

POLIO DEJA VIEW

April 2011 - May 2011

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

Mary Ann Haske,
Editor

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Saturday, April 2nd 2011 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.

The Building Blocks to EQUALITY!

The Americans with Disabilities Act – (ADA)

Kelly Hickok is a Community Advocate for Resources for Independent Living, Inc. Through education and advocacy, Kelly works with the community to bring awareness to the needs of people with disabilities as it relates to inclusion and expansion of community living options.

Saturday, May 7th 2011 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.

Life in a Support Group

Henry D. Holland, MD FAPA is our speaker. We know him from his contributions to our Support Group and his Deja View articles, "From Henry's Desk..." . Henry has vast experience as an academician in the field of psychiatry. He also has a private practice. Henry has been active in River Road Church, Baptist and in numerous historical societies. He and his wife, Brenda, enjoy their three children and six grandchildren.

Mid Month Lunches

Wednesday, April 20, 2011

Mid-Month Lunch at 11:30

We will have lunch at Azzuro Restaurant at 6221 River Road in the River Road Shopping Center For a reservation, Call Carol Kennedy (740-6833) or Barbara Bancroft (204-1688) by Monday, April 18th.

Wednesday, May 18, 2011

We will have lunch at P.F. Chang's in Stony Point Fashion Park For a reservation, call Carol Kennedy (740-6833) or Barbara Bancroft (204-1688) by Monday, May 16th.

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

Maybe It's Time.....From Your Editor

It is hard to believe that it has been nearly 15 years since I was sitting in the examining room at Washington Hospital discussing my case with the late Dr. Anne C. Gawne. She told me several things. One, I was very weak and I had "hit the wall". She said that, if I rested extensively for 3 months and if I used a power chair, I would get better. On that day, I was having difficulty feeding myself, walking, and taking stairs. I felt like I had an awful case of the flu. So, I did what she said and I did get better. Two, I had "fought the good fight" and it was time to take care of myself. My volunteer days were over! I listened to the first admonition but I think I had a mental block when it came to the second.

When I was 13, my mother became ill. I cared for her until she died 4 years later. I also took care of my father and sister until the day I was married. I had 6 children. We took in Fresh Air children in the summer. I volunteered left and right. Well, that is just a little idea of who I was. It is hard to put on the brakes when one has spent a lifetime caring for others. When I moved back to Richmond 10 years ago, I was near family and friends. I took people to the doctor, babysat, ran to the airport and the train station. I was on call for my nearest and dearest.

Then, I began to be the "go to" person in my condo. Slowly but surely I was doing for others in my building. It's amazing to me how this being available to others can creep up on one. Until..... one day.....a lightning bolt hits, not me but a transformer. Here is the story. My 91 year old, across the hall, neighbor is blind in one eye and has to have frequent injections in the other eye. Last fall, she asked me to take her to the eye doctor, something I did quite often. It was a strange day. There was a forecast of storms but the day was beautiful. On the way, we passed what appeared to be a bank robbery. (It was.) Police cars were everywhere. Then I dropped my neighbor off and I went to do some shopping. (Her visits take a few hours.) I went to several stores. Everywhere I looked there were police cars. (They were pursuing the robber.) The robbery, police cars in large numbers, sunshine when the forecast was bad all made the afternoon a little surreal.

When I exited the final store, it was raining. I headed east and drove into the sunshine. However, in my rear view mirror, I could see dark clouds and rain. I heard the thunder but I was continuing to drive into sunshine. When I reached the medical arts building, the rain was almost upon me. I raced my chair into the building and took the elevator to the 2nd floor. (Can you guess what is coming?) My neighbor said she was just going back to get her injection when.....THE LIGHTS WENT OUT! The doctor came out and told my neighbor to go home and come back the next day as he could not safely give her an injection by flashlight.

