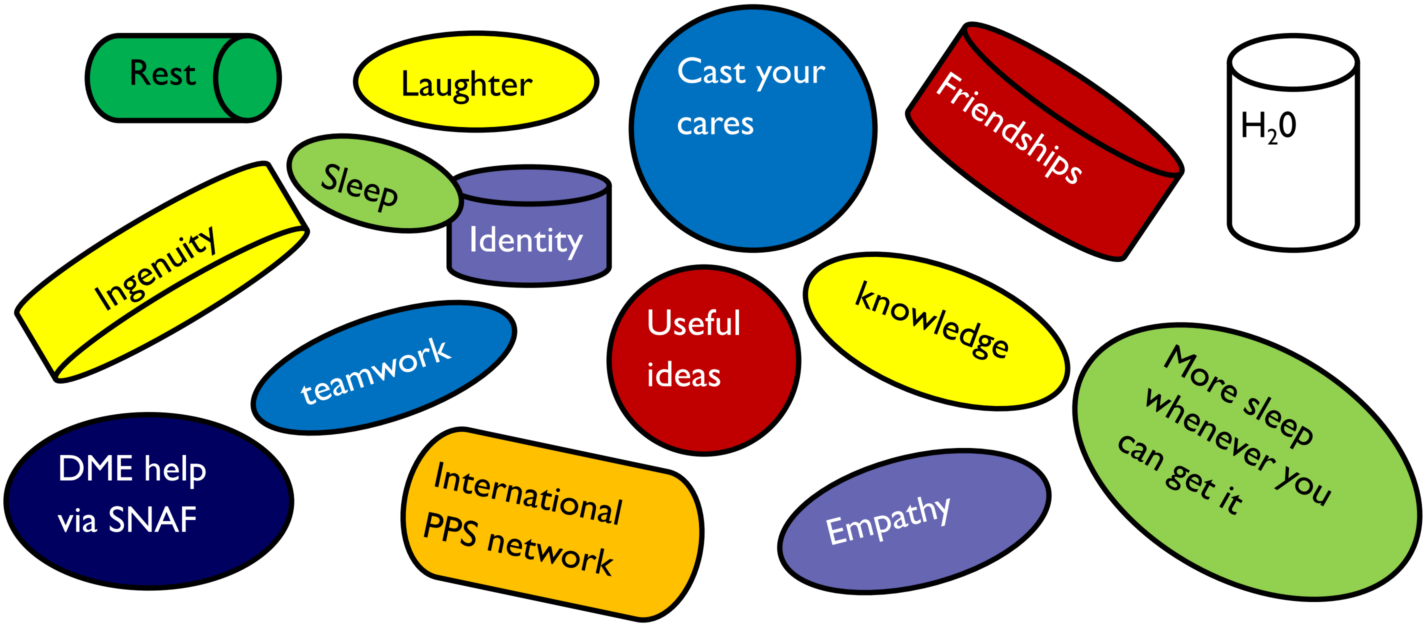
Wednesday, November 9, 2022. For this month we met on Wednesday to accommodate the presentation by the Costco Hearing Center. We also met in the FODAC conference room. Going to FODAC for our meetings has many advantages. It is in Stone Mountain, not downtown Atlanta, and not far off the beltline. Some of us had called ahead for repair appointments with FODAC, so we went home with improved equipment. We enjoyed lunch compliments of Costco and Rita's excellent cookies. Meeting at FODAC also has the advantage of being able to peruse their wonderful Thrift Store, right down the hall from our meetings. I'm amazed at the quality of many of the donated items there. All our purchases go to the great work that FODAC does.

I hadn't been particularly interested in hearing aides, but Costco Hearing Center staff did quite a job pricking our interest. I did not know that hearing loss can involve more than our ears and cannot be fixed by just turning up the sound. Hearing is translated by the brain. As we might slowly lose hearing, our brain will try to compensate. Subconsciously we start watching people speak, reading lips. We might not hear certain sounds . We might lose hearing in one ear, and compensate with the other before we notice. Costco now can supply hearing aids from several of the top vendors, over the counter, and with all the benefits of the latest hearing tech.

Reading Groups: I'm grateful for the reading group I've been a part of. We tend toward history, historical fiction and or science. We meet once a month via a group phone call. A few of the members are visually impaired so we find things also available to them on audio. Most of the books are either at our libraries or easily purchased for less than $5 including shipping, through your favorite used book seller (mine is www.abebooks.com). Its through these books and our monthly discussions that I learn so much and have fun in the process. There's no homework and reading the entire book is not required to join in the fun. Some of this group lived through WWII and we have room for a few new members. If you would be interested in joining our group let me know. nancy@prime.org

The APPA Cure — Only $25/year.

