

POLIO DEJA VIEW

December - January 2009

www.cvppsg.org



*A Newsletter for the
Central Virginia Post-
Polio
Support Group*

*Mary Ann Haske,
Editor*

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**Mark your
calendars for:**
• **December 3,**
our Christmas Luncheon

December 5th Meeting Annual Christmas Luncheon

The Luncheon will be held on Saturday the 5th of December at the Grape Vine Restaurant, 11055 Three Chopt Rd., Richmond, VA 23233. The phone number is 804-440-9100.

Time: 12:00 Noon – 3:00 PM

We will order from the menu and individual checks will be given.
Our Post-Polio Group is pleased to announce that it is paying \$10.00 of each meal.

Please respond no later than November 25, 2009 (the day before Thanksgiving)
to make your reservation.

Call Bev Lordi 569-4232 or Barbara Bancroft 204-1688

Remember to bring a gift suitable for a man or woman, costing between \$10 and \$15. We will conduct our traditional Chinese Auction again this year. Please plan on joining us for this annual holiday social. Bev or Barbara will be happy to answer questions about the luncheon, restaurant or gift exchange. We hope to see you at this lively, festive occasion.

(Directions: Take I 64 West from Richmond. Exit at Exit 180 A which is Gaskins Road South (this is the 2nd Gaskins Rd. Exit). Turn right at the first traffic light which is Three Chopt Rd. Drive 9/10 of a mile on Three Chopt Rd. to the traffic light and the restaurant is on your left. Turn left on Church Rd. to enter the parking lot.

(Parking: There is ample parking in the lot. There is a ramp from the parking lot to the sidewalk at the left corner of the front of the building. You can enter the building from either the front or the back door.

January 9th Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond
*Remember to come at 1:30 for refreshments and social time!
Cookies provided – bring your own beverage.*

Damien Howell MS, PT, OCS will be our guest speaker. The topic of the presentation and discussion is "Who are you going to call – Choosing a Healthcare Professional". The discussion will include concepts of evidence based practice.

**Mid Month
Lunches**

Mid Month Lunches No Mid-Month Lunch in December!

Thursday, January 21, 2010

We will have lunch at 11:30 at P.F. Chang's in Stony Point Fashion Park

Call Bev Lordi by January 18th at 569-4232 for a reservation

Did you know?...

...Rx Information from Jenny

PROBIOTICS – THE BOTTOM LINE

(This is a follow-up to last edition's probiotics article)

Probiotic supplements have gained popularity over the past few years and are often used to promote, improve, and maintain digestion. They also have been used to prevent or decrease the recurrence of vaginal yeast infections and treat conditions that may change normal intestinal flora (ex: antibiotic-associated, traveler's, and infectious diarrhea), inflammatory and functional bowel conditions (colitis), and to shorten the duration of an intestinal infection.

For healthy people, routine intake of probiotics to maintain a healthy digestive system (or strengthen the immune system) is unnecessary. For specific indications, such as to prevent antibiotic-associated diarrhea, probiotics may be useful. Probiotics only temporarily colonize the intestine. For chronic conditions (ex: irritable bowel), it is likely that probiotics must be taken for a long period of time to be effective.

Probiotics are regulated as dietary supplements and foods, which raises concerns about quality. *Culturelle* and *Florastor* are the best studied. These products are the best choices for preventing diarrhea caused by antibiotics. You can also try these products for prevention of traveler's diarrhea. Start taking them a few days before travel, and continue them for the duration of your trip. Yogurt is a source of probiotics, but not all yogurts contain the right kinds or organisms. Choose a product with the National Yogurt Association's "Live and Active Cultures" seal on the label (ex: *DanActive* by Dannon, *Yoplait*). You will need to eat about 8 oz. twice daily to prevent antibiotic-associated diarrhea. Expiration dates are particularly important for probiotic products. Some probiotic products, especially beverages and dairy products, have short shelf-lives. Carefully follow the package instructions regarding storage.

Hope this helps clarify some confusion about probiotics.

