



First Coast Post Polio Support Group — News Letter

March & April

Jacksonville, Florida

Vol: 8 No.9

Dear Friends; **NEXT MEETING:**

I have been scrambling to find a new meeting place and have been granted the offer of a room at the **Courtyard Marriott** beside the Mayo Clinic off San Pablo Road. (Between JT Butler Blvd and Beach Blvd). It is located closer to Butler. Turn into the Mayo Clinic and take the first left into Courtyard Marriott.

We will be having lunch served to us as usual. You may choose from their menu or help yourself to their salad bar then bring it back to our meeting room. There will be a sign at the room.

We will also have a board meeting immediately following lunch. 12:00—2:00 pm.

Great Door Prizes

Regards

Janice Askwith
President
904-333-3457



Courtyard Marriott at Mayo Clinic



BOARD MEMBERS PLEASE
ATTEND THIS MEETING!
12:00-2:00



April Speaker!

Dr Thorsteinsson will be with us to go over PPS (Post Polio Syndrome) for all the new member who have questions. We can only accommodate 40 seats. This is a **RSVP** meeting.

You must reserve your seating!

April 27 (Thursday)

12:00-2:00pm Call: 904-333-3457

Gudni Thorsteinsson, M.D., Physical Medicine & Rehab...

Medical School:
University of Iceland, Reykjavik, Iceland

Internship:
Landspítalinn University Hospital, Reykjavik, Iceland

Internship:
Presbyterian University of Pennsylvania Medical Center, Philadelphia, Pa.

Residency:
Mayo Graduate School of Medicine, Mayo Clinic, Rochester, Minn.

Certifications:
American Board of Physical Medicine & Rehabilitation

Academic Rank:
Assistant Professor of Physical Medicine & Rehabilitation

Interests:
Post-polio syndrome, multiple sclerosis, chronic pain, electrical stimulation, rehabilitation of musculoskeletal and spinal cord disorders

Smiling is infectious,
You catch it like the flu.
When someone smiled at me
today, I'll passed it around...



To you!!!



HAPPY ST PATRICK'S DAY!!!

Patrick, Saint, Christian missionary, the Apostle of Ireland. He was one of the most successful missionaries in history.

The holiday was more of an American event from the very start. In fact, the first St. Patrick's Day parade took place in New York City on March 17, 1762. Irish soldiers serving in the British colonial army staged a parade celebrating their heritage.

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Fear of Falls, Risks and Practical Strategies

Kristine Legters, PT, DSc, NCS, Gannon University, Erie, Pennsylvania

When my students and I looked at falls in individuals with post-polio problems, the numbers were really staggering. About 85% of the participants in our study reported falling. Fear of falling was also a staggering and scary number – 95% of the individuals with post-polio. Another interesting fact was that many individuals who were nonambulatory and who were in wheelchairs also were afraid of falling.

What factors put you at risk for falling? Review the list below to determine how many factors describe you. This short list is used for older adults, which some of us are, but can also be used by younger polio people. You may not experience some factors, yet experience others. And, some of them you may be able to change and some you may not. I'd like to expand on a few.

What factors put you at risk for falling?

- | | | | |
|----------------------------|--------------------------|---------------------------------|--------------------------|
| Confused mental state | <input type="checkbox"/> | Use of psychotropic medications | <input type="checkbox"/> |
| Visual impairment | <input type="checkbox"/> | Balance difficulties* | <input type="checkbox"/> |
| Decreased leg strength* | <input type="checkbox"/> | Decreased sensation in feet | <input type="checkbox"/> |
| Use of assistive device | <input type="checkbox"/> | Use of multiple medications | <input type="checkbox"/> |
| Environmental hazards | <input type="checkbox"/> | Alcohol consumption | <input type="checkbox"/> |
| Urinary incontinence | <input type="checkbox"/> | BP↓s when standing | <input type="checkbox"/> |
| Dizziness | <input type="checkbox"/> | Cardiac medications | <input type="checkbox"/> |
| Decreased leg coordination | <input type="checkbox"/> | Abnormal walking pattern | <input type="checkbox"/> |
| Low activity level | <input type="checkbox"/> | Depression | <input type="checkbox"/> |

*Risk factors of falling that have been investigated in those with post-polio syndrome.

