APPA NEWS

The Atlanta Post-Polio Association

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Summer 2020

SPECIAL NEEDS ASSISTANCE **FUND (SNAF)**

APPA members may be eligible for a new benefit to help with the financial burden of purchasing or repairing much needed medical equipment. Our SNAF fund was created over 25 years ago. Page 5

What year did you have Polio? loin and contribute to our discussions on Facebook. Page 26

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Who would have thought when we changed our clocks in March that we'd be entering the Twilight



Zone? And other creative remarks people have shared about the virus and lock-down. Page 20

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Our famous APPA member Vicki Crowell wins again for fodac FODAC In the Virtual Race. Page 8

We only need physical distancing not social distancing. Enjoy all the ways to socialize with APPA

members this summer and fall. Pages 13, 15, and 26

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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.

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President's Message



Dear Fellow Survivors and Families,

Here it is already July as I am writing this note to you all! Since March we have been looking into several activities while we watched our great nation being brought to its knees with the pandemic and the quarantine guidelines. Things are beginning to openup; but, the majority of our age group will be the last to have free movement around our country.

The Shepherd Center, as you may know, has closed availability of their facility to APPA. Since early March your Board grappled with how to stay connected with our monthly meetings and Board meetings. In April we purchased Zoom to accommodate up to 100 members and guests as a replacement to our current meeting schedule.

Our last Zoom meeting on June 6th was a total success with over 42 APPA members in attendance! Rita Carlson who contacts potential guest speakers has done a great job; and, we look forward to our next meeting in August.

When this mitigation ends and it is safe for us to venture out, we have been considering some outdoor activities to be held at various locations around the Atlanta Metro area. We are hoping to have 4 events in a county, state or city park that can accommodate wheelchair accessibility and assemblage in smaller groups for our continued safety. This will also provide shorter travel time by having 4 various locations to choose from.

Since February we have defined SNAF and placed funds in reserve to insure it is flexible to all active members. We hope that all qualified members take advantage of these funds. (See pages 5-7). Please contact Leslie Schulgen or myself should a need arise.

I also strongly encourage each of you to stay in touch through Zoom, our Website, and Facebook. We are constantly trying to provide subject matter that specifically speaks to our unique group and especially in the area of health with updates on PPS.

Warmest regards,

Wayne Nichols President

From the Editor

A radio host suggested it would be better if we adopted the term "physical distancing" instead of "social distancing". We are all now learning ways to have a social life even without the physical contact.

As a support group this crisis has taught us the benefit of Zoom meetings. Now even those who cannot physically come to an event can participate; and it's been great! Zoom has extra advantages: • there is less traffic, • no dangerous rides on the Interstates coming into Atlanta, • seeing faces tagged with names. If any member wants to join the Zoom meetings but having technical difficulty, APPA is here to help. I can't hug you but I sure have enjoyed our phone calls and emails.

It seems to me we skipped from March to June all too quickly. So I am especially thankful to Leslie, Rita, Barb, Wayne, Belinda and others who have contributed to this issue.

APPA NEWS is OUR NEWSLETTER. It would be nice to hear input from more of our members. Just email me at Nancy@prime.org. If you don't want to write something, we can do an interview format over the phone. I know all PPS'ers are resilient and creative, so please share some of your wisdom and experience.

I will spare you some pages of my own cruise experience last Fall, but I will share our picture. The scooter made it entirely possible for me to go on the cruise, carry children, and luggage. That is something I couldn't do when I just used canes. So PPS brought me low but, thanks to assisted devices, not too low.



We did not think at the time that this might be one of the last cruises for a long time. Sadly the ship in the background, the Norwegian Sky, has cancelled cruises through 2020. We can only hope that the cruise industry, which employs thousands of friendly crew from all over the world, can recover.

Nancy Winter

SNAFAPPA's SPECIAL NEEDS ASSISTANCE FUND

By Leslie Schulgen and the SNAF Team



APPA members may be eligible for a **new benefit** to help with the financial burden of purchasing or repairing much needed medical equipment. Our SNAF fund was created over 25 years ago by a previous APPA Board with the intention of assisting members who were more frequently using (previously unnecessary) medical devices as the symptoms of Post Polio Syndrome advanced. At one point, most of the funds were allocated. However, over the past 18 years, donated funds were set aside to rebuild SNAF. All those eligible (see guidelines) are encouraged to call or visit the **FODAC** website (Friends of Disabled Adults and Children) for information about a specific item or needed repairs of an existing one. If a custom device is required, submit a request to help fund a prescribed need. Our SNAF committee looks forward to serving the APPA community.

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:

Any Post-Polio Survivor member with two years of uninterrupted dues payment and eligible 24 months from Ist payment can apply for up to \$1000 per year with a lifetime limit of \$3000.

