APPA NEWS

The Atlanta Post-Polio Association

Volume 32, Issue 3

Winter 2019-2020

I did not know why FDR's picture is on our dimes. Did you? See notes from events and discussions. Page 13

Dear Engineers & Techies. I would like a flying carpet so I can relax back muscles, adjust it to comfortable positions, and hover close to friends. In this age of flying out of the solar system, surely you all can come up with a flying carpet. "Other things to think about" Page 20

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atlanta post-polio association

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.

2020 APPA Board

Wayne Nichols	President Fund Raising Director
Rita Carlson	1st Vice President Programs and Public Relations Director
Billy Pond	2nd Vice President, Interim Treasurer
Barbara Mayer	Secretary
Belinda Whitaker	Member Services APPA News Committee
Pat Harris	Member Advocate
Leslie Schulgen	SNAF Director
Nancy Winter	APPA News Editor
Allie Belle Harrison	Member Services Registration Director

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Presidents Messages

Carol Crumby (Outgoing President)

The past year 2019 was an exciting year. Highlights are in the Annual Report which begins on Page 17. We appreciate your support and hope you have enjoyed the programs and services that were offered to you. Paying donations at the beginning of the year 2020 provides us with a better opportunity to manage delivery of services and expenses. Thanks to all who have thus far contributed their donations, as well as those who will soon do so.

As we continue in the spirit of Still Marching, having benefited from those who marched and volunteered to support us, let us continue marching to support ourselves and each other. It has been an honor to serve as APPA President.

Now, four important long-term members are coming off the Board. Shannon Morgan finished nine years of serving as Treasurer and Database Administrator. We are happy to report that she has just sold her house, bought an RV, and is taking to the road.

Alan Mitchell has served on the Board in many positions over the years. His article about his thoughts on APPA's history is on Page 11. David Jordan who served as 2nd VP is retiring from his position. The new Board Members are listed on the chart on the inside of the front cover of this newsletter. More achievements from the past year and looking to the future are in my Annual Report.

I have enjoyed being the APPA President these past two years. However, I was a caretaker for my mom and she recently passed. For the benefit of APPA, I felt I should leave the Board so I can tend to the settling of homes and my own health. Of course I plan to remain APPA-active and available to help the new Board. It is our hope that all APPA members can enjoy what this association can offer in learning from each other, making use of our skills, and building friendships.

Give the 2020 Board, newly elected Board Members and Wayne Nichols, new APPA President your support.

Still Marching,

Carol Crumby

Wayne Nichols, Incoming President

Dear Fellow Survivors,

My name is Wayne Nichols, one of four brothers and the only sibling that contracted polio in 1953 at the age of 3 while living in Chicago Heights, IL. Like each of you, our stories are unique; but in the same breath, we have so very much in common. I have been a proud member of APPA for the past 4 years and have enjoyed the support and fellowship of many of our APPA family.

This year 2020 gives me great pleasure to introduce myself to each of you as your new APPA President! Our objective has not changed since our conception over 35 years ago, to be support to all our members. Our Board of Directors all have one thing in common, a servant's heart.

Our goal is not only support, but public awareness of Polio and its after effects (PPS). Rita Carlson, our Vice President, has been working diligently to bring in guest speakers for our monthly meetings enlightening us on various issues that we all face.

Our February 1st Program at the Shepherd Center featured Dr. Mark Pollock, a pulmonary physician who spoke on sleep disorders.

Our next meeting will be held March 7th. I encourage all of you who are able to attend. Some of us meet in the Shepherd Center Cafeteria at 11:30 a.m. for lunch and fellowship. More events will be announced throughout the year. Announcements will be posted on the website and come to you by email. If you miss the events, you can view them online.

I look forward in meeting and getting to know each of you as we continue to walk though this journey together.

Marching On,
Wayne Nichols
Wayne Nichols
President

From the Editor

There are so many topics to choose from. Hopefully, we will touch on some in this issue and continue in the Summer and Fall. I would love for some experienced members to share their knowledge about getting assisted living or acquiring assisted devices. How about wisdom from those who have experienced PPS while caring for an aged loved-one? Or perhaps some personal experience in obtaining and getting around with a power chair. Maybe we can cover some PTSD research and remarkable resilience of polio victims. Military stories or stories about our support groups beyond APPA.

