

POLIO DEJA VIEW

February 2011 - March 2011

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

Mary Ann Haske,
Editor

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Saturday, February 5th, 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 Primary Prevention of Strokes: Diet, Meds, and Exercise

Gregory. Leghart, MD specializes in stroke, brain injury, geriatric rehabilitation, management of spasticity associated with neurological conditions, electrodiagnostic medicine, spinal cord injury, and management and treatment of musculoskeletal conditions. A native of New York, Dr. Leghart received his medical degree from Albany Medical College and moved to Richmond to complete his residency at the Medical College of Virginia. He lectures on topics that include stroke rehabilitation, spasticity management, and exercise for the elderly. He is a member of the Richmond Academy of Medicine, Medical Society of Virginia, American Academy of Physical Medicine and Rehabilitation, and the Virginia Society of Physical Medicine and Rehabilitation. Currently, Dr. Leghart is an Associate Clinical Professor in the Department of Physical Medicine and Rehabilitation of the Virginia Commonwealth University Health System. When not at work Dr. Leghart enjoys spending time with his wife and three children, and also enjoys landscaping, music, running, biking and swimming.

Saturday, March 5th, 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.

General Discussion

Bring questions, ideas, anecdotes and comments. This is the members' time to share.

Mid Month Lunches

Wednesday, February 16, 2011

Mid-Month Lunch at 11:30

We will have lunch at Maggiano's Restaurant in Short Pump Road Mall

1800 W. Broad St. (Located between Nordstrom's & Dillard's)

For a reservation, Call Carol Kennedy (740-6833)

or Barbara Bancroft (204-1688) by Monday, March 14th

Wednesday, March 16, 2011

Mid-Month Lunch at 11:30

We will have lunch at Firebirds Wood Fired Grill, Midlothian

11448 Belvedere Vista Lane

Directions: Huguenot Road South to Robious Road East,

Take a left off Robious on to Belvedere Vista Lane

For a reservation, call Carol Kennedy (740-6833)

or Barbara Bancroft (204-1688) by Monday, March 14th

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

From Your Editor...New Year Resolutions

The Newsletter is put together a month before the date that appears on the title page. Therefore, I always feel some articles are a bit out of sync. I am writing this on New Year's Day. I am thinking of Dr. Bruno's article in last month's newsletter where he spoke of our need to rest. He made reference to "New Year's Syndrome" and the fact that we are overly tired and weak because of all the holiday preparations. I am also thinking of my article a year ago where I wished for snow storms so that I was forced to remain in and rest. So, here I am typing away while battling chills and a sinus infection. It does not matter that just about everyone in my building is struggling with the same thing. I know that I became way too tired and pushed way too much. So, what am I going to do about it? I know, make resolutions; after all it is New Year's Day.

I resolve that:

- 1.) Next year, on Christmas Eve, I will use paper plates and other paper goods instead of hauling out all the "good stuff".
- 2.) There will be just one meal prepared. I will not fix a "children's meal". In the words of Marie Antoinette, "Let them eat cake!" (Or cookies!)
- 3.) There will be one dish in a crock pot and one dish that needs to be heated and everything else will be eaten cold. No more will I look like a sweat ball!
- 4.) Family will bring beverages so that I don't have to tote in heavy bottles.
- 5.) Family can bring items that do not have to go in the oven.

I am writing this so that next year I can see it in print and follow through. Hauling china and crystal out of a china cupboard is tiring. Putting it back is even more so. It is easy, over a year's time, to minimize just how difficult it was preparing a meal for 13 or so people. I can say to myself that it was not that hard and I can do it. Here it is in "black and white" and I am sure I have friends who will point this out to me next year.

What does this mean for you, the reader? I hope it will encourage you to look at some aspect of your life that may be too much and find a solution. I want to continue with the tradition of the Christmas Eve Dinner but I have to find a way I can handle it. Maybe there is something that you need to analyze and change. Happy New Year!