APPA's SNAF funds will pay

- a) One time \$25 FODAC membership fee
- b) FODAC's cost for parts (see attached Service Charges), 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 appointments for a specific devices (lifts, hand controls etc).
- APPA will cover all expenses for APPA polio survivor members involved in using FODAC services up to the previously stated limits (#1,2).
- 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)

GUIDELINES – CUSTOM MEDICAL DEVICES

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

A Post-Polio Survivor member must be an active APPA dues paying member with two years of uninterrupted dues payment and eligible 24 months from Ist 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..

S	NAF APPLICATION for CUSTOM Devices				
	1. Last nameFirst				
	DEVICE and/or SERVICE requested (be specific)				
COST and description of for any custom MEDICAL device (not current available at FODAC).					
\$_	Amount requested				
	Description of medical Device or equipment needed (attach any documented quotes)				
	Medical need verification – Doctor prescription (please attach copy)				
	Vendor (name, address, phone)				
	4. Approximate date needed				
	Mail or email application to: 1036 Parkway Ct., Buford, GA 30518 OR contact the SNAF committee at appasnaf2020@gmail.com				

The FODAC VIRTUAL Run, Walk 'N' Roll

Vicki Crowell

This year was a very sad year for our annu- credit for them!! That was \$1,448. Then al May Run, Walk 'N' Roll at Stone Mountain because we were not able to go in person. I missed seeing all of the friends I have made through the years.

I don't remember what year I first went to FODAC for help. I got my first lift for my car from there. I have acquired numerous items from them; the last was the scooter I am using now. I had actually ordered one and paid for it. But, it was so uncomfortable that I talked to them about it. They called me when they had one for me and it is so much better on my back. I took the one I bought and swapped. I don't even remember what all I have gotten from them, but they are just a great organization and have done so much good.

If you have any needs, try them first.

Now the Run, Walk 'N' Roll is a lot of fun and raising money to help them makes me feel so good. I have a lot of friends that help me out every year. I think I have won first place for 3 years in a row. This year was my best ever, but I had some help.

Doug Turnbull (of WSB Traffic-helicopter fame) married in April. He asked that donations be made to FODAC in lieu of wedding gifts. He then arranged that I get the

Chris Brand. President/CEO FOFDAC also made a donation to sponsor me. My raised amount for FODAC totaled \$3,698.

Every year at the Run, Walk 'N' Roll we have dated t-shirts. The other day I wore my 2015 shirt. I know I have been doing the Run, Walk 'N' Roll since, even before that year.

I want to thank everyone that donated in my name and sent checks to me. I appreciate it so much! Get ready—because next year I plan to enter again. Save your pennies because they add up.



Event Highlights January—June 2020

January 2020. Traditionally we don't hold an APPA event in January because it is a time for the new Board/Officers to get acquainted with their tasks. This year we had a change of five Board Members. Past-President Carol Crumby handed the meeting over to our new President, Wayne Nichols. Shannon Morgan who has served nine years as Treasurer and Data Management passed the torch and took a well-deserved break.

February 2020—Better Breathing and Sleep. Mark T Pollock, MD of Pulmonary & Sleep Specialists, was our guest speaker. His presentation is available in the Media Room of the APPA Website. A large number of APPA members attended which leads me to believe lots of us PPSers have sleeping issues. Dr. Pollock was kind enough to field many questions. From my 4 pages of notes: here are a few highlights:

- We need sleep so our brain can do important functions. Sleep replaces chemicals and eliminates waste; without this process we experience sluggishness.
- Sleep sorts out our day's experiences, tossing out the less important, and laying down memory of what is important.
- Sleep provides clear thinking, energy, healthy memory, better mood, and high quality of life.
- We require 7-9 hours of sleep. Everyone has a circadian rhythm genetically usually with the light of the sun. However, with modern life, some of us larks, and some of us are night-owls.
- If you go to bed at 8:30 pm, do not be surprised to wake up at 4:30 am you evidently will have had enough sleep.
- A short nap during the day is natural and increases alertness, corresponding to your natural sleep cycle.
- The natural melatonin in us works when it is dark.
- CPAP = Continuous Positive Airway Pressure. Watch the meeting to get more on pulmonary aspects of sleep.
- 20 minutes/day of exercise or some PPS-friendly activity helps sleep at night.

Website https://www.pssatl.com/

March 2020— Bingo. Fifteen people came to play in this APPA event, including a few new PPSers. Vicki Crowell called 13 games of Bingo so everyone had a chance to win a \$10 gift card. The last game was a total card "blackout" and the winner (Joe Drogan) won a \$25 Visa card. Everyone had a good time! ——By Barbara Mayer

Event Highlights continued

April 2020 — Zooming to APPA events.

