

First Coast Post Polio

October-November

Northeast Florida Chapter
Jacksonville, Florida

2005
Vol: 8 No.6

We are having a
great time and
your missing it!
Stop in and visit with
US.



Next Meeting: October 20,
2005 on Thursday

Guest Speaker:
DR. JOHN DAVENPORT
Chiropractic Physician

Place: Perkins

At the corner of Beach
Blvd and San Pablo Rd
(Go east on Beach past San
Pablo Road,
Restaurant on left with
huge American Flag)

Phone: (904) 333-3457

Time: 12:00 Noon -till....

Please come as we would love
to meet all of you.

THIS ISSUE:

- P.2 Climb Every Mountain
(Do You Remember Claire)
- P. 3 Age and Gender
(How it effects polio survivors)

Registration Form for
First Coast Post-Polio
news letter.
Up-date and dues: \$15.00

On Thursday September 15th, Mark C. Hofmann, M.D.,P.A., Board
Certified-Physical Medicine and Rehabilitation, Jacksonville, FL
Honored Us With His Presents.

Topic "MANAGEMENT OF SYMPTOMS FROM POST-POLIO SYNDROME"
Some of the topics discussed were:

Risk factors for developing post-polio syndrome

1. Greater severity of illness when polio occurred
2. Greater recovery after polio
3. Older age at the time of developing polio
4. Greater activity in the years following polio illness
5. Female gender

Management of fatigue

1. Energy conservation at home and at work
2. Pacing with regular rest periods
3. Use of assistive devices (braces, crutches, can, or electric scooter)
4. Improvement of sleep

Management of muscle weakness

1. Non-fatiguing exercises-avoid overexertion
2. Assistive devices may be needed to compensate for new weakness
3. Weight loss

Management of pain

1. Avoidance of certain strenuous activities may be needed
2. Physical therapy/exercise is often helpful
3. Assistive devices can decrease joint and muscle pain
4. Pain medications, injections, heat/cold, electrical stimulation, & massage

Questions & Answers followed..

Thank you Dr Hofmann!

We are still looking for a cure for
this dreaded Post Polio Syndrome
and appreciate your patience with us.



GREAT JOB Dr MARK HOFMANN!
THANK YOU FOR CARING...
YOUR FRIENDS AT
FIRST COAST POST
POLIO SUPPORT GROUP
JACKSONVILLE, FL.

I would like to take a moment and thank all of you who attended our last meeting. It was great to see new faces in the crowd. We had 29! Dr Hofmann was very informative and helped to fill in the blanks for those of us who are new to the group. I realize the members who have been with us the longest have and never will stop looking for answers. As will all of us newer ones who are just now being effected again with weakness, pain and stress.

OH AND I LOVE TO FILL UP EVERY CHAIR!!!!

Thank you, Vice President, Janice Askwith



Do You Remember Claire?

“CLIMB EVERY MOUNTAIN”

In my polio story published in the May-June Newsletter, I told you that I was headed to Cusco and Machu Picchu, Peru with my Spanish Class from FCCJ. I returned in June after almost thirty days in Peru. The wonder of this incredible country and my feeling for the people I met and the things I saw would take up the entire newsletter. I'll spare you all from a (ZZZZZZZZ) "slide show", but I would like to share with you my wonderful experience at this ancient Incan wonderland.

Upon arrival in the city of Machu Picchu, on a beautiful sunny Friday, I was bringing up the rear and following the other students to check in to our hotel. I had my cane with me and walked a rutted sidewalk in awe of the native children playing on the tracks that run down the middle of the shopping and restaurant district. The city, Machu Picchu and the tourist area, is not accommodating to people with even slight disabilities. The conveniences that we take for granted here, are non-existent in Cusco. I never fully appreciated hand rails on stairs, sidewalks that fade to street level, raised toilets and other blessings that assist us here in the United States.

My walk to the hotel was interrupted when I fell flat on my face. Six local men came to my assistance and had me in a wheelchair and seeing a nurse in a matter of minutes. Apparently I fell right in front of the local infirmary, blood everywhere. After being told to take it easy for the rest of the day, my friends returned from their day trip to the ruins of Machu Picchu to inform me that I was not going to be able to handle the climb to the top of the ruins that I had been looking forward to so much. Their plan however, was to get me there come hell or high water and that is exactly what they did. With my cane in my left hand, Debby Cook from Yulee holding my right arm and Tancy Campbell from Jacksonville behind me, the three of us walked the hundreds of steps, one by one, over a period of several hours to the top of Machu Picchu. I was able to look down on the Plaza where a female llama and her new baby were getting to know each other. My birds eye view of this wondrous place and the unsolicited gift of assistance from two women I had known for less than a week is something I will never forget and be eternally grateful for.

LIFE IS WONDERFUL!

Claire King

Claire has inspired me with her determination to never give up. There is always a brighter tomorrow.

Thank You Claire King for your fantastic story.

Vice President, Janice Askwith

DO YOU HAVE A STORY TO SHARE?