Visual impairment: Recognize that your ability to adapt to the change in light decreases as you get older, and remember that fact when you walk into a very bright room or a very dark room. Also, conditions such as glaucoma, cataracts and macular degeneration increase your risk for falls.

Use of assistive devices: The issue with assistive devices is the proper use of them. For example, if the legs of your quad cane are in your pathway, as opposed to properly being towards the outside of your pathway, you are at risk for falling.

Decreased sensation in feet: Decreased sensation in your feet puts you more at risk for falling because you don't know where your feet are. It may or may not be a result of **post-polio**. It could also be because you are diabetic.

Urinary incontinence: Nobody wants to talk about it, but if you are having to get up frequently in the middle of the night, that puts you more at risk for falling because you are not as alert and your pathway may not be well-lit.

Dizziness: Talk with your physician about any dizziness you may have because there are many, many causes of dizziness, including cardiac issues, blood pressure concerns, inner ear problems and medication issues. For example, psychotropic medications, and even cardiac medications, list dizziness as one of the side effects.

Multiple medications: The red flag number is four. If you are on more than four medications, you are considered at risk for a fall. I am not saying stop your medication. Instead, I am saying go to your physician and talk about all of your medications. You certainly may need all of them, but there may be other kinds that won't cause the side effect of dizziness.

Blood pressure decreases when standing: When this happens you will have a sensation of lightheadedness or dizziness. Discuss this with your physician, also.

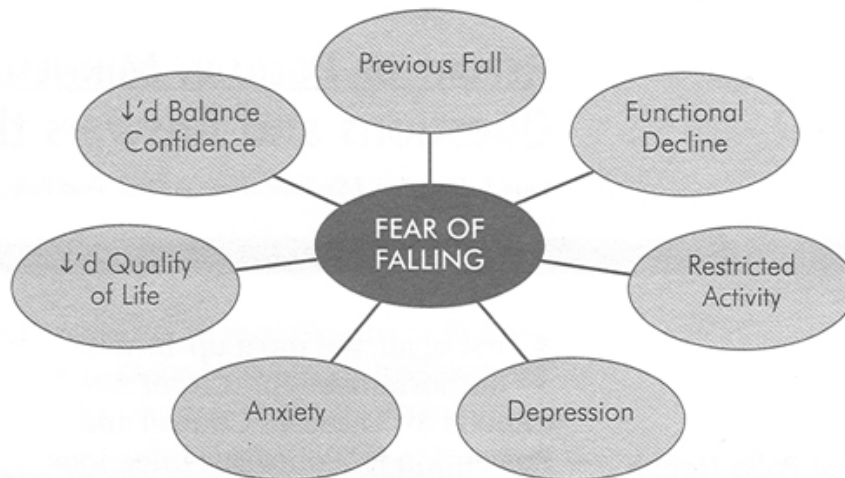
As I look at the list, I know I can check off several and I am not an "older adult" yet. Therefore, I need to look at what strategies I can do so I am less at risk for falling.

The fear of falling issue has many causes and you don't have to fall to have a fear of falling. If you look at the diagram, there are many things that contribute to your FOF and, unfortunately, it's a cycle.

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FACTORS THAT CONTRIBUTE TO FEAR OF FALLING (FOF)



The factors that contribute to FOF in older adults are multi-factorial. The prevalence of FOF in those with post-polio syndrome (PPS) far exceeds that of the community dwelling older adult. Those with PPS report FOF when they are *tired*, when they are *outside* and when they are *weak*. Falls in those with PPS are most frequent while walking, when *outside* and often involve an *environmental hazard*.

For example, it's really difficult for me to walk outside if I am not using my crutch, or if it's at the end of my workday. So, I make the choice not to go out with my friends or family and I stay home. Then, my friends and family stop asking me to go out because they know I always say no. With this restriction of my social activities, I possibly lose strength and because of the weakness, I lack coordination, which makes me more at risk for falling, and I continue this cycle. We, as polio survivors, have some power to intervene in this cycle and to make some changes. For example, do more difficult chores in the morning after a good night's rest. Here are other strategies we all can use.