The planned meeting at Shepherd Center was cancelled. However, the APPA Board met online using Zoom, thanks to the expertise of Leslie Schulgen.

The Zoom meeting worked well. So it was decided we could continue this format into the future. The fun part is being able to connect names with our faces (if you choose to join with video). We can type public or private remarks and questions on the side, during the meeting, without interrupting anyone. We can virtually raise our hands and politely talk in turn. No traffic, no commuting, just friends and information.

May 2020—Memoirs

Highlights by Rita Carlson

Fran Stewart, an award winning author, presented a discussion about writing memoirs during our May meeting through Zoom. Fran has published 24 books, including 15 mysteries, a writers workbook, and most recently her 6 volume bookkeeping memoir. She believes that everyone of us has a story to tell about our life. She has led numerous interactive memoir workshops through the Gwinnett County library system as well as teaching Brenau University's Lifetime Learning Program.

Fran presented tips about writing a simple remembrance from each of us from four ideas: pet, what is seen in a mirror, an "ah-ha" moment, and a favorite tool. She also presented information about prompts which would lead to the history of an individual's life. This included prompts such as farm animals, picnic, and my great mistake. Each of the members then wrote about experiences as remembered from the past and discussed it as a group discussion.

Fran taught us that when you will tell your story of how you overcame what your were going through, that it will become part of someone else's survival guide.

Follow her on facebook.com/FranStewartAuthor

For the APPA News, Fran has shared this verse with the back-story from her poem "Reflection"
•The gift my mother gave • To me the night she died • Was a deep, strong, heart-committed knowing •That I will never close my fist and wait • for Death to come and open it.

My mother was such an unhappy woman, and much of that unhappiness came from her inability to open her heart. Her nearly crippling arthritis was a bodily expression of how completely she had shut herself off from the goodness of life. She spent her entire life expecting others to make her happy, but no matter what we did, it was never enough. When her hand relaxed after Death took her, I finally knew that my approach to life could never be to close my fist (a metaphor for my heart), since waiting for Death was waiting too long. I have tried ever since to remain open to the expectancy that I will find life and love when I look within for nonjudgmental acceptance of others and for generosity & happiness — not when I demand them of others.

June 2020 —Dr. Dale Strasser: Comparing the COVID-19 and Polio Viruses

Highlights from presentation

By Barbara Mayer



In the last few months there have been many comparisons of the current pandemic novel coronavirus (COVID-19) and the polio epidemics of the 1940s &1950s. An epidemic is defined as the rapid spread of disease to a large number of people in a given population within a short period of time. On the other hand, a pandemic is an outbreak of a disease that occurs over a wide geographic area or throughout the world and affects an exceptionally high proportion of the population.

Epidemics and pandemics have occurred throughout human history. Two well documented pandemics were the Bubonic or Black Plaque in the mid 1300s which killed 1/3 of the European population, and the Spanish Flu pandemic in 1918 which targeted young adults, and killed more people than died in battle during WWI.

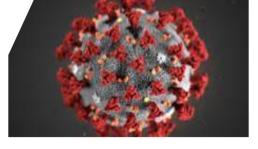
Poliovirus begins as an intestinal virus that in a small percentage of cases migrates into the spinal cord where it destroys motor nerves, causing paralysis. Problems with breathing would only occur if the chest muscles or diaphragm were affected causing the person to physically have trouble breathing. This virus is shed in the stools of infected individuals and acquired through contaminated water or food. You cannot acquire polio by being next to an infected person. Polio was 40 times more common

in July and August than the rest of the year, and it affected primarily children and adolescents. It could be fatal but more typically left its victims with paralyzed arms and legs. The Salk vaccine was deemed safe and effective in April 1955. Polio has been eliminated world-wide except for Afghanistan and Pakistan. Many polio survivors are now dealing with the late effects of polio.

COVID-19 is a respiratory virus that has systemic effects. It is spread through respiratory droplets produced when an infected person coughs or sneezes. These droplets can land in the mouths or noses of people who are near or inhaled into the lungs. The spread of this virus is more likely when people are in close contact with one another. The virus attacks the lung tissue, infiltrates the lung cell, and hijacks the cell to

make more viruses.

COVID-19 can affect all ages, but it ap-



pears to be most serious and fatal in older adults and those with underlying medical conditions. Some victims of this virus are experiencing increase in blood clots. The long-term effects of COVID-19 are unknown along with the potential of a second surge of infections this Fall. Many pharmaceutical companies are working on a vaccine, but until then, containment (social distancing) is the only way to control the spread of this deadly virus.