For this issue, and being somewhat an APPA newcomer, I wanted to learn more about when APPA got started and how its various programs were established. Linda Priest has written for us "The Genesis of APPA" starting Page 7. Alan Mitchell, who has served in many APPA positions, including President and APPANEWS Editor, dictated some of his thoughts about the history which are on Page 11. Alan directed me to The Memory Book, which you can read from the APPA website. I enjoyed every story and wrote some highlights starting on Page 6 This issue will also be about programs, members, SNAF, and more. So dig in and I'll leave you with this poem.

My day place and the
APPA News Office

I've been working at the APPANEWS since Fall
And decided to research some history for you all.
For this post-polio organization, you will see
Was well set on a course for longevity.
I'm a relative newcomer to this friendly group
We have all sought ways to stay in the loop.

Year after year as volunteer or just member
APPA has given us friends to remember.
I've recently met some who were there at the start
They worked for APPA with by-laws and heart.

I have learned to love you all, my polio peers
And hope that APPA might serve another 40 years
(And that this silly poem will not drive you to tears)

Nancy Winter

Letters to the Editor

Hmmmmm….. Silence …...

History of APPA circa 1980 to 2020

Reflections on The APPA Memory Book

Nancy Winter

I sought out Alan Mitchell about APPA history; he asked if I had read the **Memory** Book, which can be found on the APPA website. So I did. Alan collected this treasure of memories from APPA members and published it in 1997. A few highlights I'll share below and hope you find time to read it yourself.

APPA first began in about 1980 when Linda Priest met Betty Wright at Warm Springs and sparked the idea of a support group.

Thankfully the idea for an Atlanta-based support group grew. They used a Warm Springs alumni mailing list and held the first official meeting in around 1985. About 40 people attended.

In the 1997 Memory Book, Linda Priest recalled the reason polio victims tended to avoid support groups: "We had consciously separated ourselves from our peers because we did not consider ourselves as being disabled."

First Board included Linda Priest, Webster Cash, (co-chairs) Betty Wright, Neil Penn, Virginia Dunbar, and Nancy Van Dyck.

That same first year the organizers created the name Atlanta Post-Polio Association (APPA), established by-laws, set monthly meeting on first Saturdays, published a newsletter and, on top of it all, hosted a regional post-polio conference.

That is quite a foundation! No wonder this organization has lasted 35+ years.

Here our some thoughts after my reading of the Memory Book.

- APPA members are really good writers.
- Come from all around the USA.
- Our polio memories cover the spectrum of quarantine experience: some with families, others a long time in the hospital.
- A common thread in the hospital experiences was poor conditions but kind staff. There is a notable story about Grady Hospital.
- Some realized early the value of camaraderie with other polio victims while others (myself included) didn't learn this until we experienced post-polio symptoms and found APPA.
- All of us can claim remarkable resilience and have discovered clever ways to accommodate for our condition.
- Some recognized their post-polio symptoms way back in the 1980's.
- Some wondered if we had known about PPS would we have done less during our "good" years.

Continued on page 12

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. 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

Continued on next page

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 conserved 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.

Continued on next page

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.

Let's return to the beginning of APPA. What we didn't know when we were working so hard to build a network in the Atlanta area, is that small groups of polio survivors 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. 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.

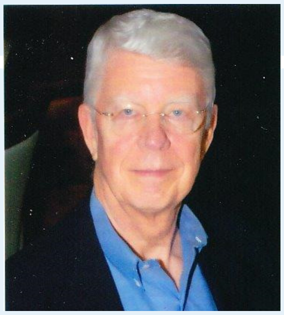
The work we did to promote APPA didn't seem like work. It was so good, so right, and so rewarding. We knew we were helping so many people, including ourselves.

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

My thoughts on the History of APPA

Alan Mitchell



I came to APPA in late 1980's. At the time we were meeting over at Emory at the Rehab Center. APPA held conferences with polio oriented physicians from Warm Springs. Dr. Dale Strasser, was the post-polio expert at Emory.

Linda Priest was APPA President. Problem with Emory was poor parking and not built for people with wheel chairs (which was strange for a physical rehab center). Emory parking was dark/dank parking; my memories there were of getting wet.

