

CONNECTIONS

First Coast Post Polio Support Group



Spring, 2011

Volume 14, No. 1

It's That Time of Year!

Cold Intolerance:

Why is This a Problem for Many of Us?

By Linda Wheeler Donahue

Cold intolerance is a major problem for many polio survivors. Why do we feel the cold more than people who did not have polio do? This may be a question perplexing you. I would like to share what the polio experts tell us about why we have the difficulty of cold intolerance. Then I would like to explore some practical suggestions to help you obviate this problem.

Fortunately, the major polio physicians and researchers are quite consistent in their appraisal of this issue. Let's take a look at what they have to say.

Dr. Julie K. Silver, Director of the International Rehabilitation Center for Polio in Framingham, Massachusetts, explains that polio survivors' sensitivity to cold is due to atrophied muscles that do not contract adequately, and are therefore unable to assist blood vessels in bringing warming blood to the extremities.

Dr. Richard R. Owen, Emeritus Medical Director of the Sister Kinney Institute, is one of the first experts to describe "polio feet"; in fact, he coined that phrase. People who had polio often have blue, red, or violet feet. Part of the explanation for our colorful tootsies is that the poliovirus not only attacked our motor neurons, resulting in paralysis of our muscles, but also attacked sympathetic nervous system neurons within the spinal cord.

When it did that, we lost our ability to control the blood flow into our veins and arteries. When our veins are unable to contract, they become too open. Blood then "pools" in the feet, giving the skin a bluish tint and causing puffy swelling.

Our "polio feet" get colder than the feet of someone who did not have polio,

Linda Wheeler Donahue, Professor Emeritus of Humanities, is a polio survivor, a disability activist, writer, and speaker. She is President of The Polio Outreach of Connecticut and a frequent presenter at conferences, focusing on the social/emotional complexities of disability.

In This Issue:

President's Message	2
Christmas Party Revisited	3
Looking Back	4
Food to Boost Your Immune System	5
Quiz	8
Power Chair Rental Update	9
Mark Your 2011 Calendars! meetings are planned for	12
<u>Feb. 26</u>	
and	
<u>April 2</u>	
<i>(Details on back page)</i>	

From the President

Just Jim's thoughts.....

Dear Polio Survivors,
I hope that your Christmas was a blessed time with family and friends and that you practiced the PPS theme of "Conserve to Preserve".

This theme has been around since the mid 1980's when many of us were realizing we were having new and disturbing symptoms that were yet unexplained. I need to remind myself to heed this edict on a regular basis, often after I have already overdone.

If you were at our very enjoyable Christmas party at the country club you know that I had an intrathecal morphine pump implanted on Monday of that week to deal with the pain from severe degenerative spinal arthritis.

For many years I have had a strong pain indicator to tell me it was time to rest and it is still a work in progress for me to realize that a rest break is needed, even though I only have minor pain as my indicator.

I still periodically go too long before resting if I'm not careful and end up dealing with fatigue & breakout pain that is with me while the morphine tries to catch up.

The day of our Christmas party was a difficult day because I was paying the price since I had overdone on both Thursday and Friday.

When I left our party I headed to the Westside of Jax to catch-up with the already-in-progress birthday party for our nine year old granddaughter.



Jim Powell

As I plopped down on the couch to watch Harmony and her friends learn to play with her new video game system I soon realized that my new found energy was not only depleted but my inner "energizer bunny" battery was on overload and smoking.

I toughed it out for a little over an hour before declaring it time to get home for a much overdue recliner nap where I quickly fell sound asleep for over two hours!

I'm now doing better with the task of pacing myself but still learning some lessons the old fashioned hard way!?! The say "you can't teach an old dog new tricks" but this old dog is struggling to learn some.

I hope you are looking forward to getting back into the routine of attending our group meetings, the first two of which are detailed in this newsletter.

Please let me know what PPS related questions we can research and answer for you at our February 26th meeting. Also let me know if there is a PPS topic of interest that you would like to have us address that day or as the topic of a future meeting.