Polio and the late effects of polio do NOT, in themselves, cause immune compromise. Therefore, polio survivors are no more likely to contract COVID-19 than people who never had polio. However, most polio survivors are over 60 years old which places us in the "higher risk" category with a greater likelihood of developing severe disease after being infected with the virus.

Polio survivors who had breathing muscles involvement with their original illness and/ or now have respiratory problems of any kind are in the "high risk" category.

What can we do to take care of ourselves? Follow the CDC Guidelines: wash your hands often, disinfect frequently touched surfaces, cover your nose and mouth when coughing or sneezing, stay home and avoid non-essential trips. If you must go out, wear a mask or face covering and maintain at least six feet between yourself and others. If you have people come into your home to provide services, it's important that they also follow the recommended guidelines, including wearing a mask.

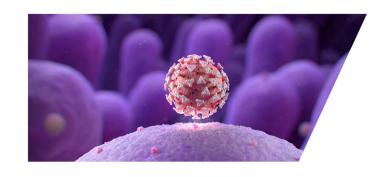
If you do develop a cough or fever (temperature over 100 degrees F) call your health care provider for advice about what to do next. If you have trouble breathing, go to the Emergency Department. If able,

have someone call the Emergency Department ahead so they can be prepared for your arrival. The same goes for if you need an ambulance to transport you. It is important to tell the doctor, nurse, or health care provider that you have a history of polio with weakened respiratory muscles (if that is the case), and are sensitive to anesthetics.

In the meantime, stay well! Eat healthy, drink plenty of water, don't smoke, and stay as active as possible. For further information go to www.polioplace.org and for the latest information about COVID-19 check the CDC's website at www.coronavirus.gov.

Additional reference:

"Comparing the Polio and Coronavirus Epidemics" by Daniel J. Wilson, PhD Post-Polio Health, Spring 2020, Volume 36, Number 2



More photos from Dr. Strasser's presentation.

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Zooming into APPA

On June 6th, APPA had its second meeting via Zoom and what a success it was! We had over 40 in attendance from all over Georgia, one in Florida, plus our speaker who was in Tennessee. Although we would prefer to see each other in person, during this pandemic when we need to keep ourselves safe, using technology is the next best thing. How nice it was to see APPA members that for one reason or another have not been able to attend meetings at the Shepherd Center. For those members who do not have access to a computer or internet, there is a way to join Zoom meetings using the phone. Just think – you can attend an APPA meeting from the comforts of your own home and not be has-sled with traffic, parking, or getting yourself to the meeting room.

We are not sure when it will be safe for us to gather together again, but during this difficult time, it's important for us to stay as connected as possible. Our next APPA meeting via Zoom will be August 1st. Hope to "see" you there.

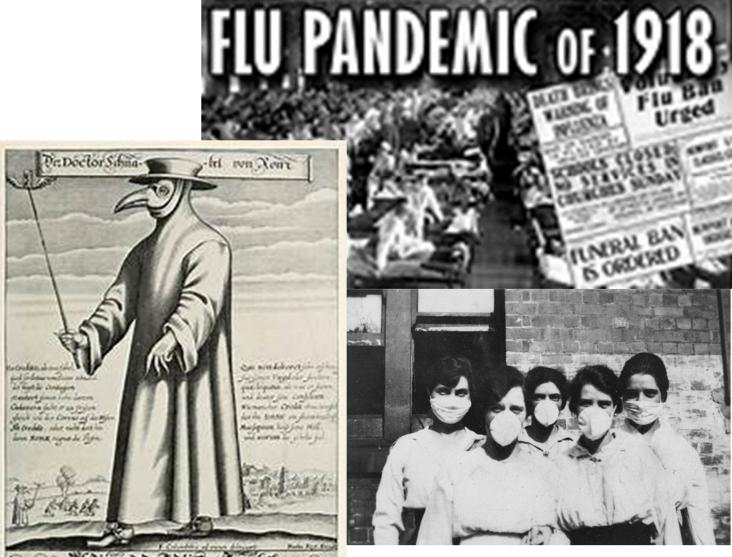
Barbara Mayer

Pandemic of 2020



Thank you to Dr. Strasser for sharing these pictures from your PowerPoint presentation.

The entire presentation is available on the APPA website.



Editors note: The masks from 1918 –2020 are similar. The masks doctors used in the middle ages were really creepy but functional. The beak held herbs.

Upcoming 2020 Programs

August 2020 — Cathy McIntire

Cathy McIntire will be the guest speaker at the APPA meeting which will be held Saturday, August 1st from 1-3 pm. Cathy is an APPA member and has always been a lover of animals, an observer of people, and an artist. She is happy to have days in front of her with no place to go. This allows her time to spend with her creative thoughts, planning, and making art in her home studio.

As a child she drew horses instead of practicing piano.