Assess your home environment. Do a home safety check to be sure that you are rid of environmental hazards in your home. For example, get rid of clutter, do not use throw rugs, remove electrical cords in your path, use cordless phones, clear outdoor walkways, repair uneven walkways, use handrails, put a non-skid surface or reflective marking on steps, improve lighting, use nightlights, store frequently used items within easy reach, put grab bars in the bathroom, use a shower seat, and adjust the toilet, bed and chairs to the proper height.

Assess yourself. Have you had annual vision and hearing examinations? Are your feet and toes pain-free? Do your shoes fit? Do they have flat, low, wide heels with non-skid soles? Do you avoid walking without your shoes and in your sock feet? Do you wear clothing that doesn't drag? Have you had a physical to check for unstable/low blood pressure, or to seek help in reducing frequent trips to the bathroom in the middle of the night, or to discuss with your physician if you are on more than four medications?

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I received this thoughtful letter from a fellow post polio member last Easter and was unable to print it at the time. This year I have made room for it and wanted to share it with all of you.



ONE DAY AT A TIME: BY JACK BRIGGS

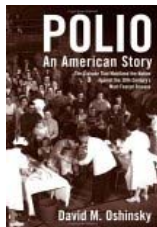
EASTER

HAPPY EASTER TO YOU.. AND A GLORIOUS SPRING-TIME TOO! EASTER BRINGS THE BIRD-SONG AND LEAFY TIDINGS OF SPRING. THIS IS A SEASON OF BIRTH, A STARTING POINT FOR NATURE IN ALL HER GLORIOUS BOUNTY. IT'S THE SEASON WHICH HEARALDS NEW LIFE AND BUDDING FLOWERS AND IS A STARTING POINT FOR A MYRIAD OF THINGS. AS I PLAN AHEAD, I CANNOT HELP BUT REVIEW THE PAST, AND THINK OF MY MANY FRIENDS. FOR YOUR FRIENDSHIP I AM MOST GRATEFUL. WHILE THE TREES AND LAWNS AND GARDENS RENEW OUR WORLD WITH VERDANT BEAUTY, I HOPE OUR FRIENDSHIP WILL CONTINUE AS TIME GOES ON. I DO HOPE THAT THIS SEASON OF EASTER AND SPRING WILL BE A HAPPY ONE FOR YOUR AND YOURS.

SINCERLEY,
JACK

I think this letter says it all. Have a Happy Easter and a wonderful New Year!!
God Bless Janice

GREAT BOOKS TO READ!



"Polio: An American Story"

By David Oshinsky
Oxford University Press

The author tells the story of Isabel Morgan, perhaps the most talented of all polio researchers, who might have beaten Salk to the prize if she had not retired to raise a family

This is just one of the many stories told in this book.

Photo of the month

WRINKLES:

Something other people have.
You have character lines.



My Great Aunt and Mother
who has always been available for me!

What's In The News!

With the Olympics and Women History Month in March
I thought this was a great time to run this little article on Wilma Rudolph.



Wilma Rudolph –

Three-time Olympic gold medalist

Wilma Rudolph was no stranger to adversity in sports or life. As a child, she suffered from double pneumonia, scarlet fever and **polio**, which caused her to lose the use of her left leg. At age nine, she was able to walk without the metal leg brace. A basketball standout in high school, Rudolph was recruited to run track for Tennessee State University. The rest is history — Olympic history that is. Rudolph went on to win three Olympic gold medals in the 1960 Olympic Games in Rome. With these victories, she became the first American woman to win three gold medals in track and field in one Olympic Games.

Fear of Falls, Risks and Practical Strategies:

Know yourself and your post-polio syndrome problems. Pay attention to your body's signals – pain, fatigue, time of day, level of activity for that day or the day before – only do "risky" tasks at times when you are at your best. If you don't know your fatigue level during the day, I suggest you keep a log and record the time of day when you are having more difficulty and/or record a particular activity that makes you more fatigued.

Be as active as you can be, given your post-polio symptoms. If you are able to exercise your feet and legs, do so. They are the key to good balance.

Take your time. Remember to move at speeds that are consistent with your energy and ability. Rushing to the phone is not worth a fall. They will call back or leave a message. Also, remember to have your cordless phone with you at all times.

