



## First Coast Post Polio Support Group

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### Our Staff of Directors:

President/Editor	Bill Hamilton
Vice President	Janice Askwith
Treasurer	Eulie Nahm
Secretary/Editor	Sheila Kilgore
Sunshine committee	Sue Massey
Board of Directors	David Brynildson
Board of Directors	Dr. Stuart Caplin
Board of Directors	Joe Raker
Founder 1990	Sue Bridges

### In this issue:

- Minutes of February meeting
- Nominees for President and Vice President
- Dues form
- Information of Warm Springs conference
- Conference Registration form
- Guest speaker-Dr. Alan Berger
- New president's featured story

### New Luncheon Time and Place:

First Coast Post Polio Support Group Meeting  
Golden Corral—4250 Southside Blvd, Jacksonville, FL 32216  
April 4, 2009  
10:00 am—12:00 pm  
Everyone must buy something in order to enter the meeting place.  
Per Golden Corral. Thank you!

DISCLAIMER: The articles, opinions, ideas and suggestions presented in this news letter and from our meetings is not to be taken as an endorsement or approval of any medication, product or individual. Always check with your Doctor first about your condition. First Coast Post Polio Support Group of Jacksonville, Florida does not assume any responsibility for individual reader's action. Information in this newsletter was obtained from various national and local sources which are considered reliable and/or reflect the opinion of the authors. Medical advice must be sought from competent licensed physicians.



## *Spring is just around the corner.*

With it comes lots of changes.

- We have a new President for First Coast Post Polio Support Group, BILL HAMILTON was voted in as President at our February meeting. I admire Bill and I have every confidence that he will do a great job for our group. Read his story on page 2 of our news letter. Bill will be preparing our news letters in the future.
- I have stayed on as interim Vice President until someone shows interest in the position. We are hoping to fill the position soon. I will stay in touch with you and maintain our web site.
- My body has experienced new pains with the cold that I do not recall in previous years. I have also experienced more fatigue this last winter. I know that most of you are going through these changes in your bodies also. Remember to rest. It is so important to take that afternoon nap.
- We had Dr Alan Berger as our speaker in February. I want to thank all of you who came to support our group at that time. What a wonderful crowd we had. Twenty-four of us in all. I applaud you!!!
- We have six people who are going to Warm Springs, Georgia on April 23-25, 2009. There is still time if anyone else wants to go. We would love to have you join us. More info inside news letter.
- I will miss leading you as President however I felt in need of a rest. Please show Bill the great support you have always shown me.  
I will still remember each and everyone of you in my prayers.

*God Bless Always,*

*Vice President, Janice Askwith*

### **Visit our website:**

**Our new website "[FirstCoastPostPolio.com](http://FirstCoastPostPolio.com)" will now post our news letter.**

**We are getting more and more feedback from the website and adding new members who have found us through the web.**

**We have links on there to other websites in Florida and around the world which have lots of info on Post Polio Syndrome.**

**Please make use of the internet.**

**If you personally need to get in touch with us our e-mail is**

**[<firstcoastpostpolio@yahoo.com>](mailto:firstcoastpostpolio@yahoo.com).**

**As the world changes and the internet helps us to grow we need to grow with it.**

**Thank you for all the years of support for our news letter.**

**We how ever still need your help in supporting our website.**

**So we ask that you pay dues in November. We will welcome all donations of any amount.**

**I will notify you through the website of any new developments with PPS.**

**We have added new members stories and hobbies.**

**You will be notified of our meetings and where they will be on the web.**

**Janice Askwith, Vice President**



## Bringing Up the Rear



I had Infantile Paralytic Polio when I was two years old. My left arm was paralyzed and my central nervous system was attacked and compromised by the polio virus. Born in 1955, I did not receive the vaccination which was developed, that year because the wide distribution of it began in 1957.

The very year I got polio!

The polio epidemics in this country peaked in the mid 1950's which means my class very likely could have been the last one that was threatened by the polio virus because the Salk vaccine, and later the Arthur Sabin vaccine, effectively eradicated its threat in this country.