I remember Dr. Don Leslie coming out to Emory and giving a talk. Afterwards we spoke with him and he offered us meeting space at The Shepherd Center. That gained us plenty of parking space and access for handicapped. Our Saturday APPA meetings have been there since.

Probably less than 6 months into my joining APPA, the editor of the newsletter was battling cancer and they were looking for someone to take over. I had a bit of experience with newsletters so I volunteered. At that time we used the dot-matrix printer. Dot matrix is hard to read. I eventually found a printer. He printed it for us, I put on labels, and mailed them.

Some of the early newsletters were on the website. But logistics were difficult, moving from the old 5-1/4 floppy discs. Over the years we transitioned to Publisher and Word.

I also became database manager when we converted the files to Excel and Access. We already had a set of by-laws and published them in a newsletter.

We held a conference in Atlanta about 1995. It brought in a lot of money and we started the fund now called SNAF, to help post-polio survivors.

Dick Weir, who has since moved to North Carolina, was another early member and APPA President for awhile. Then we created the original APPA logo and the 2nd by-laws that we've been using since 1993.

Other things I recall: George & Bonnie Bonham were both in wheelchairs with 2 children all active in APPA. After 10 years as editor, Bonnie took over the newsletters even while she was President. After that Joe Drogan took on both jobs. And I remember when David Jordan ran in the Peachtree race.

This year (early 2020) I decided not to serve again on the APPA Board. Parkinson's has added new dimension and not a pleasant one.

Thoughts from the Memory Book, and APPA Archives and Photo Albums

Continued from Page 6

Two of the Memory Book writers included the perspective of their mothers during their polio hospital and recovery years.

Vicki Crowell joined APPA in 1988 and wrote in the memory book about the connection of the polio expert physicians in Warm Springs and the creation of the polio clinic at the Shepherd Center with Dr. Donald P. Leslie around 1990.

George Bonham described meeting Elizabeth Kenny. Before reading the Memory Book I had never heard of the Kenny method. You can watch very good dramatized polio history in the old movie on YouTube. Search "sisters of mercy Rosalind Russell"

Jim Doherty contracted polio at age 13 in Chicago's tough West Side wrote the following which I think resonates with most of us: "[polio] substantially altered the course of life.... In retrospect, I have long believed that the alteration was providentially for the better."

My search for history continued after Carol Crumby let me borrow the boxed archives of APPA photos, newspaper articles, and documents.

In an AJC article (4/29/2001) on Betty Wright, an APPA Charter Member, recalled her mother's advice, "never say you can't."

There is another article which mentioned that Linda Priest was the State Coordinator for the Americans with Disabilities Act under Governors Miller and Barnes.

In a Gwinnett Post article (6/20/2001) Margo Gathright-Dietrich was a professional dancer from her wheelchair in the "Full Radius Dance" company. (Curiously, on the flipside of this old newspaper clipping was an article about George Lucas deciding digital photography was better and he would use it in his next episodes of Star Wars.)

Alan Mitchell is in an AJC article (12/27/1995) about the benefits of the Internet, giving people with disabilities the opportunity to connect. It mentioned that the APPA newsletter at that time went out to 400 people.

APPA History quiz: identify the people in this picture. Answers on Page 16.

Notes from APPA 2019 Events and Discussions

Your editor enjoys most APPA Programs thanks to Allison Stockton who records and puts them in the "Media Room" on the APPA website. What follows are highlights from the many pages of notes I took from watching the meetings online. I trust our readers here will have some time to also watch and listen to these events & discussions.

August — The movie "Breathe" and discussion.

September — Medicare. Make sure your treating physicians accept your plan's prices.

October — Live Music by Patricia Emerson and the Four Season's Chamber Orchestra. Patricia's violin studies were interrupted by polio at age 15 in 1949. After many years of education and having a family, she managed to work her way back to playing the violin. Then until 2016, she played 15 years with the Atlanta Community Symphony Orchestra.

After the presentation, Lynn Frisco recommended a podcast called "Kill me with your best Shot" Episode 7 . This podcast has lots of polio trivia. i.e. FDR's face is on our DIMES because of his personal involvement with polio and the March of Dimes. At some point 207 million dimes were collected and mailed to the White House to fund polio research. In this podcast there was also discussion about the vaccine-derived vs wild polio virus. Which thankfully was explained even more in the November meeting by Dr. McKinlay.