Call me if you have any questions!

Jenny Aveson (804) 730-9498



Paralysis and Christmas

Various forms of paralysis have plagued humans since the origins of recorded history. Earlier this year the Christopher and Dana Reeve Foundation published a study involving statistics of the different causes of paralysis in the United States. Paralysis is usually caused by vascular disease, trauma, birth defects, diseases of the central nervous system (brain and spinal cord), which include infectious diseases such as polio. The published study revealed that 5.6 million Americans have some form of paralysis and about one quarter are spinal cord injuries. The Foundation funded the study but did not run or design it. The goal was to get accurate data, improve fund raising and increase services. The lead investigator was Anthony Cahill who is the director of the University of New Mexico School of Medicine's division of disability and health policy. The findings are based on a phone survey on 33,000 households. 7% of those with paralysis from an accident or an injury occurred in the military. Two thirds had average household incomes of less than \$30,000.

See the chart and the rest of the story on page 4

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If you would like to talk with someone about Post-Polio Syndrome, you are welcome to contact the above members. If you send an e-mail, please refer to APPS@ in the subject heading.

We would love to have any of our members write an article for our newsletter. It can be about your lifestyle adjustments, comments on post-polio or any subject, humorous or serious, that we may all benefit from.

Please send articles for or comments about our newsletter, as well as changes, additions or deletions for the newsletter mailing list to:

Mary Ann Haske, Newsletter Editor
2956 Hathaway Rd, Richmond, VA 23225
or contact me at: (804) 323-9453 or mahaske@hotmail.com

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval of the Central Virginia Post Polio Support Group.

Please note: Our articles may be used exactly as written provided credit is given for each article used.



Paralysis and Christmas

Cont'd from page 3

Causes of paralysis

Stroke	1,608,000
Spinal cord injury	1,275,000
Multiple Sclerosis	939,000
Cerebral Palsy	412,000
Post Polio Syndrome	272,000
Traumatic Brain Injury	242,000
Neurofibromatosis	212,000
Unspecific birth defect	110,000

Once again we find ourselves in the holiday season. Those of us who celebrate the Christmas season in our churches find this time of year to be a time of family gatherings, exchanging gifts, inspirational seasonal music and the reading of Christmas Bible stories. The Bible has lots of stories involving various physical disabilities including skin diseases, seizures, blindness, deafness and paralysis. In the gospels there are five events involving people that are probably paralyzed for one reason or another. Jesus is involved in helping these people in these five events or healings. They can be found in:



Mark 2:1-12
 Mark 3:1-6
 Luke 13:10-17
 Matthew 8:5-13
 John 5:1-9

This story in the gospel of John has some interesting clues. The story is recorded below:

After this, Jesus went to Jerusalem for a religious festival. Near the Sheep Gate in Jerusalem there is a pool with five porches; in

Hebrew it is called Bethzatha. A large crowd of sick people were lying on the porches—the blind, the lame, and the paralyzed. A man was there who had been sick for thirty-eight years Jesus saw him lying there, and he knew that the man had been sick for such a long time; so he asked him, “Do you want to get well?” The sick man answered, “Sir, I don’t have anyone here to put me in the pool when the water is stirred up; while I am trying to get in, somebody else gets there first.” Jesus said to him, “Get up, pick up your mat, and walk.” Immediately the man got well; he picked up his mat and started walking. The day this happened was a Sabbath.

First, the types of sick people which are emphasized are the blind, the lame and the paralyzed. The man who had been sick for thirty-eight years could easily be one of the paralyzed. He obviously is not able to move with any speed, has a mat and he does not have any help. One possibility for the cause of his paralysis could be polio. Also, after thirty-eight years this man could have Post Polio Syndrome. This is speculative because we know very little about this man. One could speculate that this man’s disorder originated from childhood. If the original disorder was polio, perhaps this man managed to survive or compensate as so many of us have done for thirty or forty years until PPS began to unmercifully slow us down. Now, after thirty-eight years this man needs to lie down a lot or can no longer walk or get around on his own. He is slow in motion and cannot get into the pool because he cannot move fast enough.