Cathy graduated from college with a BFA and has always worked in the arts field-both commercial and fine art. As a fine artist she earned her Signature status in two professional painting societies, inclusion in regional and national juried exhibitions, and participation in numerous gallery exhibits that include two solo shows. Cathy will be presenting a video of her work through Zoom, and will discuss the influence of being a polio survivor to her art.

For more information call (404)350-7631 or consult our website at www.atlantapostpolio.com.

Maybe this Fall or maybe not:

APPA is considering hosting several catered APPA picnics for you and your family in a park or other sheltered, open location near you. Covid may prevent this happening this year.

Watch for the announcements

October — Medicare Updates—TBA

November — **Dr. Geza Kogler,** Associate Professor of Prosthetics and Orthothotics and Director of the MSPO programs at Kennesaw State University

December — Annual Christmas Party, if possible.



How to manage in a wheelchair?

Interview with Belinda Whitaker

Belinda Nancy



I know some of us PPSers might, like me, wonder how we could manage to live independently in a powerchair, if PPS brings us to that point. So I was very glad to find an expert in APPA willing to answer all my questions. What follows is our interview with how she does it. Links and references mentioned are at the end of the article.

First, when and where did you have polio? Were you able to walk awhile? Are you able to walk a little bit now?

My family lived in Aurora, Illinois in 1956 when I contracted polio at age 5-1/2 years. I have no memory of fever or headaches, but I remember I couldn't wiggle my toes. Mom called the doctor, and he diagnosed me with polio. I was checked into the hospital. At first I was in a private room by myself and then moved to the ward with other kids for two more months.

I was fitted for long metal braces that had the shoes attached. I could walk a bit with those. While I was in the hospital, my family moved into a two-story home with the bathroom being upstairs. For years, I used standard crutches to walk, then graduated to forearm crutches. My son was in school at Morehouse. When I came to see him, I decided to stay. Ten years ago, I broke my weak left leg and had surgery to place a rod in it. My knee doesn't catch, so instead of wearing out shoulders and arms I turned to the power-chair.

After surgery, a worker in rehab asked, "Who is your polio doctor?" That is how I first learned about Dr. Strasser.

He told me about three PPS books* which I read and continue to refer to when things come up. I was amazed reading the first book, it seemed like the author had been over my shoulder knowing my experience. Dr. Strasser's advice was, "Take care of your shoulders or you won't be able to move."

How did you get the first powerchair?

Getting the powerchair through Medicare was part of the physical therapy process. They brought in a seating specialist to access your height and weight. Then they recommend a chair for you. Medicare takes a long time for the process. When powerchair dies, Medicare won't repair it, but if you wait 5 years they will replace it. When APPA had the field trip to FODAC last year, I happened down an aisle and noticed the new version of the Hoveround. It had only been at FODAC for two days. I got the receptionist's email so she would reserve it for me. I called Dr. Strasser and he sent the prescription to FODAC and I got that newer Hoveround within a week.

How did you get to FODAC for that APPA field trip? Tell me about getting a van and the ramp to get into it.

At that time, I still had my working vehicle with a ramp. First van I got with a grant through Braunability. They do modifications on the van which came from Mobility Works in Marietta. That first van was about 9 years old. I used that van about 5 years, until it was totaled in an accident. I got this last van from someone at church. It was already 18 years old when I got it. It was not in good shape and needed a lot of repairs.

How do they convert the vehicles to get them accessible?

Mobility Works has locations around the country, and they can ship from stock. They take out the middle seats for the ramp, lower the floor and make it kneel (the van leans to the passenger side so the ramp is not as steep). There are two types of conversions. One that folds out and the other slides under the van. There is also a rear entry ramp.

How is it getting around in your home?

I live in a senior apartment building. The hallways and doorways are wide enough for my chair. Each bedroom and bath have an emergency pull cord in case someone falls. It alerts others who call paramedics. There is also laundry and trash facilities on each floor

Do you cook and do dishes from your chair?

Yes. There are accessible apartments, but I don't have one. I can reach the controls on my stove/oven, dishwasher and microwave from my chair.

How did you get established in your senior living building?

This is a four-story building close to the Braves' Stadium. I got the application from the leasing office. There was a waiting list,

Wheelchair Continued

but I was given this apartment in less than a year.

I know that you were at APPA meetings when they were at the Shepherd Center. How you get around town?

Locally, I can ride my scooter to get groceries at Aldi. It takes me about ten minutes each way. Today I went to church, picked up groceries and came home all within chair distance.

My daughter pushed me around New York City with a wheelchair. I would never have braved alone some of the curb ramps. They were broken, badly sloped or covered with leaves so you couldn't know what you might be wheeling into. How do you find the sidewalks and curbs?