November— Mark McKinlay, PhD, Director Center for Vaccine Equity and the Task Force for Global Health, located in Decatur, Georgia. This is the group which organizes the task of global disease eradication. Dr. McKinlay explained how the Task Force has organized the global polio eradication partnerships including CDC, Unicef, WHO, Rotary, drug companies, and the Gates Foundation. Together they have created the infrastructure to get whole populations vaccinated. The distribution of donated vaccines is being accomplished by local workers using sometimes primitive means of transport into remote villages. He explained the biology behind the oral vs injected vaccines and the different between the "wild" and the "vaccine derived" polio viruses. In 1988 there were 350,000 polio cases and 35,000 polio deaths in 123 countries. Since then they have had 99.9% reduction, but there are still the challenges: (1) large unvaccinated populations moving across borders. (2) the need for the safer oral vaccine, and (3) information to contest anti-vax rumors. The results of these efforts has saved an estimated 17 million people from polio paralysis.

APPA'S CHRISTMAS PARTY

Rita Carlson

MAGGIANO'S
LITTLE ITALY

APPA
December 7, 2019

Course One
Freshly Baked Bread
Stuffed Mushrooms
Bruschetta
Spinach Salad

Course Two
Rigatoni & Vegetables with Tomato Pesto
Grilled Chicken, Tomatoes & Basil
Tilapia, Lemon & Herbs

Course Three
Gigi's Butter Cake
Fresh Fruit Plate

Freshly Brewed Regular and Decaffeinated Coffee
Hot Tea Selection, Iced Tea & Assorted Sodas

Please ask for Replenishments

2019/12/07

The Atlanta Post Polio Association met Saturday, December 7, 2019, from 11 a.m. to 2 p.m. at Maggiano's Little Italy located at 4400 Ashford Dunwoody Road, Atlanta. There were 34 members and guests in attendance.

The food was served as a family style lunch.

After the dessert was served, Nannette Stariha played Christmas songs on her keyboard and led us through several Christmas songs such as "Jolly Old Saint Nicholas", "I wish you a Merry Christmas", and "Jingle Bells". Nanette is a retired music teacher and currently has 14 students in addition to sharing her musical talents with seniors at the senior center in Gwinnett.

More pictures on next page

2019/12/06

2019/12/08

2019/12/06

A quilted centerpiece of a Christmas tree with poinsettia leaves and a candle in a Kerr jar were given as gifts to two guests at each of the five tables. A poinsettia was given to members and guests in attendance.

Note from Editor: Rita made this quilt which was raffled off

Maggiano's service was outstanding and everything went as clockwork.

It was my pleasure to be responsible for such a wonderful occasion to start the Christmas holidays.

Thanks to Vicki Crowell and her team for the pictures.

Let's do it again next year.
Rita Carlson

Rita (2nd from left) made the quilted table toppers too.

Answers to quiz:

1985 APPA Board of Directors 1994.
(very back) Alan Mitchell, Newsletter Editor
(middle row, left to right) Dick Weir, President, Vicki Crowell, Historian; Dick Collins, Vice President/Programs.
(front row) Bob Urie, Newsletter Editorial Advisor/Parliamentarian; Bonnie Bonham, Secretary, Cathy Bruce, Past President; Margo Gathright-Dietrich, Treasurer.
(very front) Wallaby, Sergeant of Paws.

APPA 2019 Year-end Review

Carol Crumby

Thank you for your support of the 2019 APPA theme "*Still Marching*", in celebration of volunteers. A deep purple ribbon was branded for the *Polio Survivor's Conference* with Dr. Richard Bruno. This year was full of exciting presenters, and opportunities to learn from *each other as well..*

In 2019 APPA added former board member Alan Mitchell back, as well as Allie Harrison, spouse of a polio survivor, to the board. They brought tremendous experience and expertise to our board. Alan was a former APPA News editor and the publisher of *Memories: A Tribute to Polio Survivors* (ref: APPA website). Allie has raised our registration/attendance to a new level of efficiency for meetings and events. The major highlight of the year was sponsoring the Polio Survivors' Conference featuring Dr. Richard Bruno. Wayne Nichols directed the effort to a successful conclusion. Several neighboring post polio groups joined APPA to share in this awesome opportunity. Another major accomplishment was the purging and updating the database, a mammoth task handle with precision by Shannon Morgan and her dynamo team, Pat Harris and Alan Mitchell.

