

POLIO DEJA VIEW

August - September 2010

www.cvppsg.org



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

Mary Ann Haske,
Editor

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August 7th 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.

Hurricanes – Are You Ready?

Lyle Alexander will present a program on hurricane preparedness. Lyle is a meteorologist at the National Weather Service office at Wakefield, VA. He has been with NWS since 1987 and at Wakefield since July of 2008. His area covers northeast NC, eastern VA (including Eastern Shore), and portions of lower MD.

September 11th 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.

Wheel Chair Evaluations

Sherri Pearson, Sheltering Arms, and Robin Kolbe, West Home Health, will be doing wheel chair evaluations. Sherri Pearson is a registered and licensed Occupational Therapist (OTR/L) and an Assistive Technology Professional (ATP). Robbin Kolbe is an Assistive Technology Practitioner whose goals for all clients are mobility and independence.

(Note: The meeting date is the Second Saturday in order to avoid Labor Day Weekend)

Wednesday, August 18, 2010

Mid-Month Lunch at 11:30

Cheesecake Factory - Short Pump Town Center
11800 West Broad St, Richmond • 804-364-4300

For a reservation, call Barbara Bancroft (204-1688) or
Carol Kennedy (740-6833) by Monday, August 16.

Wednesday, September 22, 2010

Mid-Month Lunch at 11:30

Q Barbecue

2077 WalMart Way, Midlothian • 804-897-9007

(It is located between Sam's Club and WalMart on Midlothian Turnpike on the North Side of the street. It is about 2 miles west of Chesterfield Town centre at the end of a group of shops called "Shoppes at Stonehenge".

For a reservation, call Carol Kennedy (740-6833)
or Barbara Bancroft (204-1688) by Monday, September 20.

(Please note: Our lunches are now held on Wednesdays!)

**Mid Month
Lunches**

From Your Editor...

Several months ago, one of our Board Members sent me a GREAT article on "fats". It was copyrighted and I was unsuccessful in obtaining permission to print it. I shrugged and let go. Shortly after that, I had to change my way of cooking because Neil's cholesterol was too high. That was hard. Southerner's like cooking with butter and cream and eggs and cheese. However, I had a responsibility to keep Neil as healthy as possible. So, I learned. His cholesterol did improve.

Amazingly, when I returned to Richmond and saw my doctor, my cholesterol was close to normal. My doctor was so excited and so was I. So this is not an official paper on fats but I will, informally, describe some of what took place.

I knew that the body needed some fats to help absorb Vitamin D and to help in the building of cells. Neil wanted no part of any fats at all but I finally convinced him that he had to eat the "good fats". So, we ate avocados, nuts, dark chocolate and coconut and I was very happy with that. (They think I made up the coconut thing because I liked macaroons but I did not make it up.)

Neil's doctor was not too keen on Neil having dairy but we worked some in. We used a lot of no fat Greek yogurt in many fun ways. He drank skim milk and I went to 1% milk with the hope of changing to skim in the future. I fixed many dishes without the beloved cheese. Cream rarely entered into the picture.

I learned that there were those horrid fats like LARD, butter, anything solid. Neil used some sort of fake butter and I have not made it to that yet. I did cut WAY back on butter. We used olive oil and canola oil. I found that I could put a lot of herbs in olive oil and it is delicious on bread.

I used full fat peanut butter because the low fat has sugar. Neil went with reduced fat. Oh, I learned to eat more sandwiches with mustard rather than mayo. I used sliced chicken rather than roast beef. I also would use part yogurt and a little mayo in some dressings.

Then there were the turkey meatloaves. Neil, when he was well, would make up lots of those things and he had me doing the same thing. I mean lots. I became so used to it I did the same thing when I returned home. Will I live long enough to eat all of them???

Actually, it is good to have slices of them in the freezer to pull out when I am too tired to cook.

We went through a tofu phase and that was going real well until we found that Neil's inactive body could not tolerate it. I am going to try it here because I found if I used just a little of the meat a recipe called for and added tofu it was quite tasty.

We ate a lot of fish and cooked most things in a huge, non-stick skillet. Once every few weeks we had a piece of beef tenderloin, but, other than chicken and occasionally some pork tenderloin, we did not have meat. Neil ate eggbeaters daily and I went for oatmeal or Fiber One.