Does the above description seem similar to some of us? We have gotten slower, weaker, need to lie down a lot and everyone else of our generation is moving with comparative ease. I don’t believe any of us expect a man with healing power to walk up to us and tell us to get up, pick up our mat (or brace, scooter, wheelchair) and walk. However, we do have folks who will help us get into the pool and feel better. At this time of the year we probably should be grateful that medical science and other healthcare professionals can help us and provide a better quality of life for all of us. Our support group is also a major help in its efforts to provide shared experiences, sound advice, educational opportunities, advocacy, mutual support and fun. One of our most enjoyable social events is our holiday party which is scheduled for December 5. We meet on the Sabbath for some and the day before the Sabbath for others.

Follow-Up on “From Henry’s Desk...” (Oct/Nov 2009)

Have you written your polio story? Are you wondering what to do with it now that you have done all that work? Here are a few suggestions. Share it with your family. Send a copy to me, the editor of the newsletter, and I can use excerpts for a future article. We might have a program some month in which we share our writings. Finally, The Salk Institute has a new website and one can post one’s story in writing or video on it. The articles on the website are interesting. <http://www.poliotoday.org> Don’t be shy. Get to work and share your story.

Finding causes of and managing fatigue in PPS

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*Presented at Post-Polio Health International's 10th International Conference: Living with Polio in the 21st Century (April 2009).
(www.post-polio.org)*

Summary

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However fatigue is not very specific and a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of the two fatigue sessions.

In Session I the focus will be on the magnitude of the problem of fatigue in PPS, the different forms of fatigue and the factors playing a role in fatigue in PPS. In Session II the focus will be on the assessment and treatment of fatigue in clinical practice and what people with PPS can do to reduce fatigue.

Contents

Session I on Friday 11.15 - 12.30 AM covers the following topics:

- the problem of fatigue in PPS; prevalence and severity
- types and definitions of fatigue in PPS
- the mechanisms and factors contributing to fatigue in PPS

Session II on Friday 2.45 - 4.00 PM covers the following topics:

- how to assess fatigue in PPS
- how to treat fatigue in PPS
- energy conservation techniques

Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as 'a persistent, subjective sense of tiredness that interferes with usual functioning'. This refers to the general feeling of fatigue, however local muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: 'new muscle weakness or abnormal muscle fatigability'.

In post-polio syndrome fatigue is most frequently related to physical factors.

Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscle to generate force. Several factors have been identified that may play a role in this:

- I - Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio - the precise mechanism is not understood;
- II - Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recovery phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle;
- III - Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in strength have to work at an increasing level of their maximal capacity and this

Finding causes of and managing fatigue in PPS

will be inversely related to the duration physical activities can be maintained.

IV - A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported.

V - Especially less and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence they are less loadable.

General fatigue

General fatigue, the feeling of being tired, may have several causes.

I - People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in case of two affected legs.

II - Brain alterations due to polio virus damage have been suggested as a possible cause of general fatigue.

III - Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.

IV - Deconditioning of the cardio respiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary life style.

V - Psychological factors, such as 'giving up the fight', social factors related to the persons life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

Other causes of fatigue

It is very important to rule out other causes of fatigue. Of course the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, depression need to be mentioned.

Factors associated with fatigue in PPS

In a recent study, so far unpublished data, several of the above mentioned factors were found to be associated with fatigue.

Lower physical functioning, more pain, sleep problems, lower well being and an active coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

Pharmacological treatment

No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT's) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that no drug was found to be effective.

Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, Neurology 2008 confirming the negative results reported earlier by Chan KM in Muscle and Nerve in 2006.

