

# **POLIO DEJA VIEW**

**Central Virginia Post-Polio Support Group**

[www.cvppsg.org](http://www.cvppsg.org)

**December 2005 – January 2006**

*Carol T. Ranelli, Editor*

## **December 3rd Meeting**

### **Annual Christmas Lunch**

**At Joe's Inn, 6512 Mechanicsville Turnpike**

**Plan to be there at 1:00 as we only have the room reserved until 4:00**

**We will have a private room and can order off the menu so you can get whatever tempts your palate! Joe's Inn has a very extensive menu so everyone can find something they like.**

**Please respond no later than November 30th to:**

**Bev Lordi at 746-3864**

**Remember to bring a gift suitable for a man or woman, costing between \$5 and \$10. We will conduct our traditional Chinese Auction again this year. Please plan on joining us for this annual holiday social.**

## **January 7<sup>th</sup> Meeting**

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

**General Discussion**

**If you have concerns or questions about post-polio, please attend. Our group is a wealth of information on who, what, when and why.**

**Note: During the winter months, if there are questionable weather or road conditions, feel free to call an officer to check on meeting cancellation.**

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**HAPPY HOLIDAYS TO OUR MEMBERS  
AND THEIR FAMILIES**

## 2006 Retreat Up-date!!!

You will be happy to know that arrangements have been made so we can resume our annual Retreat in September, 2006. Thanks to the hard work of Frances Thomas, we have reserved space at a lovely new facility in Ashland, VA, right off Rt. 95 for the weekend of September 22-24.

Working with Emma Foster, Director of Sales, we have reserved all the handicapped rooms and 15 guest suites at the Holiday Inn Express Hotel & Suites ([www.hiexpress.com/ashlandva](http://www.hiexpress.com/ashlandva)). The hotel serves a multi-course breakfast and we have arranged to have two dinners and lunch catered by a local caterer. We will have the use of the conference rooms, heated indoor swimming pool, hot tub and exercise facility.

The suites have microwaves and refrigerators, TV, coffee makers and hair dryers. There is a sitting area separate from the bedroom. This facility opened a year ago and is beautifully decorated and maintained.

We are thrilled to offer all of this for approximately \$100 a person for the entire weekend, including all meals, (We think this will be the final price, but will know definitely by the next newsletter.)

We are looking into a speaker for Saturday morning and will hopefully know something soon.

This is the nicest Retreat setting yet and with an unbelievable price. Mrs. Foster has essentially given us free reign of the hotel and its amenities for the weekend. Please plan on joining us again this year for what always proves to be a fun weekend.

## New Ukrop's Golden Gift Program

### Introducing the New Golden Gift powered by Benevolink

Starting October 1, every time you purchase items from Ukrop's family of brands, a percentage of your spending will be donated to the nonprofits of your choice.

You'll earn automatically *all year long!*

Add your UVC cards today so your purchases will count starting in October. Once you start earning funds through your Ukrop's shopping, you will be able to give your funds to your favorite **local** charities four times a year!

If you wish to donate your Golden Gift earnings to our support group you must register your UVC card on-line ([www.benevolink.com](http://www.benevolink.com)) or at your local Ukrop's store and note that your charity is "Central Virginia Post-Polio Support Group". We have been approved as a listed charity.

Donations are made every quarter and you must designate your charity of choice every quarter.

IN MEMORIAM

It was with great sadness that our support group learned of the death of long time member, Charley Brower, on September 17<sup>th</sup> at the age of 92. Charley was our liaison with the March of Dimes and a true advocate for our group and its work, education and support for polio survivors. Charley could always be counted on to provide funds for some member who couldn't afford to attend a conference or Retreat.

Until his failing health in the past couple years prevented it, he attended most board meetings and monthly meetings. He and his lovely wife, Mary, attended most annual social events and many of us developed a wonderful friendship with them both. He will be sorely missed.