Since I do not tolerate the cholesterol lowering drugs, my doctor and I had resigned ourselves to high cholesterol. Really, I never thought these "almost" minor changes could bring such good results. To put it in a nutshell (no pun intended), we tossed almost all of those solid fats and did not use processed food with those bad fats (whatever they are). I don't really understand those fats in processed foods so I just avoid anything that looks "dangerous". We lowered dairy fat, gave up a lot of meat, and ate good fats. One of my daughters, who was not into studying too much in her youth, said, when she was in graduate school, that if she had realized how little effort it took to make an A she might have tried for more in high school and college. Well, if I had realized it was not that difficult to make changes in cooking, I might have tried a lot earlier. I hope this totally unofficial report can help someone to make changes.

Mary Ann

Another Milestone and a Big Thank You.....

At our June Luncheon, Carol Ranelli, on behalf of the entire support group, thanked the long serving officers and members of the board for their dedication and service in keeping our group going. So many support groups around the country are disbanding for various reasons and without the efforts of our board, we would most likely be among them.

In particular, we recognized Carol Kennedy, for serving ten years as president of our group. Carol was presented with an engraved crystal vase and flowers. Over the past ten years Carol has taken countless phone calls, requests for PPS information, listened to life stories, kept our group organized, done the hours of paperwork to get and keep our non-

profit status and filled in whenever necessary with any duties that came her way. I don't think she has missed a single meeting, retreat, board meeting, luncheon or dinner in the past ten years!

Many thanks Carol and to all who keep our support group running smoothly!



Iron Lung Dependency

As most readers know I have been using a ventilator 24/7 for eight years and have used ventilators intermittently since 1967. The current technology allows me to travel in the accessible world with respiratory technology that only weighs sixteen pounds. The first effective respirator was the iron lung. The first effective iron lungs were developed in the 1930's. There is ample evidence that the iron lung saved many lives during the polio epidemics of the first half of the twentieth century. At that time, no one really foresaw that some polio survivors might become iron lung dependent and actually survive. The words below are from an article written by me several years ago.

One of the first polio victims to receive significant publicity regarding chronic dependency on the iron lung was Fred Snite, Jr. Snite was from a wealthy Chicago family, a devout Catholic and was a graduate of Notre Dame. He joined his family on a dream trip around the world in 1936. While in Peiping (now Beijing) he came down with polio. He was twenty-five years old. He was admitted to the Rockefeller Memorial Hospital. This hospital

The rest of the story is continued 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.



Cont'd from page 3

Iron Lung Dependency

was known as the John Hopkins of the Orient. His physician was a graduate of the Harvard Medical School. This hospital owned the only iron lung in China. At the time there were just over two hundred iron lungs in the world. This iron lung weighed 1200 pounds.

After fourteen months in the iron lung, Snite had not been able to leave the iron lung. Arrangements were made by his family to move him from China to Chicago. Snite was moved from the hospital to a railroad baggage car by means of a generator powered iron lung placed in an ambulance and traveled 900 miles by train to Shanghai. At each stop people gathered to see the "Crazy Foreign Devil." Snite then boarded the ocean liner, President Coolidge. A staff of 25 doctors, nurses and medical personnel cared for him on the trip home. He made it home and news accounts at the time were both pessimistic and optimistic. Months in the iron lung turned into years, but Snite was able to spend short periods of time outside of the iron lung with the use of a portable respirator that could be strapped to his chest. The public remained interested in his story and the press followed him to Lourdes, France in 1939. Snite was able to bathe in the healing waters and he said, "If it's God's will that I be cured. I will be; if not, I won't. I figure I have a right to ask only one thing; the strength to face up to it." Snite remained in the iron lung and in the public eye. His determination resulted in his becoming a tough bridge player. He became a legend at Notre Dame. He traveled to Notre Dame football games in a special trailer equipped

with an extra iron lung. The Fighting Irish publication wrote, "Enter the visiting team, polite cheers. Enter the home team, loud cheers. Enter Frederick, pandemonium." In 1939 he married Teresa Larkin, a woman he had known before polio. They had three children. His medical problems took their toll and at the age of forty-three, Snite died in 1954 from heart and lung failure. His long time nurse felt he died after "eighteen years in that hunk of steel."

Snite's courageous story helped the fledgling National Foundation for Infantile Paralysis or March of Dimes get a jump start. Snite was fortunate to come from a wealthy family, but most polio victims did not have the advantage of wealth.