I asked the doctor if the building had a generator. He said it did not. I told him not to worry because I had a book, some goat cheese and some bread. If he loaned me his flashlight I would be all set for the night. It sounded reasonable to me but, apparently, not to him. He had the staff calling 911 to come and get me out. 911 said they had "bigger fish to fry" as the storm had people trapped in cars under fallen trees, flooded streets and other catastrophes. So, the staff proposed all kinds of wonderful ideas like carry me and my chair down the stairs. The chair weighs 250 lbs. I weigh.....wait, we are not going there. I thought they could roll me down the stairs like the pig in the butter churn in "The Three Little Pigs" but that did sound painful. I finally came up with this plan:

1. They find a manual chair.
2. I transfer to the manual chair (taking my goat cheese with me).
3. They push me to the stairs and I get out and bump down on my backside. (By the way, I was very sore over my entire body the next day.)
4. They get the manual chair downstairs.
5. I transfer to the chair and they push me to my car.
6. I drive my neighbor home, call another neighbor and have her come to my car with a manual chair and push me to my condo.
7. I eat my goat cheese and go to bed.
8. The next morning we do the whole thing in reverse. (Well, almost. The elevator was working by this time and they could bring the manual chair down and take me back up in it. Can you believe, they wanted to DRIVE my power chair out to the car even though they had never driven one?.....NO WAY!)

Now, if this is not a wake-up call, then what is? I had already committed to taking a neighbor for her cataract surgery in a few weeks and so I did that. That surgery is the last helping-hand run that I've done for anyone in the condo. I will probably do some things for my children and grandchildren. It took over 14 years for me to get the message. I think I would still be pushing and overexerting if the power outage debacle had not been so dramatic. I know I am a pretty bright person so how could I be so dense, so obtuse???? Is it just hard to admit that we, who have had polio, are fallible? Is that Type-A Personality so strong that we are trapped in our thinking? Is it just too hard to say "NO"? Probably all of the above are causes for this helping mania. Maybe it is time to really honor Dr. Gawne's memory by really listening to her and acting on all of her advice.

Mary Ann Haske



The Wheel and Polio

Ancient historians believe that the wheel was first utilized around 4000 to 5000 BCE. In both ancient times and in the twenty first century we all use wheels every day. Whether it is something as simple as driving one's car or rolling one's luggage, the wheel is almost taken for granted in our everyday life. As children most of us were rolled in baby carriages, strollers and rolling toys before we mastered walking. Many of us can probably remember the first tricycle or bicycle that we learned to ride. This article will be somewhat autobiographical, but often the personal parallels the universal.

I got my first bicycle when I was about seven years old at Christmas time. It was a twenty two inch Fox bicycle. It did not have training wheels and I learned later that it was not actually new. My grandfather had bought it used, took it apart, cleaned it up and painted the metal parts blue with white trim. I learned to ride that bike by trial and error. At Christmas time in December 1949 when I was ten years old, I received my first twenty-six inch bike. It was a Roadmaster bike. It had a horn and a front light. It was a one

The rest of the story is continued on page 4

CENTRAL VIRGINIA POST-POLIO SUPPORT GROUP

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Barbara Bancroft, Social Committee	(804) 204-1688	babancroft@gmail.com

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.

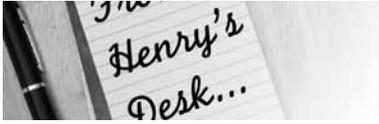
We would love to have any of our members write an article for our newsletter. It can be about your lifestyle adjustments, comments on post-polio or any subject, humorous or serious, that we may all benefit from.

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

The Wheel and Polio

speed bike, but it could go any speed as long as I pumped the pedals harder. I loved that bike and used it almost daily in my middle class neighborhood on the north side of Richmond, VA. On September 17, 1950 I was felled by the polio virus. Three months later I left the polio rehab ward of the Medical College of Virginia Hospital wearing two long leg braces and using wooden crutches. I did not attend school at all during the school year 1950-1951, but I had a home bound teacher and kept up with my class. By summer I had been able to discard the brace on my left leg and the crutches. I could walk slowly without aid and I could climb steps one step at a time.

