



APPA NEWS



The Atlanta Post-Polio Association

Volume 40, Issue 1

Spring 2025



To APPA

40 Years

Rest in Peace Linda Priest

In Remembrance:

Linda died April 27, 2025, at noon at the Highland Senior Living in Norcross. Her arrangements were with Lovin Funeral Home in Nashville Georgia where she was to be buried in the family plot a celebration of life to be announced at a later time.

In the Winter 2019-2020 APPA News featured Linda and the history of APPA. Pages from that issue are copied starting on page 11. APPA news issues, going back many decades are also found via our website:
(<https://www.atlantapostpolio.com/>).

Linda Priest and others started APPA back in the 1980's. The official 501-c-3 status was set in 1985. Thus, 2025 we are celebrating our 40-Year Anniversary. A few months ago, the APPA Board voted

Linda as President Emeritus.

Linda used to tell us that she didn't know what position she held, because everyone just pitched in to get APPA going. They worked hard to find all the other polio survivors who might be having PPS without understanding what was happening in their otherwise active lives.

Many thanks to those who founded & maintained APPA 40+ years.



SNAF: SPECIAL NEEDS ASSISTANCE FUND

APPA's SNAF Program works!

About 6 APPA Members have benefitted from SNAF to help them acquire durable medical equipment (DME) beyond what Medicare can provide.

If you need used equipment or repairs under our SNAF program, call FODAC and arrange a visit. You qualify if you have been a dues-paying APPA Member for the past two years.

Email questions to the SNAF team:

appasnaf2020@gmail.com



**Stone Mountain Park
Next Spring 2026**

APPA and our SNAF program has a connection to FODAC's (Friends of Disabled Adults and Children). Their fundraiser is the Spring at Stone Mountain Park. APPA member, Vicki Crowell has won the fundraising competition for many years and she also volunteers also at FODAC. Next year, more of us should try to join her. They have other events:

Give online at www.fodac.org/events. It is a wonderful organization, and if anyone needs any equipment, please give them a call at 770-491-9014. Let them know you are an eligible APPA member.

Some changes in APPA for 2025

As you might have heard, we have shuffled the APPA Board and added two new Board members.

So now the Board includes:

President - Nancy Winter (nancy@prime.org)

Vice-President – Barbara Ruecksties

Secretary - Paul Suwak

Treasurer - Belinda Whitaker

Assist. Treas.- Nancy Truluck

Member Records – Joe Drogan

Member Services - Pat Harris

SNAF- Leslie Schulgen

Tech Support and more - Wesley Moss

Archivist :Wayne Nichols

Webmaster:Allison Stockton

New Address for APPA:

**2731 Woodland Terrace
Apt. 320
Smyrna, GA 30080**

THE APPA VISION: The Atlanta Post-Polio Association (APPA), for 40 years, has helped to educate the public and the health care community concerning the late effects of polio. We respond to the needs of individuals who suffer from post-polio syndrome. We offer group meetings, educational programs, newsletters, website, online discussions, and advocacy. APPA has a Special Needs Assistance Fund (SNAF) to help members who need to be financially assisted with devices that increase stability and mobility. (Our mission and vision has not changed!!!)

APPA Zoom Meetings — our future plans

For the past several years, Rita Carlson (past President) arranged our APPA Zoom meetings on the first Saturday of each month. We email you the notice and the Zoom-link and phone connection twice before the meeting. They also will be on the APPA website. Many of the past meetings are archived there as well.

Now we are going to need everyone to take on this task. One thing to think about is whether First Saturdays is the best time to meet. This time goes back to the earlier APPA traditions of meeting together when most members were still in the workforce. Now that we are older and wiser and technically capable — would more of us be able to attend APPA Zoom if we picked another regular time?

As far as topics, we find that PPS'ers do not lack in ability to talk, and we have a lot to learn from each other. Some months we might not do a formal presentation, but we can still meet. On April 5th, each of us answered two questions: What is something you once feared but found a way to overcome that fear? If you could be present at some historical event, what would you choose? What a variety of answers we got.