Snite's life was a great inspiration to many people, especially Catholic Christians. In 1958 Snite's story was included in an elementary reader used in Catholic schools. The story was titled "The Man in the Iron Lung" and was written by Leonard C Hawkins and Milton Lomask. The story revealed Snite's life in the iron lung and his trip to Lourdes. The story carries a religious message and ends with these words:

"As the years went on, he was constantly asking himself what he could do to help others and to get closer to God himself. He never questioned God's will where his illness was concerned, but he was often plagued with the feeling that his prayers were not worthy in God's eyes. He had no intention of coasting into Heaven in an iron lung. Frederick was determined to earn his way, just as the rest of us must. 'This life is preparation for the next,' he often said. 'I have a job to do like everybody else.'"

I have a copy of this book and it is a realistic account of Snite's life in the iron lung.

The iron lung shown here is in the museum in Wytheville, VA.

References:

Department of Museums, Wytheville, Virginia, photos of iron lung, courtesy of Linda Logan, 2005
Hawkins, Leonard and Lomask, Milton; The Man in the Iron Lung, Double Day and Company, Inc; Garden City, New York, 1956.



Retreat Survey

The Future of Our Retreats/Jolly Good Weekend!

The committee planning Retreats would like input from our membership. (We have added a new question, #12.

If you already responded to the survey, would you please send us an answer to #12?)

Please respond to the following questions by emailing:

Ckennedy1619@aol.com or ChanNLinda@aol.com or by mailing to

Linda VanAken, 14606 Talleywood Ct., Chester VA 23831

or calling either Carol Kennedy at 804-740-6833 or Lind VanAken at 804-778-7891.

You can also bring your responses to our next meeting.

1. Are you still interested in having annual weekend Retreats? _____
2. Are you still interested in the Support Group as a means of learning and sharing? _____

3. Would you prefer the Retreats to be more of a social event and less of an educational event? _____

4. Would one day (10:00 – 4:00) be a better option than a two day event? _____
5. Is it too physically difficult for you to continue to pack & travel in order to attend a two day event? _____

6. Can you attend just a one day program? _____
7. What kind of social activities would interest you? (I.e. cards, games, entertainment)

8. If we don't have a professional speaker discussing PPS would that prevent you from attending? _____

9. Would you travel if we choose another location outside of the Richmond area?
(If so within what limitation, i.e. 1 or 2 hrs?) _____
10. Do you have any suggestions for a location for either a special day event or a weekend long Retreat? _____

11. Should we change the time of year from the 3rd weekend of September to another time frame? If so when? _____

12. What amount would you be willing to spend per person for room and meals for a long weekend?
\$100, \$150, \$200? (that's per person) _____

Thank you for your assistance in our planning endeavors!

2011 Budget

**Income/Expense Budgets
Jan., 2011 to Dec. 2011**

Revenues

Gifts, grants, or donations	\$2,700.00
United Way receipts	\$550.00
Advertising in Newsletter	\$650.00
Memorial donations	\$200.00
Total Income	\$4,100.00

Expenses

Newsletter Printing	\$1,700.00
Postage	\$600.00
Gifts, grants (Children's Hosp., Nat'l PPS)	\$200.00
Fund Raising expense	\$100.00
Speakers gifts	\$200.00
Library Maintenance	\$0
Retreat	\$0
Professional fees (Bank acct, Web Master)	\$250.00
Meeting expenses	\$200.00
Lunches & Xmas Party	\$800.00
Misc	\$500.00
Total Expenses projected	\$4,550.00

The Social Committee is funded by our Brown Bag Auctions

Some Thoughts About Polio

(The following article appeared in "Polio Outreach of Washington, Spring 2010.)

The majority of patients seen in the Post Polio Clinics throughout the nation are those who contracted polio during 1950-56, the time of the last major epidemic before the vaccines were developed. The current age range of the group, assuming polio was contracted before age 25, is 54 to 85 years of age. There are now 6-7,000 people from this group in the state of Washington.

The concerns expressed by these patients in almost all of the cases center around a decrease in function compared to function skills they achieved two to five years after the attack, sometimes up to 10 years later. The function decreases experienced for some began to occur about 20 or more after initial attack.

The areas of function that are diminished might include walking, stair climbing, posture maintenance, transfer skills (e.g. getting out of bed, on and off chairs), personal hygiene skills (e.g. bathing, toileting), dressing skills, eating skills, swallowing, breathing, avoidance of falls, and performance of responsibilities at home, work, school, and the community. The symptoms associated with these function losses, can include fatigue, reduced endurance, pain, and a perception of weakness.