During the summer of 1951 I realized that I needed to learn to ride my bicycle again. I had one major problem: I had to unlock the knee joint on the brace in order to be able to pedal. This meant that if I leaned to the right while sitting still, I would fall to the right because my leg would be flaccid unless the brace was locked. After many falls I developed a technique to begin riding the bicycle again. This feeling of movement on my Roadmaster was exhilarating despite the dangers. I could ride almost anywhere in my neighborhood and even long rides out of my neighborhood. Those two wheels improved my feeling of freedom and helped my self esteem.

From the summer of 1951 to the summer of 1954 I decided to raise New Zealand White Rabbits. This enterprise involved learning about sex and breeding patterns. I had four females (does) and two males (bucks). I would schedule the breeding of the four females to birth their litters about eight weeks before Easter. During the week of Easter I ran an ad in the newspaper and sold the rabbits as Easter bunnies during that week. I always sold all of them for five dollars each. After two years I had made enough profit to purchase a new style English bicycle. This bike had three gears, smaller tires and hand brakes for both the front wheel and rear wheel. With this bike I could climb hills with more ease because of the gears. I enjoyed the added freedom of this bike until I entered high school and learned to drive a car. When my family acquired a car with an automatic transmission I learned to drive with one foot, my left foot. I drove with that left foot until Post Polio Syndrome felled me and I stopped driving in 2002. All of us benefited from being able to drive a car and enjoy the greater freedom that four wheels provide.

I went to a small college in Lexington, VA and I did not have a car for four years. I really did not need one, but walking long distances simply took me longer. One of my three roommates did have a car my last two years and he helped me get around for longer distances.

When I entered medical school in 1962 a personal microscope was a mandatory piece of equipment throughout the first two years. The microscope was rather heavy, but could be carried in a case sort of like take-on luggage on a plane. However, I soon learned that carrying that microscope and books was overwhelming. I had an uncle who was an excellent carpenter. He extended a handle on the microscope case and added two wheels at the base of the case. These modifications made it possible to pull the microscope case on wheels, similar to an old fashioned golf cart. This was all made possible because of two small wheels.

From 1964 until Post Polio Syndrome began in 1991 I did not need any extra wheels. I began wearing out making rounds in hospitals. I found a used scooter in my respiratory therapist's office. I bought it and that little scooter saved immense energy until 1997 when I obtained a newer scooter. Also, in 1991 I had obtained a van with a hoist that made it possible to carry my scooter anywhere. For the first time in several decades I could visit any accessible store, park, historical site or hotel without expending great amounts of energy. The three wheel scooter and the scooter hoist made this possible.

In 2002 my breathing muscles began wearing out because of PPS. I had used a ventilator at night for over three decades, but after June 2002 on doctor's orders I began using a ventilator 24/7. However, because of modern computer technology I still have good mobility. I have used a power wheelchair for the last nine years and my ventilator only weighs seventeen pounds and is easily carried on my six wheel wheelchair. Any place that is accessible is still usable by me. I am blessed by modern technology, but am always mindful of the wheels that move me along. I control these wheels and they usually do what I expect.

Ezekiel 1:14-20

14 The creatures themselves darted back and forth with the speed of lightning. 15 As I was looking at the four creatures I saw four wheels touching the ground, one beside each of them. 16 All four wheels were alike; each one shone like a precious stone, and each had another wheel intersecting it at right angles, 17 so that the wheels could move in any of the four directions. 18 The rims of the wheels were covered with eyes. 19 Whenever the creatures moved, the wheels moved with them, and if the creatures rose up from the earth, so did the wheels. 20 The creatures went wherever they wished, and the wheels did exactly what the creatures did, because the creatures controlled them.

Ask Dr. Maynard



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Question: Can a Grade 3 concussion cause the onset of post-polio syndrome (PPS)? I developed the symptoms during recovery from a concussion and have been diagnosed as having PPS.