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



How APPA's SNAF in collaboration with FODAC, worked for me again

I am so glad I went to FODAC this year to find a used power chair. It has taken me a few months to get used to moving around by joy-stick, but I actually brave the higher speeds now on the paths I have practiced. The best part is being able to work in the kitchen. I realized a few years ago, I could not cook a meal and clean kitchen on the same day. Kitchen work involves much standing and too many steps. Now with the chair I can do both with alacrity and clear the table as well. I still make use of the rollator but the warning about the arm strength (muscle soreness) worried me, so to step up to a power chair has saved many steps, allowed me to use energy elsewhere without crushing fatigue, and my arm soreness has disappeared too. Thanks to all the PPSers who have provided me with the wisdom **not to hold off in getting the power chair,** and to FODAC and the APPA SNAF program.

Nancy Winter

FODAC in the news.: I was so proud to hear the radio announcing the FODAC relief effort following Hurricane Ian. This picture is off their website: FODAC.org.

APPA met at FODAC on Wednesday November 10th. My hope is that we will meet there again. Remember to donate any used DME's to FODAC and donate good items for their thrift store as well. Our Electricity Co-op Snapping Shoals donates to FODAC via their "Round Up" Program.

How to join in the Zoom meetings of other PPS Groups

Each month the Boca Area Post-Polio Group (BAPPG) newsletter provides the updates. To see any of their fantastic newsletters, go to: https://postpolio.wordpress.com/newsletter/ To find the updated list of Zoom meetings, click on the most recent newsletter and scroll until you find the page that looks like the one here.

FREE POSTPOLIO 'ZOOM' MEETINGS
(they are 16 hours ahead)

'NEW' **First Monday, Sunday 7 PM Eastern**
Australia Polio Community – Steph Cantrill
www.trybooking.com/BOBOW to register; personal link will be emailed to save/use for all meetings.

Third Monday, 3 – 3:45 PM Eastern
Yoga For You, Quebec
https://us02web.zoom.us/j/9022299642

'NEW' **First Tuesday,** 11– 12:00 PM Eastern
***South Denver*, CO PPSG**–Hal Goldberg, PhD
303-212-0017 or halgoldberg@halgoldberg.net

Tuesdays, 7 – 9:00 PM Eastern
Polio Quebec - Mona Arsenault
https:/us02web.zoom.us/j/3776897370?pwd=VnZSMWdVV1h2U2x6QXMxazEzMzY5QT09
Passcode: 3500

First Wednesday, 12 – 2 PM Eastern
PPSG of Dallas Area, TX – Marcie Sandall
Meeting ID: 529 820 1630 Passcode: PPSG

Wednesdays, 2 – 3:30 PM Eastern
March of Dimes Canada – Kaylia
https://us02web.zoom.us/j/84879826164?pwd=allxVjkxUHU4bmNyZ0JheWRYZWNqdz09
Passcode: 0000

Wednesday/Thursdays (Qtly), 4:30–6 PM Eastern
5/4/2022, 8/4/2022, 11/2/2022, 2/2/2023 etc.
Marin County Polio Survivors, CA – Francine Falk-Allen

'NEW' **First Saturday, 2 PM Eastern**
Sacramento Region Polio Survivors, CA – Loretta Haynes
https://us02web.zoom.us/j/88167157156?pwd=NUx3alhQd2tVWVZBU0JobFgxUDJ2Zz09
Meeting ID: 881 6715 7156 Passcode: 992536

Second Saturday, 1 PM Eastern **odd months**
Polio Epic, Inc., AZ – Mikki Minner
https://us02web.zoom.us/j/3248283812?pwd=Q3R5RUNxdGtUbEtrVWkzUjU5Y3R5UT09
Passcode: 2020

'NEW' **Third Saturday,** 12:00 – 2:00 PM
North Denver, CO PPSG–Jill Eelkema, LCSW
720-675-9902 or jille@westerncarepartners.com

Third Saturday, 1:30 – 3 PM Eastern
PSG San Gabriel Valley & W. Inland Empire, CA – Marci Ellison
https://us02web.zoom.us/j/81428179432

Third Saturday, 1:45 – 4:00 PM Eastern
San Francisco Bay Area Polio Survivors, CA – Stella Cade – stellacade@aol.com
Meeting ID: 854 335 70308 Passcode: 1955

First Sunday (ex. Holiday wknds), 3–5 PM Eastern
Nebraska Polio Survivors Assn. – Elaine Allen
https://us02web.zoom.us/j/825M60100877?pwd=MndVRENFcm9WenNoTC9ZVUg2eW9HZz09

DON'T BE LEFT OUT –
IT IS SIMPLE TO 'ZOOM'

1) Download 'zoom.us' on your desk/laptop, tablet, or

Bits from Bruno Bytes … update

Bruno Bytes is offered by the Pennsylvania Polio Network and can be accessed via
https://www.papolionetwork.org/encyclopedia.html
www.papolionetwork.org/bruno-bytes

On the topic of **Poliovirus Antibody Testing to Determine Immunity**
Dr Bruno's Original Post: Testing for Types 1 and 3 Antibodies
The case of paralytic polio in lower New York State, caused by the mutated Type 2 vaccine, has prompted survivors to ask whether they had been fully vaccinated and have antibodies to all three types of poliovirus. Commercial laboratories will test for the presence of poliovirus antibodies but only for Type 1 and Type 3, since wild Type 2 poliovirus is no longer circulating. Unfortunately, it is the mutated Type 2 oral vaccine strain that currently is circulating and being found in wastewater.