The cause of the function losses is multifactorial in most patients. These factors include: (1) the severity and location of muscles completely or partially paralyzed; (2) the degree of joint destruction and deformity secondary to the lost muscle strength at the joints, particularly at the knee, ankle, foot, hip, shoulders, hand and spine.

Additional factors include diseases acquired over time that are not directly related to the original polio but which can magnify the functional losses. These factors include: (3) thyroid disease, (4) heart disease, (5) pulmonary disease, (6) cancer, (7) diabetes, (8) other neurological and muscle diseases, (9) osteoarthritis, (10) significant weight gain, (11) stroke, (12) the effect of injuries and (13) depression. For some patients, the polio residual is not the primary factor in causing

function losses and associated symptoms.

A major additional factor contributing to the development of function losses is: (14) the normal aging process that begins at about age 25 to 30, and affects all of us whether we had polio or not.

The effect of this aging process for those with significant polio muscle weakness can lead to a profound effect on these muscles causing added function loss. The explanation for this is as follows.

The nerve fibers that cause muscle contraction originate in the spinal cord. Each muscle is served by many of these nerve fibers. Within a muscle, many individual muscle fibers attach to each individual nerve fiber. The number of nerve fibers per muscle and number of muscle fibers that are attached to each nerve fiber varies with the size and location of the muscle.

In acute polio, the virus attacks the cell bodies of the nerve fibers. Some escape the attack, some cease to function but then recover and some die. Therefore the muscle involved can end up totally paralyzed, partially paralyzed or fully recover. The partially paralyzed muscle ends up with less than the normal number of nerve fibers and hence less working muscle fibers. It is this group that is affected by the normal aging process.

The normal aging process causes all of us to lose about 1% of the nerve fibers to a muscle per year. In partially paralyzed muscle that already has a reduced number of nerve fibers, such additional losses can lead to a reduced ability to perform ordinary daily functional activities, and the appearance of fatigue and pain when performing activities that were not fatiguing or painful before.

The therapeutics used in post-polio clinics vary from patient to patient, but all are directed at reestablishing or delaying the losses in the functions enumerated above.

The therapeutics may include:

1. Bracing as needed to substitute for weakened muscles or correct deformity with appropriate design, fitting and training
2. Appropriate prescription of walking and ambulation aids

3. Suggestions to modify the environment to reduce energy costs of an activity

4. Surgery recommendations for some deformities

5. Referrals to other specialists to decrease the influence of non-polio related diseases

6. Education about what polio is and what it is not

7. Teaching a maintenance home-performed active range of motion, a stretching program, and aerobic conditioning

8. Exercise to strengthen muscles that were not involved initially may be prescribed

Strengthening polio involved muscle should usually not be done as they are likely to be already at maximum strength. Such exercises may enhance fatigue. Any exercise that produces fatigue should be avoided or performed at a lower intensity. Any activity that one enjoys except for the fatigue that occurs can usually be managed by interspersing short rest periods and then resuming.

The polio group from the 1950's is a proud bunch. They have been highly productive. They have great pride in the fact that they "beat polio". They understandably are disappointed to find out that the polio is still with them. As long as they maintain their focus on function and come in time to worry less on how they now need to do some things differently, they will be able to say, "I beat it a second time".

You may have noticed that I have not used the term "post-polio syndrome". I dislike it because it suggest a whole new disease, which it is not, and also implies that everybody with it are alike, which they are not. I prefer to say "post-polio, late effects as modified by the normal aging process and health status".

Walter C. Stolov, MD
Professor and Chair Emeritus
Stepping down Director of the UWMC Post Polio Clinic
University of Washington
Department of Rehabilitation Medicine
Seattle, WA

Come Sail with Us!

For several years, members of the support group have talked about taking a cruise together preferably out of Norfolk so there would be no flying involved and members could take power chairs or scooters easily.

I started to look into this a few months ago for spring of 2011 and unfortunately, Royal Caribbean Cruise Line won't be sailing out of Norfolk after this year, but they will be going out of Baltimore.

Linda and Dave VanAken, Carol Kennedy, Mary Ann Haske and myself have already booked for a 9-day cruise out of Baltimore for the Eastern Caribbean, leaving on May 5th and returning on May 14th. There is secured parking right at the dock in Baltimore, so unloading will be easy and won't involve a shuttle bus. Parking is \$13 a day.