Answer: Regarding your question about a Grade 3 concussion (the most serious level): After headaches and cognitive problems (poor concentration, attention and memory), fatigue is one of the most common post-concussion symptoms. Frequently, it is reported as “very low energy for doing anything” and “feeling exhausted after doing nothing”. A need to sleep 12 to 16 hours per day is common. When a polio survivor has a serious concussion, these symptoms may mimic those of PPS or aggravate mild, non-distressing fatigue present before the head injury. If an individual’s usual activity level is seriously reduced due to post-concussion fatigue and/or other symptoms for more than a few days, disuse weakness and fatigue can rapidly develop.

This type of new weakness and fatigue may, in fact, be no different than “typical PPS” new weakness and fatigue. However, it does have an other explainable cause (diagnosis) for developing, and therefore does not meet the most commonly accepted definition for PPS (March of Dimes. Post-polio syndrome: identifying best practices in diagnosis and care, www.marchofdimess.com/files/PPSreport.pdf). Regardless of what it is called, it is especially important for a polio survivor whose PPS symptoms begin after a concussion to enter a comprehensive rehabilitation program that

includes appropriate, individually prescribed exercise. A well-designed exercise program undertaken over several months has an excellent chance of restoring function to pre-injury levels and essentially resolving PPS.

Question: Are there any nutritional issues that polio survivors should pay special attention to? Are there any particular dietary needs or concerns? Any supplements that are beneficial?

Answer: There are several important nutritional issues for people who had polio. No other issue is more important to good health than optimal nutrition, and no other is more controversial and little studied by good science.

The first issue is how to avoid excessive weight gain and obesity. Minimizing all refined sugars and grains is probably most important, particularly high fructose corn syrup which is now very widely used in processed foods and sodas. Portion control is also a central issue. Polio survivors are especially challenged to control weight and avoid developing type 2 diabetes (insulin resistance) because of their reduced muscle mass and limitation to vigorous exercise. Muscle tissue is the most important user of sugar and insulin in the body, and when there is less muscle to use, it is harder to keep blood sugar levels stable.

A second important nutritional issue is avoiding excessive sodium intake because it can increase the risk of hypertension (high blood pressure). Polio survivors have a higher risk of hypertension, again because of decreased tolerance for aerobic exercise. Another special challenge is achieving healthy cholesterol levels and lipid profiles. It is more difficult to maintain high levels of good (HDL) cholesterol and low levels of bad (LDL) cholesterol without high levels of aerobic activity.

Additionally, a number of people, including polio survivors, cannot safely tolerate statin medications that are widely prescribed for cholesterol lowering. Many limit their intake of meat, dairy and eggs because of concerns about cholesterol,

but this may leave them deficient in some essential fat-soluble vitamins only found in animal products, as well as low on essential amino acids. These amino acids and vitamins are critical to optimal muscle functioning, and polio survivors may be more sensitive to any relative deficiencies in these substances. Therefore, modest consistent intake of animal products is recommended with fish, white meats and grass-fed beef probably best.

The last issue is prevention of deficiencies in various vitamins and minerals. Vitamin D deficiency is very common today and contributes, along with low calcium intake/absorption, to the high incidence of osteoporosis in the United States. Less commonly known is that vitamin D deficiency can increase muscle and joint aches and pains, as well as lower energy levels – all common PPS symptoms. Vitamin D levels in the blood can now be readily measured and should be on survivors experiencing late effects of polio.

Adequate intake of B complex vitamins, especially vitamin B-1 (thiamine), vitamin B-6 (pyridoxine) and vitamin B-12/folic acid, are critical to nerve health and can be measured in the blood. Brewer’s yeast and whole grains are excellent sources for insuring high levels of B vitamins, except B-12/folic acid, which must come from some meat intake. Fish is an excellent source of protein, the healthiest fats for a good lipid profile and a good source of vitamin D and vitamin B-12.

