

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

February - March 2006

Carol T. Ranelli, Editor

February 4th Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

The speakers for the PPS members will be Sherri Pearson, Occupational Therapist and Carissa Bennett, Physical Therapist with Sheltering Arms.

Dave VanAken will conduct a "PPS Partners" session with another Occupational Therapist. Both groups will discuss **"Making Demands on Our Caregivers"**.

At the end of each session, we will have a joint discussion of both sides.

This proves to be an informative meeting for all those who attend.

March 4th Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

Our speaker will be Paul Izzo, an attorney with Thompson & McMullen law firm.

Mr. Izzo will discuss **"Wills and Living Wills – Know the Difference"**.

There will be time for questions after his presentation.

Mark Your Calendars for the 2006 Fall Retreat On September 22nd – 24th

At the Holiday Inn Express Hotel & Suites in Ashland, VA.

We will have a final cost and idea of programs in the next issue of

Polio Deja View. Everyone will have a beautifully equipped suite, all meals, use of the swimming pool, conference room and lounge area.

The hotel is located right off Rt. 95 for convenient access for everyone.

Please make plans to join us for a fun weekend.

Any future dues and donations to our support group should be made out to "Central Virginia Post-Polio Support Group" or simply "CVPPSG" and mailed to our Treasurer, Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831.

Mid-Months Lunches

Wednesday, February 15th, 11:15 at The Cheesecake Factory at Short Pump Town Centre, 11800 West Broad Street in Short Pump.

We must be there before 11:30 to make a reservation.

Call Bev Lordi by Monday, Feb. 13th with your reservation.

Wednesday, March 15th, 11:30 at Trak's Greek & Italian Restaurant 9115 Quioccasin Rd. just west of Regency Square Shopping Center.

Call Bev Lordi by Monday, March 13th with your reservation.

Bev Lordi @ 746-3864

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, 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 psychophysiological, noticed that the skin on the affected arm of his first polio patient was cold to the touch. This suggested a problem of blood 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 multiple 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 causing 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.

Remember, your entire body must be insulated in order to stay warm, 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.

About the Author:

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. Professor Donahue's essays on subjects of positive living, disability dignity, and increasing happiness through conscious choices have been published worldwide. Linda welcomes feedback at LinOnnLine@aol.com.

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.

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.

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?

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.

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The following article was presented at the Post-Polio Health International's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living, June 2-4, 2005.

HOW SELF ASSESSMENT CAN HELP YOU OBTAIN BETTER CARE FROM HEALTH PROFESSIONALS

Mary Kinane, BA, PGCE, Chair, Hilary Hallam, FIST, Founder, Secretary and Newsletter Editor
Denise Carlyle, BA, MA, PhD, LRAM, Treasurer, Lincolnshire Post-Polio Network, U.K.

The most reported problem to our Network, not only from the U.K., but from around the world, is that the assessment that has taken place did not find evidence of the symptoms / level of symptoms being reported.

Polio Survivors often spend months, sometimes years, putting off going to a doctor to find out why they are experiencing pain, fatigue and functional decline. To then be told that there is nothing or little wrong with them causes considerable stress. Each negative appointment causes frustration, anger, and more stress that makes our medical condition worse.

Again and again, through lack of knowledge about polio, they tell us that they had what must have been a mild case of polio because they recovered so well and managed so much in their lives. Regardless of level of recovery they are so proud of their achievements. Then comes the but ... But, after a fall, an operation, an accident, a period of huge stress, something changed because from then on the harder they pushed the worse they got. Their lives are changing so much why are they having such a hard time getting medical help?

So why is this happening? We have highlighted eight possible reasons that we believe should be taken into consideration.

1. Not enough facts about Polio and its late effects are being taught in Medical Schools.
2. Interpretation of facts in medical articles.
3. Diagnoses were made using test results, physical examination and clinical observation of the weakest part of the body.
4. The extent of recovery from Polio is often not realized.
5. There are no tests for PPS. It is a diagnosis of exclusion.
6. The way we present our symptoms.
7. The way questions are asked, and the way we answer.
8. Manual Muscle Testing – validity and reliability.

We will then show how self assessment can provide us with more information so that we can answer questions more accurately and ensure that the picture in the health professionals mind matches ours.

We do ourselves no favors when asked, "Can you get up a flight of stairs?" In just saying "Yes", without adding, "but I go up one step at a time pulling myself up each stair with my arms, and for the last year or so have had to stop halfway and rest, but five years ago I was able to walk up and down normally and carry items."

Polio survivors are notorious for being strong willed, determined and not requiring help to do even quite heavy tasks. Unfortunately we are also highly skilled in not 'seeing' or wanting to 'see' that we now need some help, human and/or aids and assistive devices. We expected that we might have to change the way we lived our lives when we got old – about 90 – but not in our 40's, 50's and 60's.

Polio survivors have a variety of muscle weaknesses in a variety of areas. There is no set pattern – a nightmare for health professionals. We will demonstrate a few of the changes that we have noticed in how we go about our lives. If the way you do an action of daily living has changed in the last few years then there has to be a reason or a number of reasons for this.