The following pages are lists of topics and speakers who have been popular in the post-polio Zoom meetings. We will try to get them on the calendar for APPA.

We also encourage you to visit other post-polio meetings. We are an extraordinary group of people with fascinating careers and interests. Our one thing in common is polio and post-polio. We often educate each other on those subjects, but we also learn so much from such wonderful people. If you can't make the APPA Zooms, try the others and perhaps share with the rest of us some of the highlights.

BAPPG (Boca Area Post Polio Group) puts out each month the list of other zooms. Go to their link via: <https://postpolio.wordpress.com/> Their April issue also includes a long list of presentations that we can consider for our meetings.

We thought about merging APPA with other polio groups but decided that our mission of support needs to be continued on a local level. Some of our presentations, we hope, might be local physiatrists, functional medicine practitioners, etc. If you have found someone in the area that could also help our group, please ask them if they would present something for us on Zoom and/or offer something for our APPA News.

Upcoming APPA Zoom Events

Saturday May 3rd. 1-3 pm We watched a presentation together. Lots of topics to choose, BAPPG has compiled a list of good ones. This time it was on Neurology. As usual we had a lot of useful discussion by our local APPA participants/experts.

Saturday June 7th Shirley Thomas will talk with us about the changes on the horizon. She will give us the latest on Social Security, Medicare and Medicaid

Saturday July 5th — Independence Day Weekend — Enjoy it anyway you can. Maybe chat on the phone with an APPA Member you've been meaning to call. No Zoom meeting.

Saturday August 2nd — A special presentation by Susan Schoenbeck. We are very pleased that she is reserving that day for us. She has provided the list (on the next two pages). Pick out one or two and let me know.

Susie Schoenbeck is a nurse educator who teaches polio survivors around the globe how to deal with post-polio symptoms. She contracted polio at age 7 months and was taken from her father's arms and placed in an iron lung. Doctors at the isolation hospital said she would never walk. Her parents took her home. Susie's Dad took her to a weedy old lake and taught her how to swim. Eventually, she walked with one leg braced.

She became an ICU nurse and later a teacher, a Director of Nursing, and a Clinical Nurse Specialist for death and spiritual care for a large hospital trauma center. Susie has a master's degree in nursing from the University of Wisconsin-Madison.

Susie is the author of over 50 journal articles, and 6 books. **POLIO GIRL: It Only Takes One** is her latest book. **POLIO GIRL** was written to help polio survivors address their symptoms and to educate healthcare professionals how to care for the person with post-polio syndrome.

Presentations by Susan Schoenbeck

Disease Can Be a Gift: This presentation explores how our growth as human beings may be assisted by all sorts of circumstances that come our way. Commonly experienced signs and symptoms of late effect/post-polio are reviewed. Facts to support that polio is not a disease of the past are presented. How polio affects family dynamics is explored. Principles for dealing with adversity and a golden nugget to guide us are presented.

Our Heart Is Known by the Path We Walk. Examples of values engrained in polio kids are presented. This talk engages people in understanding how knowing one's values and living them influences other people's remembrance of them. The top values people say they want to be remembered for are presented. The benefits of smiling and volunteering on human physiology and happiness are discussed.

Unraveling Pain and Fatigue: Pain decades after poliomyelitis is the number one complaint of polio survivors. Most doctors and nurses have not been educated about polio pain and the late effects of polio. This class engages polio survivors to express their pain and fatigue in ways that help healthcare providers best figure out interventions that may alleviate such symptoms. Polio survivors have a responsibility to explain with words to healthcare professionals what their pain feels like, when it occurs, what helps prevent it, what helps relieve it. Number & faces pain scales do not describe the biopsychological aspects of pain. This talk introduces polio survivors to the OLDCART pain management tool and the OLDCART fatigue management tool which helps survivors educate themselves, their families and loved ones, and healthcare professionals about their pain and fatigue. How grief accompanies polio pain and fatigue is explored.

Take Charge of Your Post-Polio Fatigue: This talk shares the neuroanatomy behind the words polio survivors use to describe their fatigue. Proactive strategies that ward off fatigue along with recovery methods are discussed. The research status of a non-invasive potential treatment option for post-polio fatigue is introduced.