The sidewalks and curb ramps are pretty good. One day I went down a hill thinking I could get to a shopping center, but there was no curb ramp. So, I had to backtrack and find the way around that. We find the best routes with experience. Atlanta maintains them pretty well.

One day I came down a sidewalk to visit with friends and told them I would be fine going back on my own, using the same sidewalk. But, a work crew had been cutting limbs and left them all blocking the sidewalk. A nice stranger came along and saw the problem and personally cleared all the limbs from the sidewalk into the street.

If I need to go further, I use CobbLinc and Paratransit. All have ramps and they strap the wheelchair down. Cobblinc with ID is like \$1 trip for seniors. Buses have a ramp that folds out and kneels. Just takes a few seconds to get loaded. All buses are free during Covid-19.

I am sorry to hear of the passing of your father in Minneapolis a few weeks ago. How did you manage traveling there?

I got a "buddy pass" from a church friend to fly. My own powerchair does not fold, so I rented a scooter for this trip from Heavenly Wheels. They use an aisle chair to take me to my seat and fold-up, put the scooter in neutral and check the scooter. (Always take the key with you.) When I got to Minneapolis, they brought the aisle chair and carried me back to my scooter right by the plane door. Then I got the baggage from carousel. Family friends picked me up and managed with some hassle to get it into their trunk. The hotel was easy to manage and my cousin used his Highlander to chauffeur me around.

What about your trip back?

I got bumped from flights Friday and Saturday. I had to buy a regular ticket for Sunday. My luggage was checked and happily flew without me. I had to make a trip to Walmart to get some items I would need overnight.

On Sunday, the cab company (same one that picked me up on Saturday), sent a van without a ramp and then told me they did not offer handicap vans on weekends. All this was making me late for the flight.

You keep laughing about it now, were you laughing then?

No, I was mad. Finally, I caught a bus from the hotel to downtown Minneapolis. From there they have a train that runs past the airport all the way to the Mall of America. In the end I caught up with my luggage in Atlanta, got the train from the airport to downtown Arts Center, and the bus back home to Smyrna.

What is the app you mentioned that told you how to get this other transportation?

Google Maps

Go to Google and put in the address of your destination.

Hit the right arrow

Across the top under the address, you will get options to drive, by bus/train, walk, bike.

Choose your option and it will tell you when to leave and where to transfer.

Resources mentioned in this interview

- I. POLIO An American Story David M. Oshinsky This is a good one about the history of polio in America
- 2. Post Polio Syndrome Julie K. Silver, M.D. I use this one as a reference manual for times I wonder about a cough or swallowing or pain problems. Anything to keep up on issues.
- 3. Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors This is a great handbook with definitions for complications for those with polio. Some topics include, aging and weakness; depression; fatigue; muscle weakness; sleep apnea; swimming; ventilators.

OTHER RESOURCES:

Mobility Works - https://www.mobilityworks.com/ They have sales, service rentals and maintenance. The closest is in Marietta.

Braunability - https://www.braunability.com/us/en.html This company makes the conversions, side entry or rear entry. They can also help with some financing. If you check their website, look for a grant program. I think they offer it four times a year.

Hoveround chair – www.hoveround.com - This is the kind of chair I got from FODAC. It works well because it spins in tight places as opposed to a scooter that turns like a car.

Resources from Interview, continued

Cobblinc – www.cobblinc.com – this is the public bus system in Cobb County. The system where they will come and pick you up is called para transit. You have to apply and once you have been approved, you can schedule a pick-up to go shopping, church or wherever. (must be scheduled 24 hours in advance) The cost is \$4 per trip. The application is on the cobblinc site. Other metro counties have their own link service.

https://www.heavenlywheels.com/services-rental - This is the company I rented a scooter to travel on the plane. You can take it to the door of the plane and transfer to an aisle chair. Show them how to lower the handlebar, put it in neutral, and always take the key with you. (If the key falls out in baggage, you're stuck, keep the key). When you get to your destination, they will bring the scooter up to the plane door for you.

When Belinda gets a van, she'll be back with her business:

Reflections of isolation due to Coronavirus, circulated through email. To the unknown author(s), thanks for making me laugh.



- Still haven't decided where to go for vacation The Living Room or The Bedroom
- Every few days try your jeans on just to make sure they fit. Pajamas will have you believe all is well in the kingdom.
- Home-schooling is going well. two students suspended for fighting and one teacher fired for drinking on the job.
- I don't think anyone expected that when we changed the clocks, we'd go from Standard Time to the Twilight Zone
- This morning I saw a neighbor talking to her cat. It was obvious she thought her cat understood her. I came into my house, told my dog we laughed a lot.
- Quarantine Day 5: Went to this restaurant called THE KITCHEN. You have to gather all the ingredients and make your own meal. I have no clue how this place is still in business.
- My body has absorbed so much soap and disinfectant lately that when I pee it cleans the toilet.
- Day 5 of Homeschooling: One of these little monsters called in a bomb threat.
- I'm so excited it's time to take out the garbage. What should I wear?
- I hope the weather is good tomorrow for my trip to "Puerto Backyarda". I'm getting tired of "Los Livingroom".
- Now that I am living through an actual plague, I totally understand why Italian Renaissance Paintings are full of naked fat people laying on couches.