Special thanks to Rita Carlson and members who step up to the plate to bring high quality programing to APPA members and fellow survivors and their families. In addition to the Polio Survivors' Conference. We formed a partnership with FODAC. Leslie Schulgen worked with FODAC to create a special relationship that supports APPA members with their equipment needs through the Special Needs Assistance Fund (SNAF) to be implemented in 2020. Nancy Winter assumed the challenge of APPA NEWS editor and delivered two great issues with the assistance of Barbara Ruecksties, Alan served as parliamentarian helping to keep our Board on track. Pat Harris continues to stay connected to membership with an outstanding group of volunteers: Charlotte Terry and Billy Pond. Barbara Mayer continued as Secretary, helped with proofreading, and maintaining meeting records.

2019 APPA BOARD OF DIRECTORS

President & Fundraising, *Carol A. Crumby;* **1st Vice President Programs & Public Relations,** *Rita Carlson;* **2nd Vice President,** *David Jordan;* **Secretary**, *Barbara Mayer;* **Treasurer & Database**, *Shannon Morgan;* **Member Advocate,** *Pat Harris;;* **SNAF,** *Leslie Schulgen;* **Parliamentarian and Directory**, *Alan Mitchell; and* **Registration**, *Allie Harrison*

2019 Year End Review Continued

HERE ARE HIGHLIGHTS OF 2019!

APPA 2019 priorities for the Board of Directors were to

1. Update the database
2. Sponsor special events: Dr. Bruno and FODAC
3. Implement SNAF application process
4. Recruit newsletter editor
5. Continue quality programming

MEMBER SERVICES:

Newsletter – The new APPA NEWS editor and publisher Nancy Winter continued high standard performance producing two issues this year, and under budget. APPA volunteer Barbara Rueck-sties did the proofreading and the mailing. Other members contributed their perspectives and writing talents on the latest from the health/medical field on post-polio and related topics, as well as contemporary information.

Website – Enhanced website presentation**,** archived the meetings on the website, conduct surveys, update member information, continued tracking usage to effectively analyze benefits for members and users.

Facebook – Received and answered many questions and comments on Facebook

Regular Programs – ***Annual meeting*** February***; Arthritis:Learn More,*** April, ***Healthy Lifestyles,*** June***, "Breathe"the movie*** August; ***Medicare*** September; ***Update on Polio*** November

Special Programs ***FODAC Presentation and Tour*** March
Polio Survivors' Conference with Dr. Richard Bruno May
Chamber Orchestra Concert with Pat Emerson October

Social Activities
Continue Christmas Luncheon/meeting December

Directory – 95 active members. Annual distribution. Document with board pictures.

Outreach
Continued to *personally contact about 20 members per month* and check in on those who are sick and shut –in
Continued to *send Get Well, Sympathy cards*, *Birthdays and Anniversary* as well as some thank you note cards
Members expressed gratitude for the personal outreach and care expressed by this committee

Continued on next page

ADMINISTRATIVE FUNCTION

Legal responsibility – Assured APPA's compliance in 2019 with the State of Georgia and federal mandates

PHI Membership – Filed membership application with Polio Health International for current year

Database management – Preformed major update member files.

Financial management – Maintained financial records; and advised and kept the board and president abreast of APPA's financial status; assured compliance.

Board responsibility – Assured the satisfactory operations of APPA; provided guidance to the membership. In November elected 4 new board members: Wayne Nichols, Nancy Winter, Billy Pond and Belinda Whitaker to begin in January 2020.

OPERATIONS SUPPORT

Public Relations – Posted meetings in the AJC and other news media, as well as upcoming special activities.

Fundraising – Raised funds on behalf of APPA organization operations and member services including special projects. Funding came from membership donations, Facebook fundraising, Polio Survivors' Conference and special donations. GA Gives was postponed until 2020.

Art work – Provided artistic support of APPA Christmas activities.

Photography – Captured photos of APPA's programs and meetings for our history.

2020 PRIORITIES AND PLANS

The 2020 board will determine the direction. Below are several items discussed before the end of 2019.