Intravenous Immunoglobulines (IvIg) have been studied in two trails by Borg K, in Lancet Neurology in 2006 and by Farbu E, European Journal of Neurology in 2007. The study by Borg found effect for muscle strength and for 'vitality'. The study by Farbu found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in Neurology in 1999 and one study by Horemans HL in Journal of Neurology Neurosurgery and Psychiatry in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsmore S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

Cont'd on page 7

Finding causes of and managing fatigue in PPS

Assessment of and Managing fatigue in individuals with PPS

Assessment

I Medical evaluation

It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.

II What is meant by fatigue?

The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest.

III Are other contributing factors present?

Consideration has to be given to sleep quality, mood disorders and coping styles.

IV What is the activity pattern?

The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on.

V What is the social system?

How is the person's social environment, does he or she have sufficient support and understanding at home and work.

VI What are the own perceptions?

How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on).

VII What are the physical capacities?

What is somebody able to do given the polio residuals and co-morbidities. What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individuals various activities.

VIII Conclusion

Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

Assessment tools

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning. Diaries to inventory daily life activity are extremely useful to gain insight in what someone life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report. Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

Management

The first important thing is that the person obtains insight in the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cognitions. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called 'over achievers' who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance if they think that this may damage muscles, and they may very well be mainly fatigued due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue energy conservation skills are often to be learned. This may be done individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians.

Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

SUMMARY OF THE TENTH ANNUAL FALL RETREAT

Isn't there a saying about great gifts come in small packages? I think that would describe the weekend of our 10th Annual Fall Retreat. At first I was concerned that we did not have the large number of attendees that we usually have. I soon realized that the smaller number made it easier to move around the room and mingle with the people freely. I usually get in a spot and don't move because I have to plow through groups with my power chair. Therefore, Friday evening was a time where there was great fellowship. I spent time with people I did not know and found out how delightful they were. Dinner flowed because the lines were not too long. Almost everyone played BINGO after dinner. (One slight note, the group that usually burned the mid-night oil went to retire about 9:30 just like the rest of us. That fact really hit home and made many of us realize that, as time passes, we won't, or don't, have the same stamina we once had.)

Our original Saturday morning speaker had cancelled due to her mother's illness. Although this was a disappointment for us, Frances Thomas found an excellent substitute, Sumaiya Mamdani with the Va. Department of Health. She spoke about the Swine Flu, H1N1. She compared the symptoms of the seasonal flu and the swine flu. They are similar but the H1N1 may have gastrointestinal symptoms. The age groups are also different. The seasonal flu is harder on children from newborn to 4 years of age and the

elderly. The H1N1 virus is harder on those ages 5 – 24. Those over 64 years seem to have immunity to this virus. One should always practice good hygiene when it comes to coughing and colds. One should certainly get medical advice if there is rapid breathing, return of fever, or the person seems very ill. She did mention that one should stay home two full days after the fever breaks. (Isn't that what we used to do back in the 40's?) The speaker encouraged everyone to get their seasonal flu shot immediately. She also encouraged everyone to consider getting the H1N1 vaccine. (It will be free but there may be a fee for administration.) There is no way I can recount all that she had to say about the vaccine but you can go to www.cdc.gov and then hit the H1N1 Flu link and get the most up to date information. (I know, some of you don't have computers but your library will help you to access this information!) One of the interesting things about the speaker is that she is new at the VA Dept. of Health but she was so at ease giving the talk. She was personable and professional. The talk was informative and timely.

Another good thing about this retreat was the amount of down time or breaks that we had. I did not feel as exhausted as I usually do. There were positive comments about the ability to catch a nap and not miss activities.

Another plus was the food. Our new caterer was not only good, but she

went the extra distance to furnish rather impressive appetizers and great desserts. She also met special dietary needs.

The afternoon speaker also was unable to attend but she provided a great substitute. Dave Gau and Kim Holcomb gave a talk with the title of ACTT. In order to be an effective member of society we need to apply the principle of Attitude, Commitment, Teamwork and Trust. The exercises we did were a lot of fun and people continued to use these principle through the rest of the retreat. It is hard to put an afternoon workshop into a paragraph. Let's just say that it was a positive presentation.

