



First Coast Post Polio Support Group
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<u><i>Our Staff of Directors:</i></u>	
President	Bill Hamilton 904-505-4021
Vice President	Janice Askwith 904-333-3457
Treasurer	Eulie Nahm
Secretary/Editor	Sheila Kilgore 904-673-6316
Sunshine committee	Sue Massey
Board of Directors	David Brynildson
Board of Directors	Dr. Stuart Caplin
Founder 1990	Sue Bridges

The Salk Institute recently created a web site www.poliotoday.org to provide a forum for

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Next Meeting
October 31, 2009
Time: 12:00 till 2:00 pm.
Place: Ramada Inn



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.



DR. GUDNI THORSTEINSSON
WILL BE OUR GUEST SPEAKER AT THE
RAMADA INN CONFERENCE CENTER.

October 31, 2009

Time: 12:00-2:00

For those of you who are new to our group this is a great opportunity to hear from a doctor who knows Post Polio Syndrome first hand. The Doctor is now retired but is willing to come and answer your questions on PPS.

**Place: Ramada Inn, 3130 Hartley Road
off 295 from Orange Park take exit 5, go left on
San Jose under 295 to right on Hartley road.
From 9A take exit 5A to San Jose, Right to Hartley Road.
Ramada Inn on the Right. 904-268-8080**

RSVP lunch
The cost is
\$10.00
You will have to
call me at
904-333-3457
to
confirm by
October 19,
2009

Makes Checks
payable to:
First Coast
PPSG

Words from our President, Bill Hamilton

September 2009

To My Peers and Friends of the First Coast Post-Polio Support Group.

Hello Everyone, I hope you have all had a good summer, enjoyed the warm evening breezes and the rain, rain, rain and more rain.

My backyard sanctuary garden sure has!

And that is where I am writing this from; I am sitting in the courtyard of our garden with my computer on my lap, my Golden Retriever (Tank) and my wife (Debbie) nearby.

We closed our traditional summer break with our first meeting since the spring on September 12th. We even had a new member join us. Her name is Carol and she didn't meet a stranger at our meeting. She jumped right in, shared her story and even shared her contagious laugh with us! What a delight.

We had a good group attend the meeting and we even had three past presidents there to join me in a group photograph which we will post on our web-site soon. I was inspired, again, by how positive, friendly and bright eyed our members are. And, I was inspired by the smiles on your faces ...

This brings me to this, in April your officers (that would be Janice, Sheila, Eulie and me) attended the 10th Annual Post-polio Health International Conference at Roosevelt Institute for Rehabilitation (RWSIR) in Warm Springs, Georgia. RWSIR was everything and more than we expected.

Not only did we get to know each other even better we also got to meet our peers from around the country and from around the world. "The Spirit of Warm Springs" was evident as the staff at RWSIR welcomed 436 registrants. In attendance were survivors, family members and health professionals from 11 countries (46 individuals) and 39 US states and the District of Columbia.



In attendance was a full range of our peers from those with an early onset of PPS to those with a severe set of the progressive symptoms. And, the old and the very young, yes the young. There are some countries that do not dispense the vaccine and there was a young lady from Michigan in her early twenties who contracted the virus from the vaccine.

RWSIR is set in the beautiful country setting and the rolling hills of western Georgia. And, the campus is very inviting and user friendly. With 300 scooters, of all types, rolling through the halls you would have thought we would need traffic cops at every turn! But, the wide hallways and the wide sidewalks that lead from building to building made for good scooter. And cane, and a forearm crutch or two!

Sheila shared with us recently that one of the things that has stuck with her most is the variety of paths that led us to the conference and how the polio virus did its work, damage really, in our bodies in such a wide variety of ways.

And Janice remarked that while some of us may have had total paralysis, paralysis in the arms or legs, whether we had a full recovery, partial recovery or permanent damage the virus infected our entire central nervous system and now, in the evening of our lives we are experiencing the late of effects of having polio throughout our body.

The speakers at the conference shared how we can live with our PPS condition.

Eulie shared “the Post Polio International Health Conference speakers were amazing. They were an inspiration. I felt goose bumps listening to them. They shared their exceptional stories about how they were able to overcome their physical handicaps and be what they are now. And to think that their physical disabilities were more serious than mine. I guess, if you have confidence in yourself, you can rise above whatever challenges that comes your way. The bottom line is, if they can do it, there is absolutely no reason why I can't.