MEMBER SERVICES

Program: In 2020, we are responding for the request to invite a doctor who specializes in sleep and breathing disorders, learning more about service at Shepherd Center, and more opportunities to learn from members about their hobbies and activities. We will continue to listen to members' voices. Thanks for your ideas. We are open to new ideas for special activities.

Newsletter: Continue work. Reach out to new writers for their contributions.

Website: Provide analytics on use. Update the Board quarterly. Reach out to new writers for their contributions.

Facebook: Continue connection with Facebook.

Outreach: Connect members in a variety of ways: phone calls, emails and cards.

Administrative: All membership funding will go to operations and APPA member services. The donations will go SNAF. PHI newsletters will be forwarded to APPA members.

Operation Support: Public relations, fundraising, art work and photography will continue to support the member services and administrative work in APPA.

SNAF: Implement a 6-month trial run of SNAF.

Warm regards,

Carol A. Crumby
Outgoing APPA President

atlanta post-polio
association

Other things to think about

The Editor, again

The fun of being a part of APPA is that, even if we don't attend the events, we get to call each other from time to time.

Between books, APPA events and APPA phone discussions, lots of thoughts are swirling around in my brain. So I will unload a few ideas to you, so I can rest.

As you know we are part of a global support group. Useful links like PHI are on the website. A new group Polio Warriors is collecting a list of polio survivors and support groups. This global map sprang from one of the Facebook discussion groups.

The global connections, we now have, reminds me of an old book I read about Spinal Cord regeneration. There was a time when "notable experts" on the subject decided it was a lost cause. Then came the technology to actually look at nerves. Now the studies of neurons and synapses are flourishing.

As polio survivors we've seen how theories about polio and PPS over the causes, treatments, prevention etc. have been fluid. We did not all have the same experience when we had polio and we are not all experiencing PPS in the same way. Lots of us didn't seek out post-polio related support while we kept busy with our lives. Now, having this opportunity for communication with our polio peers has become fun? Who better to converse with to laugh about wobbly joints, that comfortable-looking floor when we suddenly hit that wall of fatigue, facing stairways or tripping over floppy feet. That laughter is good for us and, thanks again to those (you know who you are) who have laughed with me.

So back to the flying carpet idea. There is no reason why, with our global connections, vast wisdom, incredible ingenuity, that we cannot come up with a flying carpet. Newton developed the concept of gravity and came up with calculus. But do we have to stay on the ground just because of him? I want a flying carpet. I want to be able to shift to comfortable positions as I get around. Steps and narrow doorways would no longer be a problem. The carpet should be lightweight, easy to roll up and put in the car. Scientific/technical wonders start with our minds just being put to the task. The imagination is unbound. Let us continue to learn together and laugh together and maybe, just maybe come up with a flying carpet. Wouldn't it be something if the next great technological advance came out of our PPS network?

Announcements

The usual "new member welcome and thanks to donors" pages will be included in the Summer 2020 issue. Make sure to send in your 2020 membership dues soon, so we can better plan the 2020 budget and you can see **your name in big bold print** in the APPA News. Also your name will get into the APPA Directory

Please don't forget to make your annual
donation to **APPA**.
Thanks for your
continued
support.

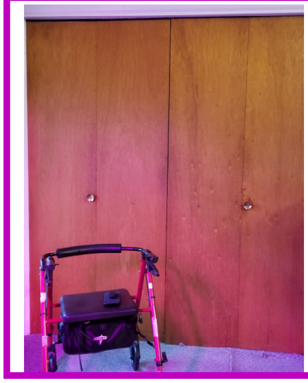
APPA is a member of Polio Health International. PHI publishes the quarterly newsletter: Post-Polio Health, which we might begin distributing to the APPA Members. Their website and searchable archives offer much information on polio, independent living and other neuromuscular phenomena.

www.post-polio.org

This organization started in 1960 under various names including GINI. Check out the Wikipedia article about the history of this network.

APPA has been approved to receive contributions of one-half percent (.5%) on every sale that is made on the APPA SMILE ACCOUNT! That's right, we can designate our purchases on Amazon to help support APPA!

PLEASE follow these simple instructions when logging into Amazon:
Copy and paste this address; https://smile.amazon.com
When in Amazon Smile click supporting"
Change to read: Atlanta Post Polio Association
Then begin searching for your items to purchase
Purchase your items .