This will be a meeting where we can learn more about the common struggles we share on our journey with Post-Polio Syndrome.

I'm currently waiting for a response from Dr. Alan Berger, Chief of Neurology at *Shands Jacksonville*. We need to book a speaking engagement with him six months in advance to accommodate his schedule and we look forward to letting you know when that meeting will take place.

I hope to see many of y'all (a Midwestern boy living in the South, just trying to fit in) on the 26th.

God bless,

Jim

Jim Powell, President

News from Denmark

Registration for the **International Polio Conference** in Copenhagen August 31st to September 2nd 2011 is now open. Check out the preliminary program and other details at www.poliocoference.com.

Minutes for our Christmas Party

Our Christmas party was held on Saturday, December 18, 2010 at the Hidden Hills Country Club. There were 45 people present



**Phil Eckert
and
Marion Boyd**

including veteran members and new members as well as a number of guests. We had a wonderful lunch provided by the country club. After lunch, Jim Powell, president, made a few comments and then turned it over to our guest entertainers.

First we all enjoyed a wonderful duet on the piano by our own Phillipia Eckert and her friend Marion Boyd.

Then the program was turned over to a quartet called the Singing Men of Faith from Fort Caroline Baptist Church. They entertained us with several wonderful selections of Christmas music. Sheila Kilgore accompanied them on several of the pieces.

Everyone thoroughly enjoyed the music presentations of the day. As everyone was leaving, they were given a Christmas bag full of wonderful candies and treats. This was one of the biggest groups we have ever had.

Respectfully submitted,
Sheila Kilgore, Secretary



"The Singing Men of Faith"

LOOKING BACK AT 2010

Welcoming New Members

Sherry Baker	Connie Kelly	Dewey Smith
Brenda Bronson	Gene Lewis	Kathy Watters
Linda Ferrill	Don Miles	Kathy Williams
Carol Gilbert	Floyd Parsons	

Saying Goodbye to Members in Death

Gerry Jordan

Claude Harper

Saying Goodbye to Members Who've Moved

Bill Hamilton moved to Tampa Florida

Ann Hazard moved to California

New Leadership

Bill Hamilton resigned after serving one term as president. **Jim Powell** took the office of president and began his leadership of our group. The other officers are as follows:

Vice-President - **Janice Askwith**

2nd Vice-President and Editor of Newsletter - **Frances Powell** (no relation to Jim Powell)

Secretary - **Sheila Kilgore**

Treasurer - **Phyllis Moss**

Sunshine Committee Chair - **Sue Massey**

We wish to thank each person for their time of service to our support group.

We had 6 meetings in 2010. They were on February 13th with 14 present, March 27th with 11 present, May 22nd with 25 present, August 21st with 15 present, November 20th with 24 present and December 18th with 45 present.

We celebrated our 20th anniversary as a support group

We had a guest speaker from the Rotary club come and speak to us.

This year also celebrates the 40th anniversary of the Salk vaccine.

(Continued at bottom of next page)

Foods that boost your immune system

by Christine J. Kim

With flu season in full swing and winter weather around the corner, those telltale cold symptoms can be tough to ward off.

But don't throw in the towel just yet, says Kim Barnouin, co-author of *Skinny Bitch*. Your diet is the main provider for your body's "daily boost of antioxidants, vitamins, minerals, fiber and enzymes to protect the immune system" – meaning a poor diet can be a huge factor. A weakened immune system can result from a number of factors, including stress and excessive consumption of such substances as alcohol and sugar, Barnouin says. So give your immune system a fighting chance with these health-boosting foods.

Lemons restore the body's acid-alkali balance, maintaining natural pH levels that support healthy bacteria instead of the viruses that thrive in acidic conditions.

Green tea and white tea are a powerful duo, stimulating and aiding your immune system in the disease-fighting process.

Garlic is "an edible antibiotic" that seems to cure everything, Barnouin says, particularly when raw.

Kidney beans and chickpeas (garbanzo beans) contain the necessary daily protein required for a strong immune system.