For me, the conference was an eye opener and very up lifting; it has helped me improve my attitude towards dealing with the health issues I am experiencing right now. Yes, we are still here and we are not alone!” This takes me back the halls of RWSIR; and all those smiles and the friends we made. Now, we know what the little trinity of “fatigue, muscle pain and weakness” is with us at all times in one way or another; but those smiles and friendly faces still fill my memory. It seems the lessons we learned during our formative years while recovering from polio has carried us through to even managing our PPS, “put a smile on your pain, don't complain, be a good sport, tough it out” has become a genuine part of our adult personalities. And that is where I get my inspiration; from those of you who have led the way for us youngsters (I am 54 and I am not telling you Eulie's age; but she is young!) with PPS. Thank you for sharing your stories, what works for you and for leading the way, even by the lessons you learned from physical therapies that made your PPS even worse.

I suppose what I am saying is I am inspired by the inspired!

And that acronym, RWSIR, has nothing on the First Coast Post-Polio Support Group. FCPPSG, now how's that for inspiration!

Bill Hamilton, President

Extraordinary people... Extraordinary people survive under the most terrible circumstances and they become more extraordinary because of it.—Robertson Davies.

Donations:

Thanks again to *Winn Dixie* for their generous donation to our not-for profit origination in 2009.

What it was like on the other side of Polio

An interview with my mother Bernetta Cole— by Janice Cole Askwith

- *What was your thoughts when I first became ill with polio?*

Mother: With 5 children all under 6 years of age and one on the way, I thought it was a normal childhood sickness at first. I was use to someone crying from teething or needing an aspirin for something.

- *What did you feel and do when I got up one morning and couldn't stand up and walk?*

Mother: We lived behind my sister at Jones Lake in Lansing, Michigan at the time and I went up to her house to call the doctor. We couldn't

afford a phone. Doctor Harris was the doctor at the hospital who was treating people who came to the Sparrow Hospital with polio. He came to the home and checked you and your older sister because she now to was running a fever. The doctor said he felt you had polio and to take you to the hospital. He treated Patty, your older sister at home and she recovered with no lasting effects of polio. Polio was everywhere in the city. Its all you ever heard about on the news from our radio. We had no television.

We heard of people dying and being paralyzed. Not being able to move arms or legs. I was scared to death that if I got polio who would take care of the other children and I was pregnant? How could I cope? Where would they take the babies off to? What was going to happen to my family?

- *What happened next after I was in the hospital?*

Mother: They took you from me and you were examined and after what seemed like hours but only minutes they confirmed you as having *acute flaccid paralysis* (AFP) polio. You were put in a room with three other girls all with polio; two of which were completely paralyzed. We could only watch you through the glass doors for the next 3 to 4 months. I walked every day three miles to see you until the 6th child was born. At that time your Aunts and Uncles would come to see you.

- *Tell me what you had to do once I came home. I imagine six children kept you pretty busy.*

Mother: Looking back I don't know how I coped. I just had to do what was needed at the time and move on to the next child. You came home in a brace on the right leg to the hip and a strap going around the waist. The brace buckled at the hip and knee and hooked to your army shoes as we called them. You were proud of those shoes because they were the first pair that wasn't handed down from your sister or a cousin. I had to continue putting hot packs on your legs and every month you went to see Doctor Harris. You eventually went to a special school for early kindergarten at age 4 so you could swim in the warm pool and have therapy. You were picked up at the door by the yellow cab company to and from school the next 3 years.

- *You had to have been stressed out with so much going on and six children. Was I more trouble to care for than the others?*

Mother: I didn't have time for stress or anger. You just had to move on and not look back. After awhile we settled in to our regular family routine of everyday living. No I wouldn't say your were any more trouble. What ever came up I dealt with it. Like dressing six kids and putting on six pair of shoes and six pair of socks. Yours just took a little longer. After I got your foot into the shoe your older brother and sister helped buckle you in your brace. I would move on to the next child.

- *How difficult was it for me in the winter?*

Mother: You played just like the rest of the children. I however would only allow you to stay out for a hour a day because your leg would get really cold from poor circulation. I would remove your brace and wrap your leg in warm towels from the oven. It was the only way to heat them up. You had a little more struggle climbing up the snow covered hill to slide down but it was worth it. The joy on your face showed how much fun you were experiencing from the speed of the sled. You always seem to be wanting to go fast at everything you did.