Links to other PPS, Polio, and Covid-19 articles

There are many online articles linking the experience of polio to the current pandemic. What follows are a few highlights and links to the articles.

"Could the Polio Vaccine Curb the Coronovirus Pandemic?" by Lipi Roy, MD, MPH. The article describes the possibilities and dangers and the science behind this idea. Cool pictures in the article too. https://www.forbes.com/sites/lipiroy/2020/06/14/could-the-polio-vaccine-curb-the-coronavirus-pandemic/

"Eighty years after polio swept North America, we're still learning lessons from 'the crippler'" by Karen Black. The article is a historic look-back from the Canadian experience. This is cautionary tale of the polio epidemic in Toronto in 1937 and what followed in North America. In the USA, support for polio victims was provided not through direct government funding but through the new Foundation for Infantile Paralysis (which became the March of Dimes) established in 1938 by president Franklin D. Roosevelt, himself stricken by polio in 1921.

https://www.thestar.com/news/insight/2020/04/19/eighty-years-later-lessons-from-the-crippler.html

I found out about this article from our Atlanta Post-Polio Association discussion group on Facebook. It includes the link to the interview with Wayne Nichols and Linda Priest. https://www.gpbnews.org/post/polio-survivors-warn-against-reopening-georgia

This article is worth looking at for the wonderful old pictures. As the world waits on a COVID-19 vaccine, here's a peek at what things looked like as polio vaccines surfaced. https://www.ksat.com/features/2020/06/23/as-the-world-waits-on-a-covid-19-vaccine-heres-a-peek-at-what-things-looked-like-as-polio-vaccines-surfaced/

The movie "Crip Camp" is an amazing story behind the effort to get the ADA into law. It is currently available on Netflix. You can see the Trailer on YouTube. https://www.youtube.com/watch?v=XRrls22plz0&t=2s

Remember this important link to Bruno Bytes and the Encyclopedia of Polio and Post-Polio Sequelae https://www.papolionetwork.org/bruno-bytes.html

MPPM Membership News

Welcome to new APPA Members

Robert Fedorchak from Marietta, GA
Susan Press, Chevy Chase, MD
Paul Suwak, Liburn, GA
Beth Valentine, Atlanta, GA
Beth Schweriner, Marietta, GA
Wesley Moss, Marietta, GA

Donations made through Network for Good via Facebook have brought APPA over \$1,000 since January 2019

Thank you to those who contributed in memory of Maurine Dorsey

Thanks to our Corporate Donors 2019-2020:

Turner Broadcasting:

The Benevity Community Impact Fund
Early Learning Property Management Inc
LOC Scientific

Mobility Works Handicapped Driver Services
Fortify IT, INC

Special Thanks to our Lifetime APPA Members

Ray & Brenda Fitzpatrick Rudolph Jones (page 26)

Gloria I. Mims Patricia |. Dorset-Bullington

Marcus E. Gunter Rich & Jenny Worsham

Cheryl & Jack Hollis Joe Drogan

Marie T. Moore Dick & Anita Weir

Wayne & Cynthia Nichols **Betty Wright**

Shirley Ann Duhart-Green Alan Mitchell

Vicki Crowell Peggy Pruett

Linda Priest Nancy Truluck **Donald Leslie** Carol Crumby

Thanks to our 2020 Advanced Level Members

Thomas Foss Robert & Jean Abney

James and Allie Harrison Bob Fedorchak

Ray Fitzpatrick **Nancy Winter Shelley T Ross Susan Press**

Karen Ragsdale Carol & Neil Penn

Beth Valentine Helen & Bobby Crenshaw

Barbara Meyer Thad & Patricia Lewis

Inge H.Thomas

Billy & Maureen Pond Leslie Schulgen,

Saundi Harrison-Cooksey David Jordan

Leo Roszkowski Michael & Jymbellyn Carthon

Paul Blazeski **Barbara & Herbert Ruecksties**

Editors note:

If you should be on this list, but I missed listing your name, I am sorry. Please let me know.

From Post-Polio Health International Introducing the Polio Survivor's Guide: Funding Resources for Medical and Adaptive Equipment.