The members of the Board have established the Charley Brower Scholarship Fund for any member who can not afford dues, conference registration, the annual Retreat, etc. If you would like to contribute, please mail your check to our treasurer, Linda VanAken. 14606 Talleywood Ct, Chester, VA 23831. Please designate that it is for this fund.

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The Central Virginia Support Group wishes to thank the following individuals and companies for their generous help with our October Conference. It was a huge success and well received; we couldn't have done it without you.

Joe Thomas, Dave VanAken, Jim Wright, Helen Bunch, Dr. Courtney Goodman, CVS Pharmacy, Mark Pizzini with Lo-Maxx Design, Ride-Away, Ukrops and Williams Bakery.

Many thanks also to Dr. Mary Ann Keenan for taking time from her busy schedule to be our keynote speaker at the conference... and helping pass out lunches and cleaning up!

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At the end of September, 2005, our group received its official IRS status as a NON-PROFIT organization. We have established a non-profit bank account and will be controlling our own funds. Any future dues or donations should be made out to "Central Virginia Post-Polio Support Group or CVPPSG" and mailed to our Treasurer, Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831.

## A CLARIFICATION OF NON-PARALYTIC POLIO

By Ernest W. Johnson, MD

(Dr. Johnson is editor of the American Journal of Physical Medicine and Rehabilitation. He is a well recognized expert on Post-Polio Syndrome.)

For many years, most physicians have understood that non-paralytic is a loose clinical term implying that neither the patient nor the clinician-examiner reported functional weakness. This determination was often made without the understanding that 50% of the motor units can be lost before a manual muscle grade of four occurs. This means that many patients with acute polio were tabled non-paralytic incorrectly, but certainly in a well-meaning way.

When the polio virus is in the gastrointestinal tract of an individual and causes symptoms, the term abortive polio has been used. This is the condition that confers immunity on the individual and also prevents the carrier state. This is why the Sabin (attenuated, live poliovirus) vaccine prevents the invasion of the poliovirus into the central nervous system, but not the poliovirus from living in the gastrointestinal tract.

In those individuals whose immune systems, for whatever reason, permit the invasion of the central nervous system by the poliovirus, a population of anterior horn cells will die. The number of these cells that die will determine whether the clinician will be able to identify paralysis.

In the late 1950s, our electromyographic studies suggested that in all patients who experienced the invasion of the central nervous system by the virus, pain, meningismus, and positive spinal fluid findings revealed abnormal irritability (fibrillation and positive waves) in many muscles that were clinically "normal".

It should be absolutely understood that patients who were told that they had non-paralytic polio did, in reality, have polio which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affected other persons with post-polio syndrome.

*Reprinted from Polio Heroes of Tennessee, September 2005.*

## NO MORE EXCUSES!

A powerchair (not Manual) or scooter is not an instrument of torture. (Although a manual chair can be!) Using a powerchair or scooter **will not** make you look stupid – at least not as much as pretending you don't need one while taking pain meds and stumbling around, falling down, requiring surgery on hands, elbows, shoulders, knees, etc.

Using a powerchair or scooter **will** give you more energy because you won't be using all your energy in trying to accomplish the impossible (i.e. – looking like you don't need one). Using a powerchair or scooter **will** actually be more freeing. You will have the freedom to go where ever you want, without having to have someone chained to you to push you here and there – and then go off to look at something else that interests them and leave you stranded. (Been there, done that!)

Using a powerchair or scooter **will** relieve the strain on overtaxed shoulder muscles and joints that were never meant to be walked on in the first place, thereby eliminating much of the unnecessary surgeries which, by the way, **will not** last unless you change the way you do things. You may also find that you don't need as much or any of the pain meds.