A high proportional intake of fresh vegetables and whole grains is recommended along with modest quantities of fruits and animal products. Organic foods should be considered since post-polio nerves may be more sensitive to the neurotoxic effects of pesticides.

Send your questions for Dr. Maynard to info@post-polio.org.

Post-Polio Thoughts ... RACKING UP SUCCESS

*Nancy Baldwin Carter, BA, M Ed
Psych, Omaha, Nebraska, (n.carter@
cox.net)*

A few years ago Hubby's dentist gave him a scruffily pathetic Christmas cactus that wasn't doing well under her tutelage. He brought it home, put in on his desk under the desk lamp, in front of an east window, next to the room's heating duct, and here it is kept throughout the year.

"Wrong, wrong, wrong!" shriek the experts. "These are tropical plants. No artificial light at night. . . keep them strictly at in a 50 degree temperature half the year. . . water them way less in fall and winter or they'll never bloom. . . stay away from heat ducts. . . place in total darkness 12 to 14 hours each day. . ." On and on they go with their endless, impossible rules.

But Hubby has a special gift. As a librarian, he may know nothing about growing the Christmas cactus, but he and this plant understand each other. At various times throughout the year, lush green foliage bursts forth with voluminous and gloriously red blossoms. Simple as that.

Who knows. Maybe the plant recognizes Hubby's sincere desire for it to do well, and not wanting to disappoint such an ardent admirer, it does. Whatever it is, Hubby's Christmas cactus cannot be surpassed.

So, experts can be wrong. The road to success may not always be paved with what we've been led to expect.

Each of us can say what we believe it takes to be a success. We decide.

Intelligence? Relentless pursuit, inventiveness? Good luck? Maybe always getting the job done well signifies success, or coming in at the top of the heap. Does being the chief of staff, the CEO, the hall-of-fame inductee do it?

Maybe genuine success is more complicated; maybe we should also mix in a heavy dose of an often elusive and somewhat mystical element. Let's add possessing the ability to leave others feeling better for having been in their presence.

I think of my Warm Springs doctor, Robert Bennett, M.D., and much later my Rancho Los Amigos doctor, Jacquelin Perry, M.D. Top of their professions, no question, but these are not simply doctors who knew what they were talking about. Beyond that they exhibited a certain touch of humanity that others didn't seem to have. In their hands, patients felt valued, appreciated, unique. With doctors like this, the patient comes out feeling like a success.

There are those who believe that having great wealth and power spell success. Others say nobody can be a bona fide success without being kind, caring. Do we have to like ourselves? See the worth in others?

Maybe we should examine how success looks through the eyes of eight-year-olds. Where do they rank the elderly neighbor whose sweet smile always says to them, "I'm glad you're here"? She, who fills the neighborhood with the aroma of her scrumptious chocolate chip cookies every morning, beckoning enthusiastic cookie-lovers to

her door. She, who teaches us all to treat others the way we want to be treated.

How about you and me? Who among us is a success? I wonder what the requirements would be.

Perhaps all it truly takes to be a success is a loving man with an uncommon talent for helping a Christmas cactus thrive.

*Nancy Baldwin Carter, B.A, M.Ed.
Psych, from Omaha, Nebraska, is a
polio survivor, a writer, and is founder
and former director of Nebraska Polio
Survivors Association.*

Source: Post-Polio Health
International (www.post-polio.org)

Social Committee Input Request

The social committee is requesting that you comment on our Spring Luncheon, our Holiday Luncheon, and Mid Month Lunches.

The plan this year is to have the Holiday party at Children's Hospital again using the same caterer but a different menu to add variety. There have been several requests for more desserts so we will definitely have more and offer something more than brownies and cookies. We plan to have assistance with carrying plates again and hopefully the youth group at Bon Air Church will be the helpers. Now is your chance to give specific feedback about what you like and what you would like changed in regard to menu, location, parking, mood lighting....whatever. However, you must understand that not all requests will be able to be met.