Pay attention to changes in your health. DO NOT assume that every change in your health is related to post-polio. It may not be. Any new symptoms need to be appropriately investigated by your physician.

Seek expertise and education. In our survey results, less than one third of us as post-polio survivors seek the assistance of health care professionals and that concerns me as a polio survivor and a health professional. Health care professionals have a lot of information but you need to be willing to talk with them. If we don't ask you the right question, tell us anyway. I will guarantee you as a physical therapist that our profession and the occupational therapists are trained to be very good listeners. Find professionals in your area who can assist you with appropriate exercises to improve your balance, the proper fitting of orthotics and assistive devices, a home assessment, a lesson on how to get up from a fall, and information about new adaptive equipment for the home.

Older adults are hesitant – and I think we can lump ourselves as people with post-polio in that group – to talk about fears but it is important that we do.

I want to finish with two ideas. If you are in a situation where there are not a lot of people in and out of your home and you are at risk for falling and/or have fallen, remember that there are several personal alarm systems (Lifeline®, 800-380-3111) available on the market. You may not think you are old enough, but I encourage you to explore this option. There is a fair amount of research that supports the use of hip protectors (Posey Hipsters, ProtectaHip). A hip protector is a garment that you wear under your clothes that has extra padding in the hip area. The padding provides additional protection to the hip area and lessens the chance of a fracture when you fall.

Safety For Older Consumers Home Safety Checklist, CPSC Document #701, is available at www.cpsc.gov/cpsc/pub/pubs/older.html.

Kristine Legters, PT, DSc, NCS (Legters001@gannon.edu) received her doctor of science degree in neurologic physical therapy. Her research and publications in the recent past have been in the area of fall prevention and inner ear disorders. She is a polio survivor who contracted polio from the vaccine. Legters presented this information at [PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well](#) in June 2005.

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We would like to thank Marilyn Parker a SHINE program volunteer for informing us about the new Medicare Prescription Program.

Marilyn did a wonderful job and help fill in the blanks at our last meeting.

If anyone still needs help with their decision please contact Marilyn Parker at the SHINE program, Jacksonville 904-391-6601 or e-mail <mmmsparker@aol.com>.

A decision has to be made by May 1, 2006

You will have one time only to change companies if you are not satisfied.

State of Florida Department of Elder Affairs

SHINE Program

**Serving Health Insurance Needs of Elders
Florida 888-242-4464**

LOOKING FOR VOLUNTEERS

Certified Medical Systems, I, INC.

David Jacob
2141 Lock Range Blvd #130
Orange Park, Fl
(904) 272-3022 or (800) 815-1211
Scooters * Wheelchairs * Lifts * Walkers
Ramps * Stairclimbers * Elevators –Home & Auto
Oxygen-Nebulizers-CPAP-BiPAP
Complete Respiratory & Diabetic supplies
New onboard * Certified Respiratory Therapist
Catherine Mitchem
Also serving: Ocala (352) 237-4146
St. Augustine (904) 810-9747

Our Staff of Directors:

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Vice President	Kathy Hutchinson
Treasurer	Eulie Nahm
Program chairperson	Needed
Recording Secretary (NEEDED)	Janice Askwith
 <i>Sunshine committee</i>	 <i>Janice Askwith & Eulie Nahm</i>
Board of Directors	David Brynildson
Board of Directors	Dr. Stuart Caplin
Board of Directors	Joe Raker
Founder 1990	Sue Bridges



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 Jacksonville, FL 32225
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 jfcask@comcast.net



Happy Easter



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

"Saving Babies, together!"



New Meeting Place!!!!
Courtyard Marriott by
Mayo Clinic
March 16th at 12:00 pm
San Pablo Road
 Guess who is coming to our next two meetings?
 Look inside!

Our Goal is to Serve and Support You!

We need your help!

Please take a moment to share your story with us. It may seem small to you but to someone else you could be touching a need in them. We all have Post Polio Syndrome and if you're wondering what you could add to the information that is already out there? Then just let me inform you that not everyone's story is the same and we would love to have the opportunity to hear yours as it could improve the quality of others.

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.