Brazil nuts are the No. 1 source for selenium, an antioxidant that helps rejuvenate our bodies and kill off germs.

Reprinted from Daytona Beach News-Journal, USA Weekend's, Nov. 12-14, 2010, column ThinkSmart.

Looking ahead to 2011

2010 brought about a year of positive changes for our group. We thank all of our leaders and supporters and our faithful members. 2011 promises to be as great a year but we need all our members to make it a success. Hope to see you at the meetings this year.

Respectfully submitted,

Sheila Kilgore, Secretary



Vintage poster donated to FCPPSG by Bill Hamilton

Cold

(Continued from page 1)

since our sympathetic neurons are damaged.

At the time of the original infection, the poliovirus damaged the sympathetic nerves, explains Dr. Lauro S. Halstead, pre-eminent polio author and director of the post-polio program at National Rehabilitation Hospital in Washington, DC.

These nerves were part of the autonomic nervous system and their damage caused malfunctioning of the sympathetic nerves. Richard Bruno, Ph.D., clinical psychophysicologist, noticed that the skin on the affected arm of his first polio patient was cold to the touch. This suggested a problem of blood



Minutes of the Anniversary /Reunion Party Meeting

On November 20th, the FCPPSSG met at the Ramada Inn off San Jose to celebrate our 20th anniversary as a support group. There were 15 members plus 9 guests present for a total of 24. We had a very nice lunch furnished by the Ramada Inn.

After lunch Bill Hamilton our previous president came in and presented the group with a very unique gift. He and his wife were going through some antique stores and found an old picture. The picture was not what captured his attention but the poster that had been used for a backing. It was an original poster that dated back to around 1938-1940 when they were made every year on the president's birthday to support the fight of infantile paralysis.

After his presentation, we played several different types of games. Prizes were given out to the winners. After the games, each person received a beautiful spiral bound booklet made by Janice Askwith. It was a tribute for our anniversary. Everyone had a wonderful time.

Respectfully submitted,

Sheila Kilgore, Secretary

Cold *(Continued from previous page)*

flow to the limb. As Dr. Bruno studied more patients, he discovered the same thing.

He deduced that the size of the polio survivor's skin blood vessels could not be regulated properly because the poliovirus killed off the sympathetic neurons in the spinal cord.

These are the ones responsible for making the muscles around blood vessels contract.

People who did not have polio may also experience coldness, but Dr. Silver explains that we polio survivors feel this unpleasant sensation even indoors in a warm room.

This sets us apart from others. We are often cold even at room temperature because those peripheral nerves that supply the muscles surrounding our blood vessels were damaged when we contracted polio.

These small muscles play a major role in warming the extremities.

What can we do to keep warm? Our polio experts all agree on this. The management of cold intolerance is largely symptomatic, that is, all we can do is treat the symptoms.

There is no known cure. How do we treat the symptoms? There are a number of easy lifestyle adjustments you can make.

One of the most important things you can do is to stay warm from the moment you wake up in the morning. Your body will be warm and cozy at that time of the day. So hold on to your body heat with warm socks and layers of clothing.

Three thin layers will keep you warmer than one thick layer. Go to a camping store and purchase clothing made of polypropylene.

Polypropylene is comprised of a thin plastic film woven into a soft fiber and is excellent at insulating your skin from the cold. Outdoorsmen have known of its warming properties for years. It is sold under various brand names such as Thinsulate and Gore-Tex.


Skiers and outdoor enthusiasts use a resourceful clothing technique called layering. This is an efficient way to stay warm and comfortable in cold weather by protecting and preserving your core body temperature. One of the

advantages of layering is that you can add or remove clothing to adjust to changing conditions. Here is how layering works.

The first layer is the thermal base layer. The fabrics used for this layer are generally stretch knits, often made of synthetic fibers. They are typically lightweight, machine washable, and fast drying.

Special occasions sometimes present a warmth-dilemma for women. I recommend silk as a first layer. Silk is non-bulky with a luxurious feel and has impressive thermal properties. It is light enough to be nearly invisible underneath blouses or slacks, yet insulating enough to provide that extra layer of warmth.