I was treated at the Fort Polk Military Hospital in Louisiana. In those early days while I was there, my parents thought they were about to lose me to the virus. But with the good treatment I received, I survived and recovered.

I now have Post-Polio Sequelae (PPS) which laymen refer to as Post-Polio Syndrome. And now, my class may be the last one to be diagnosed with PPS. So, in a way, we may be bringing up the rear for all of you who have been leading the way for us. I hope I can do my part and represent you well.

I have come to call PPS "My Companion" because it is always with me and communicates to me, in one way or another, from hour to hour and from day to day. I am still learning how to live with this "little trinity" of weakness, pain, and fatigue.

My Companion reminds me it is with me when I hurt, when I run out of juice, when the temperature is cold, when I am having trouble sleeping, and when I choke on food. It clamps down on my legs and won't let go. It taps on my arms with ticks and tremors. It grabs hold of my body in its heavy grip and lays me down with a force more powerful than gravity. When I am rested it may retreat to whisper from a distance. But it always returns with a rush to voice its loudest cry.

While my paralyzed arm was the most visible result of polio, and my arms are my major concern with PPS today, I am also having PPS symptoms in my legs.

When my neurologist told me I have PPS he explained that there is nothing we can do to stop it, that we can treat the symptoms with medication, but we can try to slow down the progressive nature of PPS. Which brings me to this lesson: If you have PPS, get to the acceptance stage of receiving the diagnosis as soon as possible and get busy learning how to manage it right away!

PPS progresses in my body gradually but the progression is often manifested suddenly and without warning, or with little warning, in subtle and sometimes startling ways. It is a maddening experience. Just when I think I have slowed the progression of PPS down, or maybe even found an early plateau, something else becomes a physical, and mental, challenge for me.

Through First Coast Post-Polio and books they recommended, I learned about lifestyle changes I should make in these books and PPS has forced me to make such changes because seemingly simple activities can cause fatigue and pain through overuse of my body. The good news is that little changes can make a difference.

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*Bringing Up The Rear*

I learned a few things about mobility and have learned to accept my cane, crutches, and scooter because they help me to comply with the PPS mantra: "Conserve to Preserve". These "assistants" keep me more active and engaged. Unfortunately, many of you with PPS had to stop working while you were at the pinnacle of your careers. I am one of the fortunate ones with PPS because my employer, Chrysler Financial, has made it possible for me to continue working under a work from home accommodation with a flexible schedule making it possible to enjoy an extended work life!

I first began showing signs of PPS with weakness and pain in my left arm, between the shoulder and the elbow, when it was overworked. But it was the pain in my legs that motivated me to go to my doctor for help. The pain set in and did not release for days. I was experiencing this kind of pain along with cramping in my legs with increased frequency between episodes. But this bout of it motivated me to get help.

With me, the pain (and muscle spasms) resultant to overuse of my body is most severe at night. Often, it prevents my ability to sleep. If I start the morning with pain, I know that I am about to face an intense day and night. This sets up a tight cycle of pain, fatigue, weakness, pain, fatigue and so on. More pain and fatigue means more reliance on medications. So, I am learning to pace myself so that I can prevent the triggers, become less reliant on medications, and suffer fewer adverse side effects from them.

Like I said earlier, I recovered from polio. And I lived a normal active childhood. In fact, I was an athlete in high school and lettered in track, cross-country, and wrestling.

Polio survivors are often driven and commonly have "Type A" personalities; traits that are attributed to the therapies we received in our formative polio years. I believe any success I have achieved in my thirty two year marriage and home life, my thirty year career in finance and in my service to my church and community came as much by God's grace and determination and enthusiasm as by intelligence or education.

My wife and I have enjoyed a fitness lifestyle but with the onset of PPS In late 2006 and early 2007 I was forced to stop my exercise routines because they became increasingly more difficult and I started to become weaker and required longer recovery periods between workouts.

I am learning to stop over using and abusing my body to slow down the progression of PPS. Rather than ignoring the signals my body was sending me, toughing it out, and pushing on despite of them I have had to learn a new kind of self discipline – holding back! It is ironic that a slower and paced lifestyle is our prescription for better health. I still grapple with that! It goes against everything I have learned about health and fitness.