To add variety, the plan will be to keep changing the June luncheon location. Finding a restaurant that is accessible, has sufficient close parking, will accommodate a party our size and offer tasty dishes is often difficult. If you know of a

location that fits this criteria, please let me know. The June luncheon usually has about 22 people. Finding locations for the parties is the most challenging.

If you can recommend a location for the mid month lunch please relay that information to me. There are many wonderful restaurants in the Richmond area. We try to move the location from the South side to the city side every other month. We try to accommodate the preferences of the people that attend most frequently and like to expand the repertoire and keep the favorites.

Now is your opportunity to have your opinion heard and how often do you get that chance? Respond by email to babancroft@gmail.com or by mail to:

Barbara Bancroft
4306 West Grace Street
Richmond, VA 23236

FYI.....

FYI: Nordstrom's Department Stores will sell mixed size pairs of shoes. One can buy very nice shoes and pay only the price of one pair even though each shoe is a different size. John W. Nordstrom, the founder of Nordstrom's Shoes, offered this service because his wife had had polio.

FYI: When one is faced with extensive repairs on one's mobility van, what does one do for a substitute van? One of our members has rented a vehicle from:

Independent Lifestyles Mobility Specialist

4880 South Amherst Highway
Madison Heights, VA 24572
(434) 846-7510
Toll Free (800) 657-5438
(Located near Lynchburg, VA)

There is also an affiliate in Tidewater, VA:

Wheelchair Gateways of VA

Norfolk, VA
Rental Department
(877) 271-9826

Save the Dates

JUNE LUNCHEON

The June luncheon will be held at the Great Seasons Restaurant on June 4, 2011 at 12:00 noon. The restaurant is in The Shoppes at Bellgrade which is at 11400 West Huguenot Road.

The group will be seated in a private area partitioned from the main large dining area. We will order from the menu and have separate checks. The menu has soups, salads, sandwiches, and lunch entrees averaging about \$10. Great Seasons also has a catering business which is evident in the taste and presentation of the food.

I hope that you will make plans to attend as this will be an assessable location that will offer delicious food and a good time for all. The deadline for reservations is Saturday, May 28, 2011. Call Barbara Bancroft, 204-1688 or Judith Moffitt, 754-1067.

NEW AND IMPROVED 2011 RETREAT !

Retreat is back and we think it is better than ever. We hope you will join us the weekend of October 14, 15, and 16 at the Holiday Inn Express in Ashland for some Retreat favorites as well as some new activities.

We will have our usual "Meet 'n Greet" social time on Friday evening with dinner being catered by Suzanne's, the same wonderful caterer we had in 2009.

On Saturday's agenda is Jessica Waugh, an Internet Medical Research Specialist who spoke to our support group last November and proved to be an informative and dynamic speaker. We will also have an interactive group, similar to the one we had at the last Retreat. Peer and Partner sessions are returning and, as always, there will be time to rest. We will have box lunches by Suzanne's and eat dinner at any of the several restaurants near the Holiday Inn - Applebees or Cracker Barrel are very close by.

We have to vacate the meeting rooms by 5:00 in preparation for some real fun Saturday evening when Masino's Casinos will host casino night complete with CVPPSG money (fake) and, of course, lots of prizes.

There will be Black Jack, Texas Hold 'Em, Roulette and Bingo games. Something for everyone!

After a year's absence, we have tried to think of some new and exciting features for this Retreat and hope we will have a good turnout. We are trying to keep the price as

Scholarship Funds Available

The Central Virginia Post Polio Support Group is pleased to announce that we have a small discretionary fund that is to be used as a Scholarship fund. We would like to remind all members that the money is there if you need assistance in paying fees for attending our events or obtaining our newsletter. Thus if you are unable to pay the fees to receive the newsletter, or cannot pay the full amount to attend our Retreat or other events, or have special needs, please contact Linda Van Aken at 804-778-7891, or at ChatNLinda@aol.com, or mail the request for assistance to 14606 Talleywood Ct., Chester, Va. 23831.

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