Using a powerchair or scooter **will** show that you are winning the battle! But you need to define your battles. You already had polio. No way to change that. You are having post-polio sequelae. Another done deal. These are battles people frequently think that they need to fight against, but there is no way to win here. It's happening. Live with it. But the battle you **can** win is the battle for independence! You can be your own person again. It has been said, "Fight only the battles you can win". Living life on your own terms is possible only if you have the stamina, the balance, and the heart for it. We all have the heart for it. . . we are polio **survivors!** What we don't have are the balance and the stamina. A powerchair or scooter can help.

Do you always walk to the grocery store 5 miles away? Do you walk to work? To Church? Of course not! You use the technology available to you – a car or public transportation. Do you mix your cake batter with a spoon? Or do you use an electric mixer? These are devices that help to make our lives easier. So are powerchairs and scooters. You are not giving in. . . you're stepping up to an easier way of doing things. And Boy! Are they ever fun!

If you are thinking about it, it is probably past time to do it. And the sooner you start using a power mobility aid, the longer you might retain the ability to walk and the easier it will be on your arms and shoulders in the long run. **I wish you well.**

Reprinted from SPIRIT, PPSG, Southeastern, WI, June 2004. and Florida East Coast Post-Polio Support Group newsletter, Nov-Dec, 2005.

**FECPPSG Editor's Note:-** As most of you know, I use a scooter – in fact, I'm on my third Electric Mobility Rascal. Whenever I see a polio (or other mobility impaired individual) that should be in a powerchair or scooter I cringe. If I question them as to why they're not using a powerchair or scooter, they're answer is usually that they don't need it – they aren't that bad. Hopefully, this article will help some realize that using such an aid will open many doors that have been closed to them – such as going to the mall, going to theme parks, taking a "walk" with the grandchildren.... Please, if you need a powerchair or scooter, look into getting one.

From Henry's Desk:

## Our God Our Help in Ages Past

On the morning of Sunday, August 10, 1941, British Prime Minister Winston Churchill and President Franklin Roosevelt met for a combined religious service on the afterdeck of the British ship HMS Prince of Wales. England had been at war with Germany for two years and the English people had endured considerable bombing of their cities. The United States would not enter World War II until the Pearl Harbor attack four months later. However, Roosevelt and Churchill had been in correspondence for

some time and England greatly depended on Roosevelt and the USA for supplies and weapons with the likelihood of the USA becoming an ally of Great Britain.

This secret conference between Churchill and Roosevelt occurred off the coast of Newfoundland in Placentia Bay at Argentia Harbor. Roosevelt arrived on the USS Augusta on August 8 and the two men met on Saturday, August 9 on the Augusta. Their meetings over the next few days brought about what later was called the "Atlantic Charter." The sea voyage had involved some risk for both men, especially Churchill. German submarines were active in the North Atlantic, but both men made their respective trips safely to this first summit meeting between Churchill and Roosevelt. The Prince of Wales and many of its crew would perish on December 10, 1941. The Prince of Wales was sunk by Japanese bombers near Singapore with a loss of 325 men who had been among the ship's crew on August 10, 1941.

Photo # NH 67209 Leaders on board HMS Prince of Wales during Atlantic Charter conference, 1941



The events of Sunday, August 10, 1941 deserve closer attention. A religious service combining the crews of the Prince of Wales and the Augusta was held with Churchill and Roosevelt present. Roosevelt had to make the transfer from the Augusta to the Prince of Wales and then walk a considerable distance to the afterdeck of the Prince of Wales. Roosevelt, the polio survivor, walked in his braces awkwardly, but with great dignity using his son's arm to maintain his balance. The two men sat side by side under a quadruple turret of fourteen inch guns.

There were three hymns sung during the service. Churchill selected "Our God Our Help in Ages Past" and "Onward Christian Soldiers." Roosevelt selected the Navy Hymn, "Eternal Father, Strong to Save." Neither man knew exactly what the future might be for the free world. However, both men sought the inspiration of God. Roosevelt was an Episcopalian and Churchill referred to himself as a "buttress" rather than a "pillar" of the Church of England. Years later Churchill stated regarding this service, "Every word seemed to stir the heart. It was a great hour to live."