I have since learned some of the simple fluid movements within Tai Chi Qigong and to adopted aqua therapy as my forms of physical therapy.

All said; I had a great go of it during the span of years between recovering from polio and the onset of PPS. With the adjustments I am making and with the love and support of my wife and family, my friends and church, an accommodating employer, the care of my doctors, and locking arms with my peers at the First Coast Post-Polio Support Group I have much to be thankful for and much to look forward to!

Most of my PPS peers are well down the PPS trail. If you are one of them, thank you for leading the way and press on as my class joins you and begin doing our job of bringing up the rear!

**Happy St. Patrick's Day!**

St. Patrick's Day is here, you see.  
We'll pick some shamrocks, one, two, three.  
We'll count the leaves and look them over,  
And maybe find a four-leafed clover.  
I'll sew green buttons on my vest,  
Green for St. Patrick is the best.  
I'll wear a green hat  
, very high,  
And dance a jig--at least I'll try!



**Bill and Janice look forward to seeing you at the next meeting. When: April 4, 2009; Time: 10-12:00 Golden Corral at 4205 Southside Blvd. SEE YOU ALL THERE. COME MEET THE NEW**

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## Living with Polio in the 21st Century

April 23, 24, 25th at Warm Springs, GA.

March 21st is the last day to register.

Call: Post-Polio Health International at: 314-534-0475

For help is you are still planning on going.

We have 6 members from Northeast Fl who will be there.

If you would like to go please make arrangements now. For your convenience, you will find a registration form enclosed in this newsletter.

### Wellness Retreat for Polio Survivors

Baycliff.org

I was looking at retreats in Michigan because that is where I was born and caught Polio. They have a video on their website that is very informative about the retreat and what is offered. If you have internet access go to baycliff.org. Check it out...



**FDOA** \* Florida Disabled Outdoors Association in Tallahassee, Fl

“Active Leisure for Life”

Thursday, April 16-6:30pm—9:30pm, SportsAbility Banquet @  
Ramada Inn on North Monroe,

Banquet tickets at [www.fdoa.org](http://www.fdoa.org) or 850-201-2944

Friday April 17—10 am-3pm, Tallahassee Community College Life-time Sports Complex

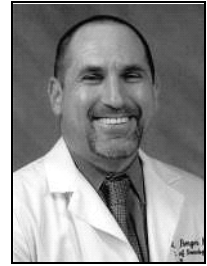
Saturday, April 18—10am –3pm, Ochlockonee River State Park

Sunday, April 19 –11am-2pm, Power Soccer Clinic/Baseball game-  
Miracle League Field at Messer Park

## Dr. Alan Berger was our guest speaker in February.

He is:

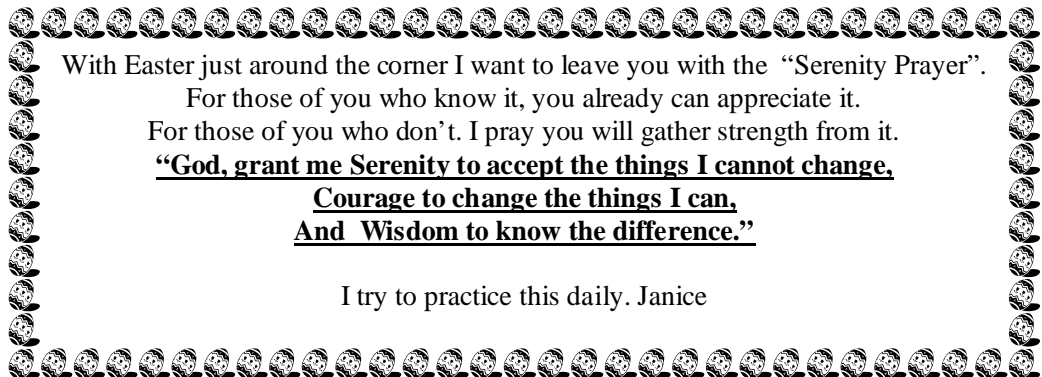
- A professor of Department of Neurology at the University of Florida College of Medicine
- Assistant Dean of Research Affairs
- Chairman Department of Neurology
- Interim Director of Brooks Center for Rehabilitation Studies
- He has three offices where he practices, one in St. Mary's and two in Jacksonville.
- He attended Bowman Gray School of Medicine in Winston-Salem, NC
- He did his residency in New York
- His specialty is Neurology with a subspecialty in Neuromuscular Disease
- He is board certified in Neurology, EMG and Neuromuscular disease
- He has written several published books and many published articles.
- He has been studying Post Polio Syndrome