Four of the nine days will be "at sea" and the four ports of call are San Juan, Puerto Rico, St. Thomas, the Dominican Republic, and Haiti.

The ship is The Enchantment of the Seas and there are a total of 19 handicap accessible rooms in varying price ranges.

You can go on-line to www.royalcaribbean.com, look up Enchantment of the Seas/deck plan and see the location and different categories of rooms.

We are using a local travel agent, Mrs. Scottie Luther with Travel Planners, as our coordinator. I have known Scottie for 20 years and she is very easy to work with and has had many years of experience as a travel agent.

Her phone number is: 804-379-0149. You can call her and get prices on particular rooms, plus ask any questions you may have.

You may think it is very early to be planning a cruise that's a year away, but accessible rooms go very quickly; especially if there is a particular price-point you are interested in. We all have bought cancellation insurance which is the wise thing to do since none of us know what next year will bring.

We mentioned this trip at our June Luncheon and there were several people interested.

We would like to have you join us, but, know up-front, that we are not your social directors, entertainment directors or problem solvers. This is our vacation too!

We will be having the late dinner seating (8:30) and you are welcome to join us, but you may prefer the earlier seating at 6:00. Whatever works for you is fine. We all have our own "style" of cruising.

Any of us would be happy to answer questions if you are interested, but, remember, if you wait too long, your room preference may not be available.

Carol Ranelli
Phone: 804-794-7359

Notifications

SEPTEMBER ELECTIONS

In preparation for the coming elections, a nominating committee has been formed. If you are interested in running for a seat on the board or if you wish to nominate someone, please contact one of the following people:

Fay Garnett804-740-2422
Jim Wells804-745-0564

Remember, you must have the person's permission to place their name in nomination.

Home Again, Home Again, Jiggety-Jig!...

Yes, after my six and a half months up in NY, I am truly home again. The very first thing I need to do is to thank all those who helped with the newsletter while I was away. You all were great about getting articles and information to me in a timely fashion. I could not have done it without Carol Ranelli (and her sidekick, Carol Kennedy) taking care of the mailings. It was wonderful that you both picked up the slack! Thanks Carols.

So, what did I miss the most in terms of my Richmond abode? My Kitchen! I can sit in my wheelchair and put my legs under the sink or under my cook top. I have a pull out counter that makes chopping, etc. easy. I really don't know how I managed to produce 3 meals a day up north in a kitchen that was not accessible.

I missed my bed and my 2 recliners. I missed being able to get to each and every room in my wheelchair. I missed the big sky views out my big windows. (Not quite Montana but still a delight to me) And, of course, I missed my Support Group.

However, I also miss NY things. I loved getting to see several Broadway Shows. I was able to visit old friends that I made during the 25 years we lived there. I liked the fact that my driving skills improved enormously. I loved visiting the ocean. The main thing I miss is my daughter and her friend. It was really nice having people in the house. Neil was such a wonderful patient that he made the caring for him easy. (Well, emotionally easy, physically it was hard.)

Did I learn anything from the expedition? I think I learned that I am adaptable. I can be happy in different venues. I really need the adaptations that make my life easier, though. (Notice that I just used two words that have "adapt" as their root. It reminds me of how important it is to "go with the flow" and to accept all the devices that we need to make life comfortable.) I learned that friends and family are important and to be grateful for whatever surprises life brings to me.

Your editor, Mary Ann

Save the Dates

- Mid-Month Lunch, July 15, 2010
 - Retreat Committee, July 31, 2010, Children's Hospital, 10:30
 - Regular Meeting, August 7, 2010
 - Mid-Month Lunch, August 18, 2010 (Day Change)
 - Regular Meeting, September 11, 2010 (2nd Sat.)
 - Board Meeting, September 15, Children's Hospital, 10:00
 - Mid-Month Lunch, September 22, 2010
 - Regular Meeting, October 2, 2010
 - Mid-Month Lunch, October 20, 2010
 - Board Meeting, November 10, 2010, Children's Hospital, 10:00
 - Regular Meeting, November 13, 2010 (2nd Sat.)
 - Mid-Month Lunch, November 17, 2010
 - Holiday Party, December 4, 2010, Children's Hospital
- (Now go IMMEDIATELY and put these dates on your calendar!)*


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