With a thin silk layer worn as an undershirt, ladies will look trim even in evening clothes. Fancy dress situations no longer have to mean women are freezing!

The second layer is called the mid layer. This is a thicker, cozy layer that really locks warmth in next to your body. 

Fleece, in various thicknesses, is an excellent mid layer insulator. My favorites are Polarfleece 100 and Polarfleece 200. This space age fabric brings comforting warmth, softness, and lightness.

The characteristics of warmth and lightweight are particularly important to polio survivors. We need warmth yet our bodies cannot tolerate dragging around excess weight in the form of heavy clothing.

Polarfleece offers a dynamic warmth-to-weight ratio, compared to traditional fabrics. Its tiny springy fibers create mul-


tiple air cells to trap warmth inside. This gives excellent protection from the cold. It does not retain moisture and facilitates evaporation so the fabric remains dry and comfortable.

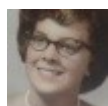
If there is no Polarfleece in your closet, I suggest you head out on a shopping trip. You can shop either in a brick and mortar building or in cyberspace.

The third layer is referred to as the shell layer. This layer must be breathable for the layering system to function. If it is not breathable, condensation will form caus-

ing chilling. The top layer, or shell, is often windproof and waterproof. It should be loose fitting to allow for movement. Polarfleece 300 as your third layer will keep you warm no matter what Mother Nature delivers.

It is wise to even layer your socks. Sock liners made of polypropylene are superior heat retainers. They are designed to be worn as a base layer under athletic socks.

You may want to try battery operated heated socks. I did not have luck with them as they had uncomfortable seams and hot spots, but they may work for you. 



QUIZ—Famous Folks With Polio Connections

by [Janice Knight Hartman](#)

1. What do Alan Alda and Donald Sutherland have in common?
2. Who invented the game of Candy-Land?
3. What is our connection to Elvis?
4. Who wrote, "Save the Last Dance for Me?" What polio connection?
5. What connects us to "Jay and the Americans? (one of my favorite groups)
6. What famous director had polio?
7. Did any olympic champions have polio as a child? (Name them)
8. What famous violinist had polio?
9. What connection do we have to famous Steiff Teddy Bear?
10. What polio survivor invented an artificial heart?
11. Name 2 Canadian polio survivors (other than Sutherland!) Neil Young, Joni Mitchell, Paul Martin...
12. What famous Olympic gymnast's mom had polio?
13. Who was Mary MacArthur's mother?
14. Who was a PT with polio patients before she was an actress?
15. What did Mark McGwire and Bob Dylan have in common?
16. Name 2 famous people whose wives had Polio.
17. Who had the first case of Polio in the UK in 1773?
18. Most all know FDR had polio, how old was he when he had it?
19. What emperor of Rome was thought to have had Polio?

especially in bitterly cold weather. Your neck region is very important. Wear a turtleneck style top to warm that area. In addition, do include a hat, mittens or gloves, warm socks, and a scarf when you venture out of doors.

At the GINI Conference in June of 2000, I purchased a fantastic product from one of the many vendors there.

These were heat-activated neck warmer and heat activated booties. You place them in the microwave for 3 minutes, then put them on and savor the rejuvenating deep heat for over 20 minutes of warmth.

I have since seen these in various home health mail order catalogs.

Many of us PPSers spend most of our time indoors, but we still have trouble staying warm. I suggest that throughout the day you take several breaks from your daily activities. Sit in your favorite chair or recliner with your feet elevated as high as possible.

I have an old twin size electric heating blanket draped on my recliner ready to warm me up like nothing else. If you do not need that large a covering, try using a warm

heating pad and a cozy lap blanket as you rest and enjoy the feeling of your extremities warming up to a comfortable temperature.

When your muscles are warm, you not only feel better, but you also move and function with more ease and efficiency.

Many of us suffer with the uncomfortable sensation of feeling cold. The foremost polio physicians offer a clear explanation for why this happens. The good news is that we can make lifestyle changes to remediate this troubling post-polio problem.