The CDC states, "Demonstrating antibodies to poliovirus types 1 and 3 does not reliably indicate protection against poliovirus type 2. In the absence of the availability of testing for antibodies to all 3 serotypes, serologic testing is no longer recommended to assess immunity."

Source: www.cdc.gov/mmwr/volumes/66/wr/pdfs/mm6601a6.pdf

What's more, infectious disease specialist Dr. Paul Offit stated that laboratories can "find" poliovirus antibodies that are in fact antibodies against "cousin" non-polio enteroviruses, making antibody testing worthless.

On the topic of **Polioviruses – Types vs Strains** —Dr. Bruno's Original Post:
You often hear doctors on television news make a simple mistake: confusing the "types" of virus with "strains" of virus.

It's really simple. Each TYPE of virus requires its own specific antibody to subdue it. But within each TYPE of virus there can be many STRAINS that are genetically different (because of mutations) but still succumb to an attack by its TYPE's antibody.

Dr. David Bodian discovered that there were 3 TYPES of poliovirus. A committee of scientists was formed and collected samples of poliovirus from North America and around the world to be certain that there were only 3 TYPES and therefore only 3 individual formulations of polio vaccines would be needed.

The findings confirming that there were just 3 TYPES of poliovirus were presented in 1952 at the Second International Poliomyelitis Conference. But also presented was the finding that there were 255 STRAINS of TYPE 1 poliovirus, 36 STRAINS of TYPE 2 and 9 STRAINS of TYPE 3. TYPE 1 STRAINS were by far the most numerous and virulent; so it's not surprising that they were responsible for the majority of polio epidemics.

RESEARCH

We can help develop better equipment and other lifestyle projects via Georgia Tech Departments that often need (and pay for) volunteers. I have done two such studies without having to travel. One was how I would instruct a home robot to do specific tasks. Another was learning Tai Chi for non ambulatory folks.

A few sites to check out:
https://techsage.gatech.edu/participate-research
https://sites.gatech.edu/sonenblum/participate-in-a-study/
https://rearlab.gatech.edu/participation/ research

Georgia Tech, Rehabilitation Engineering & Applied Research are conducting a research study to test two pressure mapping systems that connect to a SmartPhone using Bluetooth technology, and that can measure the pressure between you and your wheelchair cushion.

Eligible participants must be:

- 18 years of age or older
- Require full-time wheelchair use for mobility
- Use a skin protection and positioning wheelchair cushion
- Able to perform weight shifts independently.

Contact: Kathleen Jordan:
kjordan37@gatech.edu

Georgia Tech

rear Lab | Rehabilitation Engineering & Applied Research

New Research Study

About

The Rehabilitation Engineering and Applied Research (REAR) Lab at Georgia Tech is looking for participants for a new research study.

Help us test new wheelchair tech! Our study aims to test two different wheelchair cushion sensors to prevent pressure ulcers.

Compensation

$400 over 15 weeks as a thank you for your time

More info

Time: 2 in-person visits and 4 phone/video calls over 15 weeks

Eligibility:

- Wheelchair users over the age of 18 that are able to independently transfer

- Own and use a smart phone

Contact

Name: Kathleen Jordan
Email: kjordan37@gatech.edu

Scan the QR code for more details
or
visit us at
https://rearlab.gatech.edu/participation/

Some studies don't even need humans. Computer Simulations are working for us too. This from Washington Post, October 4, 2022: **Here's what science says about the right say to take pills**. Incase you missed seeing the August issue in the journal "Physics of Fluids", what "computational Science has worked out how fast a pill can be absorbed depends on the position of your stomach where it connects to the intestine. Sitting straight up, took 23 minutes. Leaning to the left took 100 minutes. **Leaning to the right it only took 10 minutes.** "If you are laying down after taking a pill, turning to your right side could significantly speed up the rate at which the drug is going to be absorbed by your body."

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◊ I would like to help APPA with expenses and receive the APPA NEWS in email only.

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◊ APPA phone tree
◊ Fundraising
◊ Programs
◊ APPA NEWS (write articles, proofread)
◊ Database assistance
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◊ Assist with APPA phone line
◊ SNAF Committee

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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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THE BLIND OR
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APPA NEWS

See videos of our APPA events

https://www.youtube.com/channel/
UC1hr5aec4_c2u3SDJXPOAvQ/videos

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Nancy Winter - Editor