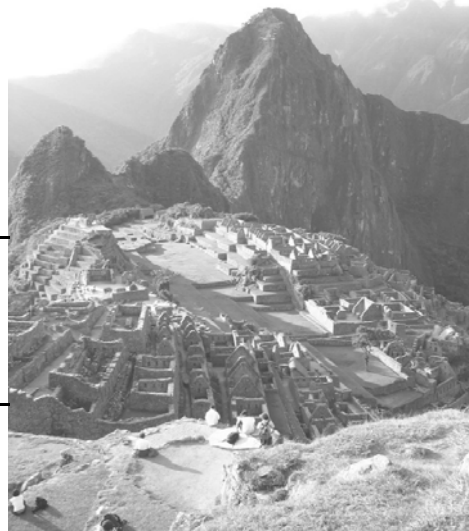
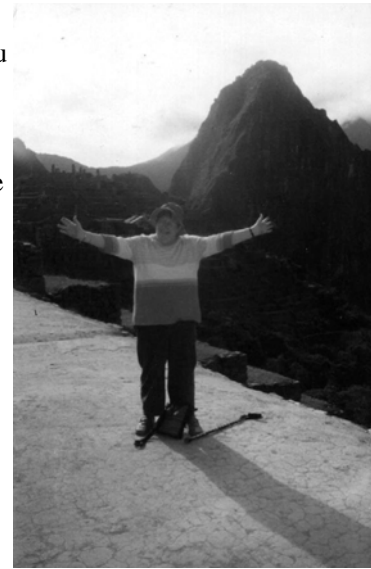
We here at First Coast Post Polio love hearing from you.

Please e-mail your story to me at:

jfcask@comcast.net

Or send to: 13119 Blackhawk Tr Ct

Jacksonville, FL 32225



Picture of Machu Picchu, Peru
Now that's a mountain!

Most Americans think of polio as a thing of the past. Although the disease has largely been eradicated, about one million Americans are polio survivors. For these men and women who contracted the disease through epidemics of the 1930s, 1940s and 1950s, many are experiencing the late effects of their struggle with polio. The University of Michigan's Post-Polio Clinic is studying the way age and gender are effecting this population



"Polio survivors are definitely an under-served population," asserts Sunny Roller, a polio survivor.

Roller contracted polio in the early 1950s when she was four, spending nine months in the hospital recovering from the initial phase of the disease, which included extreme paralysis.

"I went through rehabilitation until I was 18 years old. I had to learn to walk all over again and do as many things as I could for myself," she remembers. "I worked really hard. It almost killed me, but I learned how to come back from that disease."

Roller did 'come back,' but in middle age began experiencing new symptoms of pain, fatigue and weakness. Of the people who contracted polio in the United States from the 1930s on, approximately 40 percent of those still living had paralytic polio like Roller. These are the survivors at higher risk for developing late-effect problems, or post-polio syndrome (PPS).

According to Ann Laidlaw, M.D., a physical medicine and rehabilitation specialist at the U-M Health System, to some degree, researchers don't know what's going to happen to polio survivors as they age. This is why there is increasing focus on understanding the process and, consequently, developing the best forms of treatment.

"It is still not clear how many survivors might show the effects of PPS. Depending on the study, it ranges from 25 percent of survivors up to 75 percent," says Laidlaw.

The extent to which polio survivors will suffer from PPS depends on how seriously they were affected by the original polio attack. Patients who had only minimal symptoms from the original attack and subsequently develop PPS will most likely experience only mild PPS symptoms. People originally hit hard by the polio virus, and left with severe residual weakness, may develop a more severe case of PPS. Those who experienced paralytic polio are most susceptible to severe PPS.

Claire Kalpakjian, Ph.D., believes there may be gender differences in how post-polio syndrome affects men and women. Currently she and other experts are conducting a study looking at the impact of menopause on women who are polio survivors, as well as the differences between men and women who experience the syndrome.

"One of the reasons we want to study this is because there are so many changes that go on in a woman's body. One of our particular concerns is osteoporosis for women with disabilities who may not be as physically active. Women who aren't strengthening their bones by exercise or even walking are at higher risk for developing osteoporosis, and that risk increases as they enter menopause. If you factor in post-polio syndrome, these woman will likely have many special needs," Kalpakjian says.

Patients are seeing the benefit of this expanding scientific knowledge. Roller, who is 55, remembers her first experience with PPS and her attempts to find answers. Almost ten years ago, she started going through the gradual stages of menopause, but also the late effects of polio. Over several years, Roller went to five different physicians looking unsuccessfully for answers about the new, debilitating pains she was experiencing, and solutions for how to deal with PPS. Currently, she is a patient at the U-M Post-Polio Clinic.

"I feel I have more control of my situation now. At least we know a little bit more about what to expect and we know help is there. And, I've helped the medical community learn more about managing, alleviating and even sometimes preventing the late effects of polio," she says.

Thank you Post-Polio Health International (PHI) for this article.
And The University of Michigan's Post Polio Clinic

We would like to thank the "March of Dimes" for providing the mailing of this news letter for First Coast Post Polio.



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






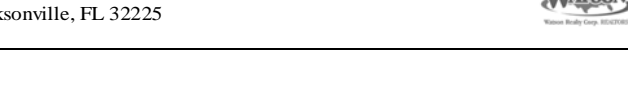
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Photo of the Month Club!

Do you have a favorite photo?
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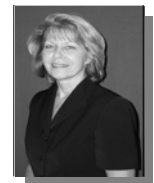


Photo taken by Janice Askwith by her backyard garden pond. "The joy of nature is ever present just look around you anywhere." ©Gods Butterfly Designs w/Style


 We have several members 
 from our PPS family that will 
 no longer be here with us. 
 They have found peace with 
 the Lord. 
 In reverence to them and 
 their family, give a silent 
 moment in Prayer. 
 • EL Barksokie, Jr 
 • Donna Sumlin 
  


Jeri Gething, REALTOR®

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