Rituals Restore Equilibrium: Rituals Help Polio Survivors Face Uncertainty: This talk discusses the kinds of uncertainty we polio survivors face. These are: We are overlooked. We are at the older end of a growing world population. Healthcare workers will continue to be in short supply. We live in uncharted waters. Historical/anthropological perspectives on the value of rituals in building resilience to reduce stress, calm us, give circulation a boost, distract from pain, soften grief, and bring balance to polio survivor days are reviewed. The science behind how rituals work is explained. The audience is presented with a wide variety of rituals that can be adopted.

Kindness: What it is. What it is not. Why polio survivors are unique vessels of kindness. Why we need kindness in this chaotic world. Ways to enact the gesture of kindness.

Presentations by Susan Schoenbeck, continued

Research findings that help us understand how best we can be the kind people we want to be. This presentation reviews early childhood polio survivor hospitalization scenarios and the biological effects traumatic situations have on our bodies and minds. It discusses how a person develops empathy, a linchpin for kindness. Why some people are empathetic, and others are not is explored. Ways to express empathy and show kindness are discussed. How important kindness is in a world where norms are being shattered is emphasized.

Spiritual Experiences: Out-of-Body and Near-Death Experiences (OBES/NDEs) are explored through the lens of those who report them to healthcare professionals and researchers. Life-altering aftereffects of spiritual experiences are discussed. How the phenomenon of being able to communicate across distances as people cross between realms is consistent with the quantum mechanics theory of physics is reviewed. Examples of practical use of knowledge of spiritual experiences are described.

Jonas Salk: Life and Philosophy: What does it mean to me? The story of how good intention, hard work, and valor against the odds led to Jonas Salk becoming a role model for selfless service. A review of the history of polio in the world and the development of the *People's Vaccine*. Salk's intention and perspective. Philosopher versus celebrity. The Salk Institute for Biological Studies. Incorporating the lessons of Jonas Salk into our lives. This talk explores how Salk's vision influences polio survivors today.

Why Vaccinate for Polio: The types of polio are described. The status of variants circulating the globe is presented. The Oral Polio Vaccine (Sabin) and Injectable Polio Vaccine (Salk) are compared. Asymptomatic carrier status is described. The differences between bulbar polio, spinal polio, and spinobulbar polio are discussed. Salk's double-blind clinical trial is detailed. That polio vaccines do not contain thimerosal is clarified. How antigens trigger the immune system is discussed. The cost of non-vaccination is reviewed. Herd immunity is explained. Traveling precautions and recommended booster shots are presented.

Grief is both Universal and Unique: Grief is a natural human response to loss. Building vocabulary to talk about grief. A walk through the stages of grief of acute polio, mourning in post-polio (PPS)/Late Effects of Polio (LEoP), and day-to-day approaches to address end-stage polio grief. Facing mortality with forgiveness and tears.

Rotary World Disability Advocacy Club, Polio Chapter

See the email below. If you would like to participate, please ask Florence Lunde to put you on the mailing address.

Hello everybody,

The last time I wrote to you, I promised you that I would let you know when the Rotary World Disability Advocacy Club, Polio Chapter will be having it's first general meeting. I am pleased to inform you that the meeting will be on the second Tuesday of every month at 10:30 AM EST so the meeting will be May 13, 2025 at 10:30 AM, EST. You will be receiving information as to how to join the zoom meeting.

As a quick reminder, this is not going to be a support group nor is it a place to vent complaints; if you are looking for a support group, this is not it. There are many support groups globally. What we are looking for is people who want to work doing effect positive changes for the polio community on a global scale.

Take care of yourself,
Florence Lunde
Chair person
Rotary world, disability, advocacy club, polio chapter

flojoy2112@gmail.com

We regularly receive news via Rotary. You can keep up via these sites, get involved and donate as you wish.