JANICE

Getting Along Swimmably

By Phil Eckert

Editor's note: We asked resident Phil Eckert about her swim experience and use of the chairlift in the Windward Commons handsome indoor pool. She and resident Rosemary Hollender, a recent hip replacement patient, are viewed with Wellness Director Deb Goin and Fitness Instructor Art Jones.

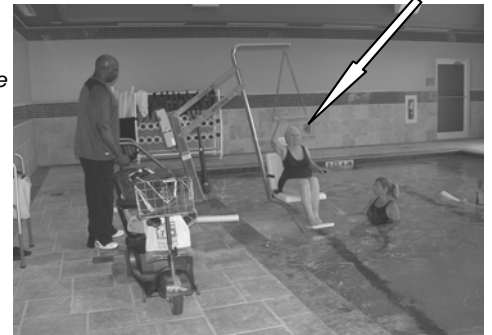
My dip in the pool was wonderful. After about 15 years' lapse, the thought of swimming again was a pipe dream. In the early 1990's I used to swim regularly about once a week. I enjoyed doing eight laps of the pool using each of the four strokes I knew so well. I had to give this up when the struggle to enter and exit the pool became exhausting. My polio-affected muscles were slowly weakening—the after effects of having had paralytic polio half a century ago in 1942. I began using a scooter full-time around 1995.

What did it feel like? I knew I had to find out if I could still swim, so I immediately dashed across the pool in the water with flaring arms and legs struggling to power me on. No, I can't swim again like before, but I am able to move around freely in the warm water with movements such as standing, raising my legs, and walking holding onto a "noodle." After my twenty-minute dip, my whole body tingled well into the night. What a thrill! I feel that was a wake-up call upon my muscles.

The new pool lift and the aid of Deb Goin, Art Jones, and Activities Coordinator Kathi Rose made this possible. I hope the once a week exercise will strengthen my stronger muscles and improve my overall functioning. I find moving around in the water and trying to stay on the "noodle" stimulating. Out of the water, I've already found my muscles work more smoothly and I have more energy.

Using the lift was a pleasant surprise because with my limited strength I was a little afraid of using it. However, the lift lowered me gently into the water where I just floated off and could hold onto the side of the pool to get my bearings. Exiting the pool was equally easy. I just sat on the seat in the water, and the ascent followed when ready. Once out of the water, Jones was at my side helping me move back onto my scooter.

Goin added this comment: "The benefit of warm water therapy for individuals with post-polio syndrome is that warm water increases the metabolic rate, heart rate, circulation, and respiratory rate. As a result, one tends to think better and feel sharper after water exercises. And, of course, muscles that are hardly used on dry land are strengthened by being used in the water exercises, and this increases stability."



One of our Beloved members has passed away.

Joseph Raker, a lifelong resident of Jacksonville, passed away peacefully in his sleep on July 4, 2009 at the age of 68. Joe was a master craftsman and wood turner, photography and computer enthusiast, and avid traveler who made countless day trips in the region and frequent vacations to Germany. Joe was the owner of Riverside Aquarium, employed by Plumbers & Pipe fitters Local Union 234, and was a graduate of Jackson High School. Joe was preceded in death by his father Winton and mother Corinne. He is survived his wife Eppie, sons Mike and Mark, daughter-in-laws Susan and Zuleika, grandsons Thomas, Brian, and Sebastian, brothers Jacob and David, and sisters Mary and Thelma.

Joe was a long time member of our support group and he also served on the board of directors for a number of years. We will miss his sense of humor and kind smile.

YOU LOSE WHAT YOU DON'T USE!

If we lose what we don't use, let us be careful not to lose our smile, our courage, our sense of humor, our strength, our perseverance, our laugh, our love. Let us show it does not take a whole body to be a whole person.

Sheila Kilgore

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Breathing & Sleep - a free symposium - Solutions for people with neuromuscular disorders such as post-polio syndrome, ALS, MS, and muscular dystrophy
 Sunday, November 1, 2009 - Noon to 5:00 p.m.
 Salk Institute for Biological Studies Auditorium
 10010 North Torrey Pines Road, La Jolla, CA 92037

People with neuromuscular conditions often encounter difficulties seeking and obtaining proper respiratory care. Too often, primary care physicians, neurologists, and respiratory care professionals treat their respiratory problems as a lung issue, rather than as a muscle/nerve problem. And too often, sleep labs look only for obstructive sleep apnea and miss underventilation.