##

References:

- Silver, M.D., Julie K. **Post-Polio Syndrome: A Guide for Polio Survivors and Their Families.** New Haven: Yale University Press, 2001.
- Halstead, M.D., Lauro S. **Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome.** Arlington, VA: ABI Professional Publications, 1998.
- Munsat, Theodore L. **Post Polio Syndrome.** City: Butterworth-Heinemann Medical Publishers, 1991.
- Bruno, Ph.D., Richard L. **The Polio Paradox.** New York: Warner Books, 2002.

Answers to Quiz on page 8

1. Both played Haweye Pierce (Alda on TV/ Sutherland in the movie, M*A*S*H)
2. Eleanor Abbott invented a game to play while recuperating from polio
3. He had a picture taken of him getting the Salk vaccine
4. Doc Pomus (Jerome Felder) wrote it for his wife who loved to dance.
5. Doc Pomus (who had polio) wrote 2 of their most famous songs: "This Magic Moment" and "Hushabye"
6. Francis Ford Coppola
7. Yes, several including Wilma Rudolph and Tenley Albright
8. Itzhak Perlman
9. Margarete Steiff, the German seamstress who made the famous bears, had polio.
10. Paul Winchell (he was also the voice of Tigger)
11. Neil Young, Joni Mitchell, Paul Martin...
12. Cathy Rigby
13. Helen Hayes, who worked with National Foundation for Infantile Paralysis
14. Olympia Dukakis
15. Both their dads had polio.
16. John Nordstrom's wife Dick Francis' wife Mary (who is believed to have written or contributed highly to many of his books until her death in 2000)
17. Sir Walter Scott
18. 39 years old
19. Claudius (10 BC-54 AD)

Medicare Change

Power Wheelchair Rental – Frequently Asked Questions

Effective for items provided on or after January 1, 2011, standard power wheelchairs (K0813 – K0831, K0898) must be furnished on a monthly rental basis like other capped rental durable medical equipment (DME). The following are questions and answers from suppliers regarding application of the Power Mobility Devices medical policy and CMS payment policy rules to rented power wheelchairs.

Q1. When standard power wheelchairs (PWCs) are provided on a rental basis, can they be covered for short term indications?

No. The change in the payment policy status for power wheelchair does not change the policy statement that PWCs are not covered for patients with short term, reversible conditions.

Q2. How will the "look back" period affect the review of PWCs?

There is a general policy that coverage of items that are provided on an ongoing basis, including rented DME, is dependent on there being continued need for the item and

continued use by the beneficiary. CMS and the DME MACs have not published any information regarding the look back period.

Q3. A PWC is being rented and the beneficiary goes into a hospital and nursing home for an extended stay. The supplier elects to pick up the wheelchair. When the beneficiary is ready to go back home, would there be a problem with providing a different model wheelchair within the same HCPCS code?

If the supplier chooses to deliver a different model of PWC within the same code, a new detailed product description must be obtained. A new face-to-face (FTF) examination or 7-element order is not needed.

Q4. If a patient who is renting a PWC moves, is a new in-home assessment required?

No

Q5. If a patient with a PWC moves and their new home will no longer accommodate the PWC that they have, will Medicare pay for a new PWC?

No. Medicare covers a replacement only if an item is lost, stolen, irreparably damaged, or reaches the 5 year reasonable useful lifetime. Medicare covers a different item only if there is a change in the beneficiary's medical condition.

Q6. If a patient who is renting a PWC goes into a hospital/nursing home for an extended time and the supplier picks up the wheelchair and the beneficiary is discharged to home, would a new capped rental period start and what documentation would be required?

Standard capped rental rules for beginning a new rental period will apply to power wheelchairs. That policy states that a new capped rental period will begin only if there has been a break in medical necessity of at least 60 days plus the days remaining in the last paid rental month.

In the situation that is described, "medical necessity" would continue while the patient was in a facility.