<https://www.endpolio.org/>

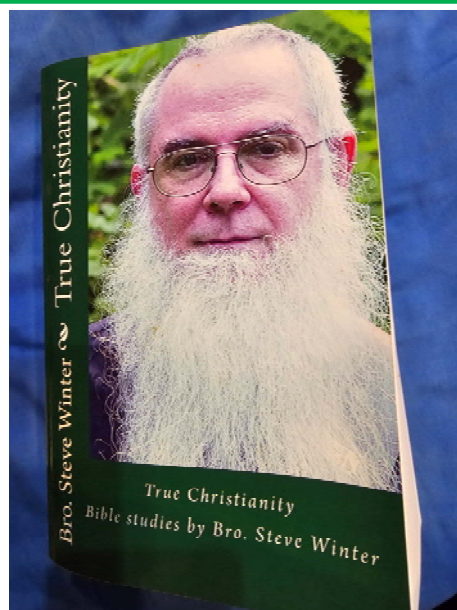
<https://polioeradication.org/who-we-are/>

If you have any questions and suggestions, please feel free to call or email me. nancy@prime.org (919-612-7841). I'm always happy to talk to APPA members. If I need a nap, I will turn my phone off. Do not worry about the time to call. Leave a message and the best time to call you back. I will look forward to it.

Sincerely,
Nancy Winter

In loving remembrance and a Tribute to my husband, Steve Winter who died on May 13, 2025. Steve was a musician, song-writer and created our home business. Most of all he was a Bible teacher and author. Our marriage started 42 years ago (\$10 to the magistrate) and then bloomed to a fine and large family.

Steve also maintained the technology to publish The APPA News.



The next pages are reprinted from earlier issues. First, from the APPA News Winter of 2020: Linda Priest's story and the history of APPA. Then another request of YOU to share your stories — not just your past or about polio, but other things you've accomplished or things you love to do (besides polio and PPS). We're trying to get to know each other so we can support each other. We are quite an extraordinary group and 40 years is a lot to celebrate. Last some puns which Dick Schultz recently emailed to make us laugh out loud.



The Genesis Of APPA

By Linda Priest

In the early 80's I was competing in wheelchair sports under the auspices of the National Wheelchair Athletic Association. It was my passion at the time. I helped start the Dixie Wheelchair Athletic Association and I competed on a national level in wheelchair track, swimming, basketball, slalom and eventually in road racing. Think about what a setup that was for the beginning of post-polio syndrome!

I think it might have been at Nationals Wheelchair Games in 1980 that I first began to suspect that I did not recover like my fellow athletes. I began to deny it even to myself. I don't know how I first heard about post-polio syndrome, but I do remember that there was a panel discussion televised in Chicago about this time that focused entirely on the subject and that it became a little more difficult for me to deny.

At the time I was married and had two young children. In a very dark part of my soul I began to worry about being able to care for them in the future. My brother began to question me, and I denied it to him. After all I was competing in long distance

road races and I had been the first woman in a wheelchair to finish the Peachtree Road Race. I was point guard for one of only four women's wheelchair basketball teams in the whole country. I was in my prime, wasn't I?

Finally, about 1983 I decided I would return to Warm Springs because I hadn't been back for at least 20 years and because they had a new polio clinic. I was skeptical but I thought I might learn something. To make a long story short, I did learn something.

At the end of the several days of testing, the doctor's recommendation was that I go into a motorized wheelchair. I was stunned! I was still competing in all the sports mentioned above! I do not remember anything else he said to me. I went home deeply depressed. I am embarrassed to say that it took another 10 to 15 years for me to accept a motorized wheelchair. But to my credit, I did stop all wheelchair sports.

It was amid all this frustration and loss that I began to face the fact that I had been lied

to by doctors at Warm Springs. To add to all the other negative emotions I was dealing with, I became angry.

When I was in my mid-teens I remember very clearly going for an appointment with my doctor in Warm Springs. I had begun to like boys and began to think about what my future would be like. It was important to me to have a clear understanding of what my future would be before I embarked on this ominous journey called love, marriage and a baby carriage. I was told that physically I would not change. That I would continue to be independent, that although I would always be in a wheelchair with paralyzed legs, my arms would remain strong and that I could marry and have a family. Essentially, live a normal life.