The evening ended with a session of OutBurst. In case you have never been to our retreat, it is a game that involves a lot of shouting out all at once. Chaos is rampant. A fun time was had by all. Again, bed time was about 9:30. Oh dear, what a change.

Sunday morning was a time for reflection and good-byes. Thank you to all who made the weekend possible.

FYI – GOLDEN ACCESS PASSPORT

I was totally unaware that the National Park Service has a Lifetime Admission Permit for those medically determined to be blind or permanently disabled until, at our retreat, Linda VanAken mentioned it. This pass seems to go by either of two names: Interagency Access Pass or Golden Access Passport. The pass is free. Accompanying passengers in a single vehicle are admitted for free also. One can obtain 50% off on cave tours and camp grounds. I knew about the pass for seniors for \$10 but I had no clue about this.

In an effort to learn more, I pulled up to the ticket booth at the Wright Brothers Monument and Museum on the Outer Banks of North Carolina. Well, they wanted me to

have proof by having a physician's statement or a disability card. I had neither. However, I pointed out my power chair and my VERY EXPENSIVE adapted van and they issued me the card. If you plan to ask for the pass, it might be a good idea to have the physician's statement.

So, if you have the pass, what can you do with it? I'll mention a few things. The Wright Brothers Museum is a given. If you are in the mood to travel, Teddy Roosevelt's home on Long Island is an interesting place to visit (one of my favorites) and FDR's home on the Hudson is also a nice outing. Since I am speaking to a primarily VA audience, I guess I'd better mention things closer to home. The Colonial National Historical

Park which includes Jamestown, Yorktown Battlefield and the Cape Henry Memorial is a National Site. George Washington's Birthplace in the Northern Neck is on the list. A tricky site is the Richmond Park Battlefield Center at the Tredegar Ironworks in Richmond. This is a two-in-one deal. The pass works for the Battlefield Center but the Ironworks is not a National Site and one would have to pay their fee. (Yes, I know, it is confusing.)

Now, if you really want to see the country, you can access the Grand Canyon, Yellowstone, etc. for free. I am very excited to have this information. All of your questions may be answered by visiting this website: <http://store.usgs.gov/pass/access.html>

Happy Traveling and Touring!

Summary of Oct. 3rd Meeting

Shawn Majete, an Elder Lawyer, Judge of General District Court and a Magician(!), spoke to our PPSG on Oct. 3rd. His lively, informative talk included information on new Virginia legislation regarding Advanced Directives (Health Care Power of Attorney.) It is important to know that, if one does not have one, the court will appoint one for you if you are unable to make your wishes known. The court would first look at appointing a spouse. That might be okay unless you and your spouse are estranged! The second in line would be the children and the majority would rule. Think of the disagreements that might occur. Third the court would appoint

parents. That can also lead to disagreements. The siblings would be next in line and that could be a donnybrook as well. If none of the above is feasible, the court would appoint a guardian such as Shawn. So, get busy and get an Advanced Directive (available on the internet) and have it **signed and witnessed**. For more information visit Shawn's website www.Majette.net, and scroll down to read more on "2009 Nifty fifty Mental Health Bills."

In Other News ...

PROGRAM CHANGE

On November 14th, Karen and Jack Wilson will speak about their trip out west. This replaces Timothy A. Powell, MPH and his talk on the swine flu.

SAVE THE DATES

- Regular Meeting, February 6, 2010
- Mid-Month Lunch, Feb. 18, 2010
- Regular Meeting, March 6, 2010
- Mid-Month Lunch, March 18, 2010

Note from the President;

Those of you who live alone or who have no one in the house able to change your smoke alarm batteries should contact your county or city Fire Marshall's office to see if they will change them for you. My county (Henrico, VA) will do so free of charge twice a year.

Carol Kennedy

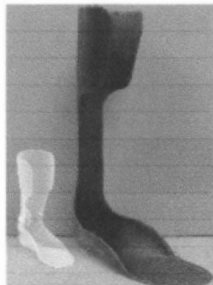
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