The seminar's objectives will identify:

- How motor neuron conditions affect respiratory muscles
- How breathing is affected when respiratory muscles are compromised
- How breathing and sleep problems differ in post-polio syndrome, ALS, muscular dystrophy and MS
- Which tests identify specific breathing and sleep problems
- How to remove secretions and prevent pneumonias
- What ventilator and what interface is appropriate for YOU
- How using the right ventilator in combination with the right interface can significantly impact the quality and length of life.

Presenters:

Louis J. Boitano, MS, RRT, RPFT, Northwest Assisted Breathing Center, University of Washington Medical Center, Seattle, Washington

Diana Guth, BA, RRT, Founder, Home Respiratory Care, Los Angeles, California

Helen Kent, BS, RRT, Founder, Progressive Medical, Carlsbad, California

Noah Lechtzin, MD, MHS, FCCP, Pulmonary and Critical Care Medicine, Assistant Professor of Medicine Johns Hopkins University School of Medicine, Baltimore, Maryland

Geoffrey Sheean, MBBS, FRACP, Clinical Professor of Neurosciences, University of California, San Diego Director, Neuromuscular Division, San Diego, California

Exhibitors:

Durable medical equipment providers will display home ventilators, masks, and other ventilatory aids.

Representatives from nonprofit health organizations will display information and answer questions

To register, please return the perforated card (or mail in registration form below or see attached brochure) or contact Gladys Swensrud 858.271.9288

or e-mail swensrud@pacbell.net

Registration - Admission to this symposium is FREE of charge to the public. Registration includes coffee/tea during the scheduled break.

Register by October 28, 2009.

Mail in your registration to:

San Diego Polio Survivors
 8176 Calle Nueva, San Diego, CA 92126

Name of Participant:

I am a Patient Family Member

Caregiver Participant

Name(s) of additional attendee(s):

- I am interested in hearing a Salk Seated Lecture
- I am interested in taking a Salk Walking Tour
- Wheelchair seating requested

Address _____

City _____ State _____ Zip _____

Preferred phone: Home Cell Work

(_____) _____

e-mail _____

Minutes for September Meeting

After a break for summer, the support group met on September 12th at the Golden Corral on Southside Blvd. We had 12 members and 5 guests in attendance. One was a new member. We all welcomed her and enjoyed getting to know her. Bill opened the meeting with greetings to everyone. Janice spoke briefly about the website and encouraged everyone to visit it. She also informed the group of Joe Raker's passing on July the fourth. He was a faithful member and will be greatly missed. Bill mentioned the conference in Warm Springs that some of us were able to attend. He then shared his story of polio, post-polio and his experience at Warm Springs with the group. Since Eulie could not be there, he briefly shared her experience at Warm Springs which she shared with him in an interview. Sheila and Janice then shared their experience from the conference. Bill mentioned several possible events coming up in the fall; guest speakers as well as a Christmas party. Everyone was excited about the possibilities. Several more members spoke and shared stories with the group. The newsletter is being assembled and should be printed and mailed soon. Meanwhile, visit the website for the newest updates. Several of the members in attendance had not been for awhile. It was so good to see them back. We had three of our past presidents in attendance as well.

Respectfully submitted,
Sheila Kilgore, Secretary

Looking Back On Our National Convention In Warm Springs, GA



I had two insights. I knew that polio survivors were affected in different ways by the poliovirus, but the magnitude of the differences was very eye-opening.

Even the effects of the post-polio syndrome are affecting us in different ways. I wish the world could see what I saw those few days of the conference—a great number of polio survivors—most of them strong, determined, unique and all very special, and each dealing with their lives in very different ways.

The second insight I had was in the session concerning the family. I had a chance to talk to a wife of a polio survivor, and she expressed that she was fearful. I have been the strong one in the family for all of these years but, with the decline of my strength and abilities, I hadn't thought about what they must feel. When I returned home, I asked them to think about what they would like to say to me on this subject, and we had family time in which they spoke and I listened. It was very enlightening

. I got an opportunity to spend more time with some of our own support group members and get to know them a little better. I had hoped when I joined the support group that I would make new friends who I would be able to share our commonality with. Except for a couple of members, I have only briefly met a few members and most I have not met at all. This trip gave me a chance to get to know a few of them a little better. It's a shame that life keeps us so busy these days that we don't invest any time in building on our current friendships and creating new friendships. Even though PPS has been published some, there are still so many who have no idea what it is. Many don't even know about Polio. It would be good to form bonds with people who know and understand their repercussions.