The appointment relieved me about my future because I had become a typical “boy crazy” adolescent and back then the only real goal for any self-respecting teenage girl was to get married and have children, many children. The point is that the medical journals prove that they knew back then about what is now called post-polio syndrome. And that makes me angry! It really does. They knew that there was this strange residual weakness that began to occur late in life, and they didn’t tell us!

What a difference it could have meant to me back in my teens to know that if I con-

served my muscles, my neurons and cared for them rather than spending a lifetime abusing them to the extreme, maybe I would not be in the shape that I am in now. At that point I pushed myself to the extreme in everything I did. And I have all the awards, degrees and titles to prove it. We were taught to achieve at all costs! And I learned the lesson very well.

But I digress, this is supposed to be an article about how APPA was born. It was against this backdrop of fear, anger, frustration and loss that I began to focus my research on post-polio syndrome (PPS). I found Post Polio Health International in St. Louis which had another name at the time. It was wonderful to talk with them and hear about the organization. Jennie Laurie who founded the organization was still alive at this time and she was a joy to talk with.

The organization basically at that time provided support to ventilator users and those who were still in iron lungs after all these years. They told me that they had just recently received a call from Atlanta and put me in touch with a polio survivor named Webster Cash. If I remember correctly Webster was a retired professor from one of the Atlanta area colleges.

It was great to find someone else who was also trying to find out everything they could about PPS. We had several conversations before we decided to meet. We

agreed to invite people who were polio survivors and who had some beneficial connections to help us start a polio organization. There were five of us that attended that first meeting. I invited Tamera Bibb who worked for State Vocational Rehabilitation and had connections in Warm Springs. (Warm Springs had been taken over by the state at this time.) I invited Ruth Ellis who was the director of PR for Easter Seals. Although I hadn't started working for Shepherd Center at this point, I had been volunteering lots of my time to that great rehabilitation center. Also, Webster invited a nurse connected with Emory Rehab.

The five of us brainstormed into the night about how to start a local support group. We tapped into every resource group the five of us knew. The name Atlanta Post Polio Association (APPA) was christened at that meeting, and in a very short time we had our first general meeting. We worked so hard and were so devoted to making it happen. We spread the word far and wide about our first meeting but being able to get mailing addresses from Warm Springs was the greatest help.

Our first meeting was located at Emory Rehabilitation Center. I wish I remembered exactly when we met. My computer died some time ago and so much of this history died with it. But I do remember it was a bright sunny day in the mid 1980's. I

am going to guess that it was 1985. The meeting room was packed! I remember being on the podium and looking out at a sea of faces, and I felt like I had come home. Honestly, I don't remember much about our meeting. I know we discussed monthly meetings and what we would offer at each meeting. We asked questions of all in attendance and handed out information about PPS. I do remember being on the podium with Webster to welcome everyone. And, I remember loving every minute of it. There were people I remembered as children who I met during my many surgeries at Warm Springs. One person I saw was an old boyfriend I had been hospitalized with during one of my last surgery and hospital stays at Warm Springs!

Most disability groups have contact with a core group that they relate to, have some contact with and have resources they can use. Folks who had polio including me were different. We survived the acute phase of polio with one goal in mind, to reenter society and blend in at all cost. We essentially ignored our disability and expected everyone else to ignore it as well. I don't know if this happened because there was a huge price to pay if you admitted you had a disability back then, or if it was because March of Dimes dropped us so cruelly and we had no choice. Whatever the reason, we had no disability group of our own.

I am and have been in a wheelchair all of these years, yet I did the exact same thing. I couldn't exactly hide my wheelchair but I could handle my chair better than anyone. I could jump curbs, tilt my chair back and go down steps and escalators. I could get in my car and pull my chair in behind me quicker than an able body person could get in their car. It was endless what I could and would do to prove to you that I did not need your help.

Back to the beginning of APPA, what we didn't know, when we were working so hard to build a network of polio survivors in the Atlanta area, this was happening all over the country. Small groups of people who had polio were coming together to create support groups all over the country and in fact around the world. One of the unique things about our APPA group was its location. We were blessed to be living in the crossroads of America.