Dr. Berger spoke to us on Post Polio Syndrome. For the new members it helped them understand what the older members were already aware of; pain, fatigue, and weakness in limbs. He mentioned the depression and anger we also deal with because of the continuous deterioration of our already weakened bodies. The information he shared was not only beneficial to our new members, it was also beneficial to those of us who have been dealing with PPS for years. We were so appreciative of the time he took away from his busy schedule to come and speak to us. His answer and question time was very informative as well.

Thank you for the great turn out. We had 26 present. When you support the new members it is so helpful. Please continue to come to the meetings and support your new President, Bill Hamilton as you have always supported me.

Janice Askwith, Vice President.



With Easter just around the corner I want to leave you with the "Serenity Prayer".

For those of you who know it, you already can appreciate it.

For those of you who don't. I pray you will gather strength from it.

**"God, grant me Serenity to accept the things I cannot change,**

**Courage to change the things I can,**

**And Wisdom to know the difference."**

I try to practice this daily. Janice

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From the Desk of Sheila Kilgore, Secretary

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2008 saw a strong beginning of attendance to the support meetings with a very weak finish at the end of the year.

**January**

4 members and 4 guests met to discuss possible changes for the year to increase interest for current members and ways to entice new members. It was decided to try meetings on Saturdays since there were some members who still worked and to meet every other month instead of monthly.

**March**

12 members and 6 guests came to this meeting to hear from Dr. Jonathan Walker. He spoke on nutrition and how we can benefit from changing our diets to help ease pain and increase our energy levels. It was very informative and very well received.

**May**

The May meeting also saw a great crowd. 10 members and 7 guests came to hear from our guest speaker Natalie Blanton, a physical therapist from Heartland Rehabilitation who has been studying Post Polio Syndrome. She had very good information to share with us and was very well received.

**August**

6 members and 5 guests gathered to have a nice breakfast and discuss their experiences with polio and post polio syndrome. There were two new members who were very eager to share and also to learn what the current members had to say about their experiences. It was a shame that there were not more current members attending that could have shared their experiences with our new members.

**October**

October's meeting was way off in attendance. With only 4 members present and 1 guest, conversation was very informal. It centered mostly on ways to encourage current members to return and new members not to get discouraged. Janice also requested at the meeting as well as in the newsletter that if any one was interested in becoming the president to please let her know as she felt someone new might have some new and different ideas for the support group.

**December**

The attendance was very low for our last meeting of the year. There were only four members present and one guest. One of the members was a returning new member with many questions and concerns. The few who were there tried to answer his questions and share stories but it would have been so much better for him if there had been more members there, especially men who are dealing with PPS. Janice shared that there was still no interest expressed from anyone concerning the presidency of the group.

### Saying Goodbye!

2008 was a sad year for several of our members and their families.

- Mary Rohr passed away in Feb of 2006
- Larry Dean passed away in July of 2008
- Betty Lloyd ( a member) lost her husband during the summer of 2008

Sara Olson passed away in April of 2008

### Good News for our members!

\* Bob and Phillipa Eckert celebrated their 50<sup>th</sup> wedding anniversary in 2008

\* Ann McClellan became engaged in July of 2008



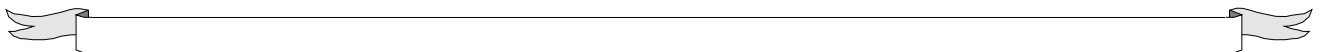
\*Janice Askwith received her book in July: "Great women of the 21<sup>st</sup> Century"- an outstanding contribution to enhance the lives of PPS survivors, in which her name appears.