History Mystery: What is in the closet? Are there APPA archives still lurking somewhere in the Shepherd Center? I am seeking information from anyone with clues. The awesome prize of getting your name listed in the next APPA News goes to the person or persons who can lead us to the whole story.

Upcoming 2020 APPA Meetings (some still in planning stages)
Usually the First Saturday of each month—check for updates online

February – Dr. Mark Pollock, specializes in pulmonary medicine, sleep medicine and critical care. Topic: sleep disorders.
March – Bingo and Discussions
April – Cathy McIntire, APPA member, will discuss artwork.
May – Possible program on braces
June – Possible program on writing our memoirs
July – No Meeting
August – TBA
September— Possibly to meet at FODAC
October — Medicare updates
November— TBA
December – Christmas Party

Thank you Pat and the APPA Membership Committee for the cards you send us on our special days. I treasure them and appreciate your kindness.

Letter to APPA November 2019

Dear APPA, I am grateful for everyones' contributions to APPA.

Dr. Bruno's presentation was very interesting. I enjoyed watching it on my I-Pad.

The newsletter is a great compilation of news and informative articles, always enjoyable reading.

Happy Thanksgiving to all.

Lauri Hunter

Remembering Members and Their Families

Carol Vish lost her husband earlier this year and has moved to Kentucky. She wants to continue participating in APPA.

Former member, **Dewey Moody,** passed away recently. According to his niece he had suffered from cancer.

Carol Crumby's mother, **Lucille H. Crumby** who sometimes attended APPA meetings with Carol, passed away in November.

SPECIAL NEEDS ASSISTANCE FUND (SNAF)

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

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

GUIDELINES for using FODAC:

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

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

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

FODAC SERVICE CHARGES

(Effective 8/22/2019)

New Client Registration Fee (one-time)	$25 fee
REPAIR & PARTS	
Individual Repair Fee	$25 each
Charger for Power Chairs	$25 each
Joystick for Power Chairs	$30 each
Armrests for Power & Manual	$5 each
Tire Drive wheels	$10 each
Footrests for Manual Chairs	$15 pair
Upholstery/Seating	$20 each
Casters	$5 each
Other Electric Parts	$30 each
Cleaning Fee	$15 each
Other manual equipment parts	$10
BATTERIES	
ES2.9-12	$50 each
ES12-20	$70 each
ES12-50	$150 each
ES12-12	$70 each
ES17-12	$60 each
M34SLDG	$195 each
22NF	$155 each
24NF	$195 each
PS12260	$100 each
PS12180	$70 each
U1SDLA	$105 each

FODAC SERVICE CHARGES , Continued

(Effective 8/22/2019)

VEHICLE ADAPTATIONS	
Boom Lift	$350
Hitch Lift	$350
Tie Downs	$350
Platform Lift	$750
Repairs per hour, after first hour	$75
NEW PORTABLE RAMPS (DONATED ARE NO COST)	
2’ Single Fold	$85
3’ Single Fold	$150
4’ Single Fold	$200
4’ Platform	$200
6’ Single Fold	$250
HOSPITAL BED & WHEELCHAIR DELIVERIES	
Bed	$100
Wheelchair	$50
Within 25 mile radius	$0
Out of radius	$50
> Exterior steps	$50
2nd level or basement	$50
If >6 ex steps and 2nd level (max)	$75

SNAF APPLICATION for CUSTOM Medical Devices (Devices to be purchased from Vendors other than FODAC)

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

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

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

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

Mail application with attachments to: PO BOX 245, Cumming, GA 30028

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

JOIN APPA

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

Additional Contribution $_________

APPA, P. O. Box 245
Cumming, GA 30028
Make checks payable to: **APPA**

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

Please **CHECK** all that apply.

◊ I am a new member.
◊ I am renewing my membership.
◊ Please update my contact information as shown below.
◊ I am unable to contribute at this time but would like to receive the APPA NEWS.
◊ 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?

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

Name(s) ______________________________________ DATE _________
Address ____
City State Zip ____
Telephone ____________________
Email Address ____

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

atlanta post-polio association

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FREE MATTER FOR THE BLIND OR HANDICAPPED

Look for us…..we're on the web.
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Nancy Winter - Editor

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