The very first year of APPA's existence we found out that all of the top docs in the country who were interested in polio were scheduled to fly into Atlanta and travel to Warm Springs for a first polio conference. We contacted each of them and got them to agree to come in a day early and present all their information to us. They agreed and incredibly, they did it at their expense!

Our support group had so many talented and resourceful people in it that we had a mega conference including booths with

great displays about all sorts of rehabilitation equipment, resources, etc. The husband of one of our members did the set-up for big vendor shows and he donated all of his equipment and expertise. There were just so many people who made it a great event.

Once again, I was on the podium with Webster, looking out over a sea of faces and I was so grateful for all that was happening.

I was APPA's president the second year and I know you won't believe it, but within 18 months those same doctors were back to have a second conference in Warm Springs and once again we were able to create a truly professional conference. And once again they came a day early before the Warm Springs conference and did not charge APPA for their time. It was magical.

The work we did to promote APPA didn't seem like work. It was so good, so right, and so rewarding. We knew we were helping so many people, including ourselves.

APPA has a rich history of supporting people who are polio survivors. It has been my honor and privilege to serve and watch it grow into the great organization that it is today.

Linda Priest



Contributors to the “Getting to Know Us” series

We’re just getting started. If you don’t see your name below, please let us get your story into the next year’s issues of APPA News. It is astounding (but not surprising) to me that we have such talented, successful, smart, (even lazy) folks among our polio peers. Not only did we survive polio, but we had interesting lives, stories to tell.

Now, together, we are finding creative ways to accommodate post-polio and senior living. Big thanks to those who have contributed your stories & pictures and to those who are still trying to locate those old pictures and thinking about your story for a future APPA News.

Winter 2019-2020: Linda Priest, Alan Mitchell on history of APPA

Summer 2020: Belinda Whitaker on getting around in her powerchair

Fall 2020: Jean McQuain, Ray Fitzpatrick, Joan Adams, Beth Valentine, Ravi Patel

Spring 2021: Inge Thomas, Barbara Mayer

Summer 2021: Robert Abney, Jim Brownlee

Fall 2021: Patsy Emerson, David Jordan, Dick Weir, Marcus Gunter

Spring 2022: Wesley Moss, Paul Suwak

Summer 2022: Charlotte Terry, Bernetta Calhoun

Fall 2022: Alan M. Oberdeck, Lilly Guerry

Spring 2023: Shirley Green, Wayne Nichols

Fall 2023: Nancy Winter, Paul Blazeski

Winter 2023: Nancy Truyluck, Leo Roskowski

Spring 2024: Alan Oberdeck

Summer 2024: Tom Foss

Fall 2024: Margarita Rovira

A fellow polio with a great sense of humor sends these PUNS to keep us smiling — Excerpts, forwarded from Canada, though Florida — Enjoy.

A sign on a blinds and curtains truck: “Blind man driving.”

In a Podiatrist's office: “Time wounds all heels.”

On a Septic Tank Truck: Yesterday's Meals on Wheels

At an Optometrist's Office: “If you don't see what you're looking for, You've come to the right place.”

On a Plumber's truck: “We repair what your husband fixed.”

On another Plumber's truck: “Don't sleep with a drip. Call your plumber.”

At a Tire Shop in Milwaukee: “Invite us to your next blowout.”

On an Electrician's truck: “Let us remove your shorts.”

In a Non-smoking Area: “If we see smoke, we will assume you are on fire and will take appropriate action.”

On a Maternity Room door: Push. Push. Push.”

At a Car Dealership: “The best way to get back on your feet - miss a car payment.”

Outside a Muffler Shop: “No appointment necessary. We hear you coming.”

In a Veterinarian's waiting room: “Be back in 5 minutes. Sit! Stay!”

At the Electric Company: “We would be delighted if you send in your payment on time. However, if you don't, YOU will be de-lighted.”

In a Restaurant window: “Don't stand there and be hungry; come on in and get fed up.”

In the front yard of a Funeral Home: “Drive carefully. We'll wait.”

In a Chicago Radiator Shop: “Best place in town to take a leak.”