Mary Ann Haske

Foods That Boost Your Immune System by Christine J. Kim

With flu season in full swing and winter weather around the corner, those telltale cold symptoms can be tough to ward off.

But don't throw in the towel just yet, says Kim Barnouin, co-author of *Skinny Bitch*. Your diet is the main provider for your body's "daily boost of antioxidants, vitamins, minerals, fiber and enzymes to protect the immune system" – meaning a poor diet can be a huge factor. A weakened immune system can result from a number of factors, including stress and excessive consumption of such substances as alcohol and sugar, Barnouin says. So give your immune system a fighting chance with these health-boosting foods.

Lemons restore the body's acid-alkali balance, maintaining natural pH levels that support healthy bacteria instead of the viruses that thrive in acidic conditions.

Green tea and white tea are a powerful duo, stimulating and aiding your immune system in the disease-fighting process.

Garlic is "an edible antibiotic" that seems to cure everything, Barnouin says, particularly when raw.

Kidney beans and chickpeas (garbanzo beans) contain the necessary daily protein required for a strong immune system.

Brazil nuts are the No. 1 source for selenium, an antioxidant that helps rejuvenate our bodies and kill off germs.

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Polio Treatment Then and Now

There was a time in the early 1940's when the treatment of polio was controversial. There has never been a cure for polio, and treatment prior to 1940 was generally bed rest and immobilization of extremities to prevent contractures and deformities. Then, along came an Australian nurse names Sister Elizabeth Kenny. She had seen polio early in her life among the aborigines of Australia. She had served as a nurse in the Australian military in WWI. She had her own ideas about polio that resulted in considerable criticism directed toward her by the medical establishment of Australia, Great Britain, and the USA. Her treatment methods did receive greater acceptance in the USA, but particularly at the University of Minnesota.

News articles in the Richmond newspapers in 1942 presented both sides of the controversy. Sister Kenny believed that muscle spasms in the acute stage of the disease were the most damaging occurrence in the early disease process. She recommended the application of hot, moist wool-packs to these affected muscles and passive motion exercises to maintain a "mental connection" with the muscles. In 1942, Dr. Joseph Moldaver of the Columbia University College of Physicians and Surgeons reported in the Journal of the American Medical Association that two of Sister Kenny's concepts were incorrect, namely, that the muscles spasms were not the most damaging aspect of polio and that there was no loss of muscle function due to a loss of association with the patient's mind.

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
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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.



Polio Treatment Then and Now

Cont'd from page 3

In addition, at a meeting of the American Public Health Association in 1942, Sister Kenny's theories were criticized on a more scientific basis by Dr. H.R. Carrell, a St. Louis orthopedic surgeon. He stated, "The scientific evidence is that the wasting paralysis does not originate in the muscles, but in destruction of nerves in the spinal cord." He said, "Any treatment directed at the muscles themselves is only tinkering with a secondary trouble. The muscles will remain paralyzed regardless of treatment if the spinal nerves are destroyed. I am certain that the one hope of eradicating the disease and its crippling aftereffects lies in immunizing people." With the last statement Dr. Carrell was quite prophetic and accurate.

Among those defending Sister Kenny in 1942 were Doctors R. Plato, Schwartz, and Harry D. Bouman of the University of Rochester School of Medicine and Dentistry. By making 500 graphic records, these doctors proved that muscle spasms occurred among muscles affected by polio and was an integral part of the damaging process.

Sister Kenny also defended herself in a 1942 news article. She quoted Dr. Frank Krusen, professor of physical therapy at the Mayo Clinic in Rochester as saying, "Her ideas are original, and she should be given full credit for having developed a new and extremely interesting concept of the symptoms of early poliomyelitis and the proper management of these symptoms." Sister Kenny also reported her own results in which she claimed that 800 out of 1000 patients recovered almost to normal.

Who really knows the effectiveness of her treatment methods? Despite her scientific inaccuracies, there are countless polio survivors who will, to this day, attest to the effectiveness of her methods. Eventually Sister Kenny's treatment methods for acute polio were used nationally and internationally. She died before the development of the Salk vaccine, but for many polio victims, Sister Kenny's name symbolized hope.