### Welcome to our New Members!

**Charles (Bill) Hamilton**  
**Carolyn Jones**  
**Brenda Dicks**  
**James Hickox**  
**Cathy Smith**

**William Colmery**  
**Jame Crowe**  
**Karl Fricks**  
**Deanna Johns**

**Kim Graham**  
**Sonia Klemens**  
**Lynda Culler**  
**Charlotte Richter**



## Now a look ahead to 2009

2009 appears to be a year with some very exciting possibilities. The February meeting will have a guest speaker: Dr. Alan R. Berger.

In April, there will be an International Convention for PPS patients at Warm Springs, Georgia. The theme is; "Living with Polio in the 21<sup>st</sup> Century." The dates are April 23-25. If you are interested, please contact Janice Askwith for more information. Reservations will need to be made soon as spaces will fill quickly. Several of the members have already expressed a great interest in attending.

The vice-presidency position was vacant for most of 2008 and is in great need of someone who would like to fill it. If you are interested please contact Janice and she can let you know what this positions entails. We need more of our members to step up to the plate this year to help make 2009 a bigger and better year for our support group. Also Janice is still looking for someone who might like to try their hand at the presidency.

Our goal this year is to enlist our current members to take a more active part in this years' meetings, to encourage our new members to return, and to entice new members to come and join us. The definition of support is just what it implies, that we meet and support each other with a new and unknown problem that has arisen through no fault of our own. Last years we met several new people who were beginning to face the symptoms of Post Polio Syndrome and aren't sure where to start looking for information about PPS. There are still new prospects this year who are looking for support and we need to be there to extend an informative voice and a listening ear.

Another goal this year is to find ways to get information about Post Polio Syndrome and our support group to the public. If you know of any ways to get this in the media, please let us hear from you.

Perhaps you have new ideas on meeting times, locations or guests that might benefit us all. Come and share these with us at the meetings. Maybe you know of an organization that might be willing to extend financial help to our support group. Please let us know.

2009's success depends on each and every one of us contributing to our support group, whether it is in attendance, information, or ideas. Many support groups have been disbanded due to lack of interest. Please let us not let this happen to our group. Let us make 2009 a bigger and better year than every before. Our success depends on you!

Respectfully submitted,  
Sheila Kilgore

### Minutes for February's Meeting

The chapter held its February meeting at the Jacksonville Golf and Country Club on Wednesday the 4<sup>th</sup> from 11-1P.M. There were 15 members and 11 guests present. It was so good to see some of our returning members as well as several new ones. Before our lunch was served, several items of business were presented by our president Janice Askwith. She began with acknowledgement to the Jacksonville Golf and Country Club for allowing us to use their facilities as well as provide a lunch at a very reasonable rate. The second item was the election of a new president. After four years, Janice stepped down and it was voted unanimously to elect Bill Hamilton as our new president. He took office at the end of the meeting today. Janice also mentioned that the return of dues was way down and requested that anyone not having sent in their dues please pay them as soon as possible. Janice then announced that the PPS conference would be held this year at Warm Springs in Georgia. The dates are April 23<sup>rd</sup> thru the 25<sup>th</sup>. If you are interested you can go to the website for complete information. Janice handed out sheets of paper about this years Polio Survivors Association slogan "We're Still Here" and an encouragement to order the pins and wear them. Eulie gave a financial report for 2008. Lunch was then served. After lunch Sheila announced the guest speaker, Dr. Alan R. Berger, M.D. He spoke for about 30 minutes and then had a question and answer time. If you are interested in the subject of his talk, go to the website and find a link to see his notes. It was very informative and the group gained some new knowledge and insight into PPS. Please plan to come to the next meeting and see what our new president has in mind as a direction for our chapter. As a note: We wish to thank Janice for all of her time and dedication to the group as president. God Bless you for your faithfulness to us.

Respectfully submitted,  
Sheila Kilgore