It's funny but at one point I was walking by myself to a class and was seeing all the scooters and wheelchairs and thinking to myself, I don't belong here; this is not me. I guess there is still a part of me that lives in denial. How funny is that? I know I am a polio survivor and I know that I have Post-Polio syndrome, yet, several times during the conference, I truly felt that I didn't belong there, that I had not reached that point in my life yet. The conflicts we create for ourselves.

Most of the time I feel that I have learned to cope with my life and limitations; even find it challenging to find new ways to do the tasks I can no longer do the way I once did. Sometimes though, I find myself having a little pity party. Then I remember some of the people at the conference and how debilitating PPS has been on them and I feel a little ashamed. That usually draws me out and back on track.

One other thing I got from the conference was I met a wonderful and remarkable woman, the wife of a polio survivor and now a PPS victim. I had actually met her before but I had a chance to spend more time with her and talk with her at the conference. I felt a connection with her and even though our lives go in totally different ways, and I don't get to see her often, I will always remember her and that friendship we forged those few short days.

Sheila Kilgore

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What it was like on the other side of Polio

An interview with my mother Bernetta Cole— by Janice Cole Askwith

Mother: You pretty much did everything the other kids did. As you got older there was rough times after surgery but you never seemed to let it get you down long. You recovered quickly and couldn't wait to get back to your friends.

- *How would you summarize your feelings today with what happened at the time of the Polio outbreak?*

Mother: Polio was everywhere and you heard about it all the time. Most all families had someone who they knew or one of their own who had the disease. I was scared like everyone else. You just learned to cope with it.

I am just glad it didn't get any worse on us. Some children at the hospital couldn't even move.

My oldest daughter your sister Patty recovered from the fever with no disabilities other than she lost some weight and the doctor said that was good for her.

We could walk and talk and we were alive. And I thanked GOD for that.

- *Thank you for reading my mother's story. I wanted to find out how she handled all that took place when I was a young at age of 3 1/2 and struck with polio. I was luckier than most and had a great family base to fall back on. All my mother's sister and brothers, always came to see me for the four surgeries I had and at our family reunions when we played baseball. My Uncle would pick me up and run the bases with me on his shoulders. I remember laughing and cheering with the rest. I didn't feel left out and never more special than anyone of my other sisters or brothers. It starts with LOVE. I was truly blessed by God.*

Janice Askwith, Vice President



Janice with 2 younger sisters 4 years after polio

POLIO PARALYSIS

- Once established in the intestines, poliovirus can enter the blood stream and invade the central nervous system - spreading along nerve fibres. As it multiplies, the virus destroys nerve cells (motor neurons) which activate muscles. These nerve cells cannot be regenerated and the affected muscles no longer function. The muscles of the legs are affected more often than the arm muscles. The limb becomes floppy and lifeless - a condition known as **acute flaccid paralysis (AFP)**.
- More extensive paralysis, involving the trunk and muscles of the thorax and abdomen, can result in quadriplegia. In the most severe cases (**bulbar polio**), poliovirus attacks the motor neurons of the brain stem - reducing breathing capacity and causing difficulty in swallowing and speaking. Without respiratory support, bulbar polio can result in death.

THE IRON LUNG

- Large polio epidemics caused panic every summer during the 1940s and 50s in industrialized countries (US, Western Europe). At that time, people with polio affecting the respiratory muscles were immobilized inside "iron lungs" - huge metal cylinders that operated like a pair of bellows to regulate their breathing and keep them alive. Today, the iron lung has largely been replaced by the positive pressure ventilator; nevertheless, it is still in use in some countries.

Children whose legs are paralysed by polio today often require crutches, special braces or wheelchairs in order to move around.

Because no drug developed so far has proven effective, treatment is entirely symptomatic. Moist heat is coupled with physical therapy to stimulate the muscles and antispasmodic drugs are given to produce muscular relaxation. While this can improve mobility, it cannot reverse permanent polio paralysis.

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.