We know that making notes is a good idea so we don't forget anything, but arriving with pages of them and articles off the internet is more likely to set up a barrier than be helpful.

Appointment times are limited – there will probably not be time to discuss more than a couple of issues. To help you remember dates and medical facts it is an excellent idea to make up a large file on yourself containing anything you consider relevant, including newspaper items, certificates, a couple of photographs, covering:

1. Medical History
2. Work History
3. Physical Ability before current problems (include sports, exercise, hobbies, crafts, housework, etc).
4. Problems with diagnosis, assessment, treatment, employer's understanding of your new problem, welfare applications, etc.
5. Current problems.

We can be better prepared if we write notes on what we want to discuss at the appointment. We can look at the file and take out the relevant information. Now look at your notes again as if you were the health professional at this appointment. If you were doing the report at the end of this appointment, what facts would you write down.

Health professionals have a variety of ways of running their appointments and we cannot dictate how the appointment will go. We can, however, set the scene with a "Good morning, Dr. X, thank you for seeing me about my" "I have made a few notes so that I don't forget anything and thought you might like a copy for your records."

Remember the health professional is seeing you as you are now, they do not know what you were capable of five, ten, twenty or more years ago. They may think Polio, and go back to the short lecture they were given at College and assume you have been as you are now since your polio.

What is important is the change in how you do actions of daily living. Why have you changed the way you do this action?

As an aide to writing your own report we provide a three columned sheet of actions of daily living. (See page further in newsletter.) We appreciate there is little room in each block to write down more than a few words. You can either write up the information on a separate sheet of paper, making short notes that will fit, or use this as a basis for your own chart. IF you can show a series of changes for some actions, then do a chart just for them with added columns. Then grade them, starting with the action that shows the highest level of change. The two or three actions that show the biggest change are the ones to demonstrate.

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The Path to Independence

The Central Virginia Post-Polio Support Group (CVPPSG) was founded in the Summer of 1986 and later this year we will celebrate our twentieth anniversary. For the last two decades we have been fortunate to have had an association with Easter Seals Virginia. Easter Seals Virginia has safeguarded our funds under the umbrella of a charitable organization. We are grateful for all of this organization's help in the past. Also we have enjoyed many fine retreats at Camp Easter Seal East. As an organization we have grown, persevered and passed through our adolescence. Early last year the leadership of the CVPPSG made the decision to seek an independent non-profit status. This decision was approved and supported by the membership. We have now achieved an independent status except for a few final small steps. Our President Carol Kennedy has done an immeasurable amount of work to reach this goal. Carol Ranelli and Linda VanAken also devoted an immense amount of time in achieving this goal. Now the CVPPSG can raise funds as an independent non-profit charity and we can pay our debts and make other expenditures in a timely fashion. What follows is a log of the events in 2005 leading up to our independent non-profit status.

- Feb 9 Special board meeting called to discuss the application and the need to move expediently.
- Feb 23 First meeting of the bylaws committee to revise the by laws to meet IRS requirements, Filled out and mailed application for Employer Identification Number. The EIN number was received two weeks later
- Mar 23 Bylaws revisions presented to the board began a draft copy of the application.
- Mar 29 Second bylaws committee meeting
- Apr 2 Bylaws revisions presented to the membership
- May 7 Bylaws revisions voted on and approved by the membership
- May 11 Bylaws committee meeting to fill out final application to the IRS. Application overnighted to the IRS.
- June 13 We were notified that the IRS had received our application.
- July 14 We opened a bank account in our name.
- July 31 Telephone call from the IRS requesting copies of our Articles of Incorporation. They also needed to be amended to include wording required by the IRS. (We had included a copy of the Certificate but they needed certified copies of the original and amendments from the State Corporation Commission)
- Aug 6 Amendments approved by the membership at the regular monthly meeting.
- Aug 8 Certified copies of original Articles and Amendments overnighted to the IRS
- Sept 19 We received the Letter of Determination from the IRS granting us tax exemption under Section 501(c)(3) if the Internal Revenue Code

The following may not be final yet, but soon will be if not already...

- Oct 10 Carol Kennedy, Carol Ranelli and Linda VanAken met to fill out the application to register as a charity with the Department of Agriculture and Consumer Affairs.

This will allow us to legally solicit money in Virginia and is a requirement to be listed with United Way

Oct 14 Application mailed to the Dept of Consumer Affairs

Nov 1 Acknowledgment from Dept of Consumer Affairs that they had received our application.

Dec 20 Telephone call to Dept of Consumer Affairs. Hopefully our application will be approved in 4-6 weeks.

We have also applied to the State for exemption from Virginia state tax but we have to be registered with the Dept of Consumer Affairs first.

Thus, we are now a fully mature organization. We have plowed through our rambunctious toddler stage, survived our own adolescence and now we are free, independent and mature. Again, congratulations should be given to our President Carol Kennedy, our Treasurer Linda VanAken and our newsletter editor Carol Ranelli.