After the service Roosevelt was given a tour of the Prince of Wales "in his chair" and he also presented each sailor of the Prince of Wales with a personal gift of fruit, cheese, cigarettes and other items that were scarce in Great Britain. Both men would carry on a close relationship throughout the war until Roosevelt's death in 1945.

Isaac Watts (1674 – 1748) was the writer of many hymns including "Our God Our Help in Ages Past." He was the oldest of nine children and the son of a school master. He had rather delicate health most of his life and was considered an invalid by his mid thirties. He was a clergyman as long as his health permitted, but early in his adult life he began writing poetry and hymns. Any older or even modern day hymn book includes several of his hymns. His hymns have been a lasting gift to the church for over three centuries.

"Our God Our Help in Ages Past" is a paraphrase of Psalm 90. Watts studied the Psalms and was a great admirer of the Psalms. We are approaching the Christmas season once again. Sometime during this season many of us will sing the hymn "Joy to the World," which is a Watts hymn.

For many of us who have lived with the residual effects of polio and now for those of us who are living with Post-Polio Syndrome, medical science and even alternative health care approaches have limitations in improving our quality of life. We have learned a lot about what we should not do to avoid an intensification of the symptoms of PPS and many of us have found compensatory ways to improve our quality of life.

Beyond the knowledge of medical science and the support of our wonderful support group, I search for "our help in ages past." Many of you may also search for meaning in realms beyond polio and the struggles of daily living. A hymn that has inspired many of our ancestors and has as much meaning for us as anyone is "Our God Our Help in Ages Past. There are six verses to this hymn. I will end this short missive with the words of three of those verses:

Our God, our help in ages past,  
Our hope for years to come,  
Our shelter from the stormy blast,  
And our eternal home.

A thousand ages in thy sight  
Are like an evening gone,  
Short as the watch that ends the night  
Before the rising sun.

Our God, our help in ages past,  
Our hope for years to come,  
Be thou our guard while troubles last,  
And our eternal home.

#### References

1. Black, Conrad: Franklin Delano Roosevelt, Champion of Freedom: published by Public Affairs in the United States, 2003, pp 650 - 653.
2. <http://www.wholesomewords.org/biography/biorpwatts.html>

## STATINS: Good for Heart, Bad for Joints?

If you are taking a cholesterol-lowering drug, chances are your heart may be protected, but your hip joint may not be. A recent study shows that the statin drugs, a class that includes Lipitor, Pravachol and Zocor, may nearly double the risk of developing hip osteoarthritis (OA) in women older than 65.

In the study of 5,674 women by researchers at the University of California in San Francisco, 745 women showed X-ray evidence of OA. After eight years, the researchers found a 92% increase in the risk of developing hip OA in the women who had been taking statin drugs. Of women already had OA, however, the statin drugs were not associated with making the disease worse.

If lifestyle modifications, such as eating right and getting regular exercise, didn't succeed in lowering lipid levels, statin medications are the first-line drug of choice for this purpose, but they are not the only choice, says John H. Stone, MD, associate professor medicine, division of rheumatology and director of the Johns Hopkins Vasculitis Center at Johns Hopkins University School of Medicine in Baltimore.

"Fibrate drugs, such as gemfibrozil (Lopid), can boost "good" high-density lipoprotein (HDL) cholesterol and improve the overall cholesterol ratio. The drug ezetimibe (Zetia) keeps the body from absorbing cholesterol, and the prescription forms of niacin, a B vitamin, can decrease "bad" low-density lipoprotein (LDL) cholesterol, increase HDL and decrease triglycerides," says Dr. Stone.

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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:

Carol T. Ranelli, Newsletter Editor, 12040 Bromwich Drive Richmond, VA 23236  
or contact me at: (804) 794-7359 or Goldlady13@aol.com

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