As polio survivors with Post-Polio Syndrome (PPS), I do not believe we have a modern-day Sister Kenny to provide hopeful treatment. Fortunately, there are a growing number of physicians and allied health professionals who are interested in PPS. However, often there is no uniformity of treatment for PPS or there might be controversy, especially in regard to exercise. I am among those who believe that most of us get adequate exercise with the activities of daily living.

When I reflect on the treatment of PPS, it really does not differ that much from the treatment of polio. That treatment was bed rest, Kenny hot packs, and range of motion exercises. Of course, many polio victims had to rely on braces, crutches and wheelchairs after a program of vigorous and painful physical therapy and rehabilitation. The generous application of rest, staying warm, and maintaining as much range of motion as possible seems to be helpful and practical treatments for PPS. Maybe PPS is nothing more than polio growing old, and a Sister Kenny type of hope is our best ally.

Reference: Richmond Newspapers archives, 1942.

(This is a repeat of a very informative article and deserves a second reading.)

Chesterfield County Public Library's Consumer Health Information Program

Our November program was a presentation by Jessica L. Waugh, M.A., M.S.I.S. concerning doing some of your own internet medical research on sites that she has found to be constantly up-dated and reliable. Jessica received a Federal grant on library/internet based medical research last year which lead to her Master's degree.

I wish more of our members could have attended because she was a dynamic and entertaining speaker with a wealth of information! We are considering having her return for our Fall Retreat to repeat her program since we were SO impressed!

Meanwhile, we thought it would be beneficial to share some of the websites that she suggested, so others could use them if they needed some specific medical information.

Jessica is also available to do specific medical research for individuals at no cost. You don't even have to be a resident of Chesterfield County. She may be contacted at:

Jessica L. Waugh
Bon Air – Chesterfield County Library
804-320-2461
waughjl@chesterfield.gov

Suggested medical information sites:

Health on the Net Foundation – www.hon.ch/

Health Improvement Institute – www.hii.org

MedlinePlus (A Service of the US National Library of Medicine) – www.medlineplus.gov

Mayo Clinic – www.mayoclinic.com

Clinical Trials – www.clinicaltrials.gov

Post Polio Health International – www.post-polio.org

National Institutes of Health Senior Health –
www.niseniorhealth.gov

Epocrates Online (you have to register for this site, but it is free) – www.epocrates.com

Up to Date for Patients (regularly up-dated medical info) –
www.uptodate.com

Ask Me 3 (how to get the best communication between the patient and medical provider – what three questions are the most important) – www.npsf.org/askme3

Compiled by Carol Ranelli

Feeling Disabled

By Linda VanAken

We recently attended a wedding at a beautiful old family estate which had been converted to a modern cozy little resort. The manor house was gorgeous old gray stone, with lots of curving staircases, many unique rooms, and much character. The setting was just as gorgeous as the buildings were. The estate was nestled in among green rolling hills with lots of trees, birds and other interesting wildlife. Across the road from the manor house was a fabulous flower garden that was ablaze in glorious spring blossoms. The resort had converted not only the manor house into guest rooms, but also other outbuildings, such as the Mews and the Gardener's cottage. Because the Cottage was the most accessible and would house our family, we stayed there. Sounds idyllic doesn't it? However, the term accessible really wasn't in their vocabulary and I said I felt more handicapped there for that four day weekend than I had in years.