Copied from:

http://polioplace.org/sites/default/files/files/PHIFundsDirectory2020.pdf

Introduction. Living well with a physical disability in the United States is an expensive proposition. Most medical insurance coverage is very limited, sometimes nonexistent, for expenses needed to acquire necessary medical equipment, even ventilators for people who are unable to breathe adequately or wheelchairs for people unable to walk. "Medically Necessary" criteria for coverage are not uniform between plans, co-pays or coverage limitations can be burdensome and spending limitations often lead to poor quality items.

Almost no insurance plans contribute to costs for architectural modifications of homes, vehicles, clothing or adaptive equipment that could increase one's independence, productivity and/or Quality of Life. Consequently, many US citizens with physical impairments feel like they pay an "American surtax on disability". This resource guide has been assembled to assist Americans with disabilities, particularly polio survivors with significant motor and breathing impairments, to find financial assistance for the costs of obtaining desired medical equipment and/or environmental adaptive modifications that are otherwise not affordable to them.

Post-Polio Health International (PHI) has a long history as an organization committed to helping polio survivors live independently despite severe post-polio disabilities and their late effects. It has always encouraged polio survivors to take matters into their own hands and to assume personal responsibility for finding solutions to any barriers they may face to achieve the meaningful lifestyle they desire. It is in this spirit that a team of investigators coordinated by Sunny Roller has produced this compendium of possible resources available to assist people with disabilities obtain the adaptive medical and rehabilitative equipment and environmental modifications they determine that they need. Users will still have a lot of work to do in "selling their needs" to potential funding sources and identifying those local or regional funding sources mostly likely to be responsive to their needs.

As a physician specialist in Physical Medicine and Rehabilitation with over 40 years of experience in helping polio survivors, I acknowledge their frustrations in dealing with our

American healthcare system because of its apparent lack of support for people with disabilities in achieving their optimal potential for independence and Quality of Life. I have also witnessed the incredible persistence, creativity and intelligence of polio survivors in coming up with effective unique solutions for overcoming their barriers.

I sincerely hope and expect this resource guide to be of assistance to many people with disabilities who are otherwise limited in achieving their personal goals because of financial barriers to acquiring needed equipment and environmental modifications.

Frederick M Maynard, MD , FAAPMR Member, Post-Polio Health International Board of Directors; Chair, Medical Advisory Committee

How To Use This Guide: • These resources are access points for direct funding or inkind gifts to meet the medical equipment for mobility needs of polio survivors. • Medical equipment and assistive technology can include, but are not limited to wheelchairs, crutches, scooters, and respiratory supplies. • Many of the resources in this guide are Loan Closets. Loan Closets are designed to give people medical equipment for a limited time without charge or at an affordable rate. Many loan closets also offer free equipment exchange programs, alternative funding options, and free equipment to keep. • If you don't see resources listed in your area, contact the relevant national or state-based resources in this guide for further assistance. • This guide is not intended to list low-interest loans or product sales. While some resources may be easy to find, others may require more exploration. If you cannot find what your independent needs are as polio survivors, the resource contact information has been included for further inquiry. • If you know of any resources that are not listed and should be added to this guide, please contact Post-Polio Health International at info@post-polio.org.

http://polioplace.org/sites/default/files/files/PHIFundsDirectory2020.pdf

This guide is accessed online and includes national as well as state-specific resources. If you need help to use this list, call APPA.

Leave a message and we can help you. 404-350-7631.

Remember APPA also has the Special Needs Assistance Fund (SNAF). Pages 5-7

Remembering Members & Their Families

Our sympathy to members who lost their husbands this past year:

Fay Baker, Marlene Cantrell, Mary-Ann Clinton, Lilli Guerry, Carol Vish

And to those who lost a family member in the past few months

Wayne Nichols' father died in February 2020 and

Wayne's son died in June 2020

Belinda Whitaker's father died in June 2020

In Remembrance

Rudolph Jones



It is with a sad heart that we report the passing of Mr. Rudolph Jones on March 24, 2020. He was a lifetime member and generous contributor to APPA. "Rudy attended our Christmas Luncheon last December and everyone at our table enjoyed lots of laughs because of him", said Pat Harris. He will be greatly missed!

You are Polio Graduate Year of what?

Want some help joining our discussions online? When you sign into Facebook. "Search Facebook" (magnifying glass—top left) look-up Atlanta Post-Polio Association Group and click "Join". Once in the group you can scroll to see lots of stuff and join in our talks.

The thread started on June 11th asked 3 questions: How old were you when you got polio? Where were you living then? What year did you get polio?

Thank you to the eleven people have answered so far. If you want to contribute to this list, scroll down through their answers to the blank by your name that says: "Write a Comment". Don't be shy, please write and click enter. You might meet fellow "classmates" whom you didn't know before.

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

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

 (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
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Nancy Winter - Editor

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