If the patient is receiving the same type of PWC (same code) on discharge that they previously had, then the rental period resumes where it left off and no additional documentation is needed (other than a new detailed product description if the make/model of the wheelchair has changed).

If the patient needs a different type of PWC on discharge because of a change in their medical condition, all the requirements for a new PWC must be met (i.e., FTF exam, 7-element order, etc.).

Q7. If, during a capped rental period, a PWC is lost, stolen, or irreparably damaged and a new PWC is provided, does a new CR period start?

Yes. Replacement of power wheelchairs will follow the same rules as any other rented DME item.

Q8. Is there any situation in which a supplier can be paid for repair to a PWC during a capped period – e.g., if the supplier has information to indicate that the repair is required due to "malicious damage" or "culpable neglect" by the beneficiary?

There can be no payment for the repair of rented items under any circumstances. Reim-

bursement for repairs is included in the rental payments.

If the supplier believes that a wheelchair repair is required because of malicious damage or culpable neglect by the beneficiary, the supplier can present the information to the DME MAC for investigation.

If the DME MAC, in consultation with the CMS, agrees that the beneficiary is responsible for the damage, the supplier can charge the beneficiary.

*Information provided by
CIGNA Government Services*

Many of us suffer with the uncomfortable sensation of feeling cold. The foremost polio physicians offer a clear explanation for why this happens. The good news is that we can make lifestyle changes to remediate this troubling post-polio problem.

Linda Wheeler Donahue, Professor Emeritus of Humanities, is a polio survivor, a disability activist, writer, and speaker. She is President of The Polio Outreach of Connecticut and is a frequent presenter at conferences, focusing on the social/emotional complexities of disability. Linda welcomes feedback at LinOnnLine@aol.com.



2011 update of Members and Dues

Name: _____

Address: _____

Phone: _____ Cell: _____

E-mail: _____

Emergency Family Member Contact with

phone: _____



Dues: \$20.00 Payable to: First Coast Post Polio Support Group

13119 Blackhawk Trail Ct

Jacksonville, FL 32225

- * Please send this back with your check for updating our 2011 records.
- This money helps support our mailing and website. **Your payment is tax detectable!**
- For those of you who have already paid your 2011 dues please disregard this notice.



First Coast Post Polio Support Group

13119 Blackhawk Trail Ct.
Jacksonville, FL 32225

We're on the web!

Firstcoastpostpolio@yahoo.com



**Printed Matter for the
Blind and Handicapped
Postal manual Part 138**

Officers 2010

- President: Jim Powell
- Vice President: Janice Askwith
- 2nd VP & Newsletter Editor:
Frances Powell
- Secretary: Sheila Kilgore
- Treasurer: Phyllis Moss
- Sunshine Chair: Sue Massey

Board Members

- Carolyn Jones
- Dr. Stuart Caplin
- Eulie Nahm



Please call if you are not the person to whom this is addressed, please call 904-333-3457

February 26th meeting

10 am to Noon

at Golden Corral on Southside Blvd

Come early to join us for breakfast or stay after for lunch.

"Answers to Your Questions"

Please submit PPS related questions to Jim in advance so they can be researched for the best possible answer. If you have a question there will likely be others with the same question. The only dumb question is the one that isn't asked! Please email, mail, fax or phone your questions or topics of interest to Jim at:

Email: Jimpowell_2@yahoo.com

Phone: 904-396-1238

Fax: 904-396-4447

Mail: 3627 Mimosa Dr., Jacksonville, FL 32207

April 2nd meeting

12 – 2 pm

at Piccadilly on Monument Rd, adjacent to Regency Square Mall.

The restaurant staff will help anyone who needs their tray carried. We will eat at noon and the 25 minute program will begin at 12:30.

Guest Speaker: *Karen Ansell, President Secure Choices, Inc.*

"The 2011 Changes in Medicare and Other Retirement Issues"

This will be an informative time of learning about how these new rules and regulations will affect Medicare coverage so we can be better informed on how to use these benefits. Ms. Ansell will **not** be soliciting business at our meeting, but rather presenting an informational public service to help us navigate the system.

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.