Our guest room was spacious, but I could barely maneuver my scooter through the small cozy parlor in order to store it and recharge it. The large bath was a far cry from being accessible. They did have a raised toilet with grab bars. The sink was placed in the center of a high counter and anyone who had to sit in a scooter or power chair to use it would have found it a challenge to reach the sink area. Oh yes, architects really do understand the needs of people with disabilities! The shower was a 5 foot by 7 foot tiled enclosure but there were no grab bars. We tried to place two of those removable grab bars, but they would not adhere to the tile. I am at my most vulnerable when I am barefoot, without a brace or shoe, and walking on wet surfaces. Most of us understand how precarious we feel in those situations. There is no way I would attempt to stand and use my crutches to exit such an enclosure totally wet. Without my braces on it was imperative that I use

my crutches all the way into the shower. I used loads of hotel towels to form a pathway so I could walk (somewhat) safely into and out of the shower enclosure. Just the act of standing from that small shower bench made me very nervous. There was nothing to grab onto and little space to push myself up. It was scary using the crutches with wet tips. I did try to wipe down the tips. Every day I felt tremendous stress using that very inaccessible shower. It was not a pleasant experience.

We ate breakfast at the Manor house. The first day I was eager to see the manor house and wanted to have my scooter so we drove up and let the valet take the car after unloading my scooter. I was able to get into the building ok, and drive down to the area where the buffet breakfast was served. I soon realized that I had another problem; all the seating at the tables was down two steps and not a ramp was in sight. Fortunately for me, I am quite able to walk, so I could simply park my scooter and go on with the meal. But my hopes of viewing this wondrous old building went out of the window as there were steps everywhere. Again I had that depressing feeling of missing out because I was disabled. It had rained heavily the night we arrived so the grounds were just too soft and the grass a bit too high for me to attempt to drive my scooter over the rolling hills. We visited the beautifully flowering gardens and I got stuck in the packed shale walkways, so had to abandon that outing.

Large "golf" carts were provided for transporting the guests to and from the guests' quarters to the manor house. We used those the rest of the weekend, but because of the small entries to each row, I had difficulty pushing myself back up if I sat in the front or middle, so had to always climb on the back and hang on for dear life to a small U shaped handle in the middle of the seat, while making sure I didn't lose my cane and

purse in the process. That was particularly harrowing when that was our transportation down the hills to the gorgeous spot for this outdoor wedding.

There was not a comfortable chair anywhere at the manor house, so the seating for the reception & breakfast was very uncomfortable. Four days of less than adequate seating resulted in my body screaming its protest for days afterwards. By the third day, all I could think of was "Won't this weekend ever end?" This should have been a glorious family event. Instead I found myself feeling isolated, uncomfortable, stressed, and often very left out. I realized afterwards that we truly have come a long way to adapting our environment to accommodate people with disabilities. I honor the people who came before me that helped enact the American's with Disabilities Act. I honor those that continue to speak up and help make changes so others are not denied access or comfort when possible. I readily understand that an old manor house cannot be converted easily for those of us using power chairs and scooters. However, there were so many areas that could have used simple solutions to make them accessible, like paved walkways, or small ramps, etc. Oh and let's not forget the grab bars in the shower stall!

May we all find more places that are accessible and find our journey full and rewarding as we travel through this time we call "life".



Promoting Positive Solutions

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Rhoda Olkin, PhD

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

Question: If I am told, “I never think of you as disabled,” should I be complimented or insulted?

Response from Rhoda Olkin, PhD:

This question created an opportunity for discussion among some of us. Some people wanted to delete “or insulted” at the end of the question, after getting feedback from a few folks who couldn’t understand why someone might be insulted. But I wanted to keep the phrase there, because I really do get why someone (myself included) might be insulted by being told, “I never think of you as disabled.” I’d like to try to explain why.

First, let’s examine what someone might mean if they tell you they don’t think of you as disabled. I believe the person means it as a compliment. S/he is saying that you seem very able, that you don’t pity yourself, that you engage in activities much like someone without a disability would, that you don’t use disability as an excuse and that you seem to have overcome your disability to the greatest extent possible. That’s a good thing, yes?

Yes. But there is a flip side. Though let’s be clear about the language: I am not a disabled person, I am a person with a disability. There is a difference. I also am a mother, female,

Jewish, a psychologist and a person who had polio. It’s one of a list of things, not the main thing, so I relegate it to the background.

But imagine someone saying to me “I never think of you as Jewish”. What might this mean? Does it mean I think, behave and talk so much like a non-Jewish person that my Jewishness disappeared? And would I be complimented or insulted by this statement? I think you can see why I would be insulted. “Ahhh”, you say, “but Jewishness is something to take pride in, while disability is not.” Isn’t it?

There is a certain pride in being a person with a disability. It means I have survived, have experienced suffering and become more empathic for it, have felt the cruelty of other children and grown stronger, learned a lot about myself as I faced discrimination, learned to choose my fights wisely, became expert in disability laws and rights, joined a disability community that challenged my viewpoints, juggled my pain and fatigue and still planted a beautiful garden and raised two children. Would I have done these things without a disability? Some of them, perhaps, but not the same way.

There are no answers to the question “who are you without a disability?” or “how does having a disability change you?” I am who I am with my disability, not in spite of it. So when you tell me you don’t even notice my disability, I hear that part of me has been disavowed.

There is another reason I might feel insulted. Disability is not a dirty word. You don’t have to lower your voice when you say it. I am not ashamed of having had polio. (I may be annoyed, fatigued, in pain, sick of it, angry, fed up, but I am not ashamed – I did nothing wrong.) So if being a polio survivor is not shameful, why would I want someone to tell me that they don’t even see that part of who I am?

Try telling another person “I never think of you as _____” - and fill in the blank with gender, ethnicity, sexual orientation, religion or country of origin. See if s/he takes it as a compliment or an insult.



Stephanie Machell, PhD

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

There’s no “right” way to feel about anything. How you feel is how you feel. From your question, I’m guessing that you felt confused or uncertain how you felt. Or maybe you felt more than one thing at once and had difficulty sorting it out. On a subject as complicated as your disability, it would be likely that you would have mixed feelings – maybe in this case both proud and insulted.

How you feel about yourself as a person with a disability most likely influences your feelings. Are you ashamed of your disability? Were you always able to “pass” as nondisabled and now PPS makes that impossible? If so, you might be proud that the other person sees you as still able to pass. Conversely, you may be proud of your identity as a person with a disability and so you might be insulted that the other person doesn’t see or accept that part of you. If you are uncertain, it may be because you feel ambivalent and are struggling with how you feel about your disability.

How you might feel about someone saying he or she forgot you had a disability might also depend on the context, including how well you know him or her, what your relationship is, what you know about the person’s attitudes towards disability and how relevant your disability is to the interaction the two of you are having.

For example, a close friend may not think of you as disabled because for him it is not the most important fact about you. People in close relationships where there are differences of gender, race or religion – or disability – often report forgetting about the differences

Promoting Positive Solutions - continued

until a situation that makes them relevant occurs. If your friend were to take you out to dinner to a restaurant that turns out to be inaccessible, your disability would be quite relevant to both of you.

You may be uncertain how to feel because you don't know how the person saying it meant it. She may not be a close friend, or you may not know how she views people with disabilities. Or her statement

might bring up some issues or doubts for you. You could try asking this person why she said this, or (if appropriate) talking about how her answer made you feel.

(Send questions for Drs. Olkin and Machell to info@post-polio.org.)

Save the Dates

Meetings:

Saturday, February 5th, 2011 Meeting & Saturday, March 5th, 2011 Meeting

Mid-month Lunches:

Wednesday, February 16, 2011 & Wednesday, March 16, 2011

FYI.....

Several people have asked the name of the catering company that prepared our Christmas luncheon. They are family owned and were a delight with whom to work. It is: Morrissey's Catering at 8901 Three Chopt Road. They are located at the corner of the shopping center with Westbury Pharmacy. The phone number is 726-3663.

There is a beautician that lives and works in the west end of Richmond that is willing to come to the homes of people that have a difficult time getting to the beauty shop.

Her name is Fatima Webster and her number is 741-9125.

If you want more information, you can contact Barbara Bancroft at 204-1688.

In case of inclement weather, call any officer to see the status of our meeting or mid-month lunch.


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