

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

October - November 2009

Mary Ann Haske, Editor

visit our website at www.cvppsg.org

October 3rd Meeting

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

Our Speaker, Shawn Majette, practices Elder Law for the Thompson McMullan Firm. He also handles cases regarding health issues. He will address the changes in Advanced Medical Directives that went into effect on July 1, 2009.

November 14th Meeting

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

Timothy A. Powell, MPH and Epidemiologist for the Division of Surveillance and Investigation, will speak to us on the Swine Flu and other influenzas.

(Please note that the November meeting is on the 2nd Saturday in November due to the Teddy Bear Run at Children's Hospital on November 7th.)

Mid Month Lunches

Thursday, October 15th

Mid-Month Lunch at 11:30

We will have lunch at Mosaic Café at 6229 River Road in the River Road Shopping Center.

Please note that they are now a full service restaurant.

Call Bev Lordi by October 12th at 569-4232 for a reservation

Thursday, November 19th

We will have lunch at 11:30 at the Olive Garden at 7113 W. Broad Street
Call Bev Lordi by November 16th at 569-4232 for a reservation

(Editor's Note: We can control many things in our lives, but not the US Postal Service. Our Bulk Mailing seems to reach the Richmond area in time for current events. However, the service seems to be too slow to have Déjà View arrive in time outside of Richmond. We cannot publish any earlier as some material would not be available. In an effort to alert our readers to up-coming events, we will begin a feature called "Save the Dates". You can put those events on your calendar. If the newsletter does not reach you in an appropriate fashion, you can then call a member to get the particulars for that date.)

SAVE THE DATES
REGULAR MEETING, NOVEMBER 14, 2009
CHRISTMAS LUNCHEON, DECEMBER 5, 2009
JANUARY MEETING, JANUARY 9, 2010

A Good Time Was Had By All.....Reflections from Your Editor

The role of Program Chairman is a very difficult one, especially for our group. We need to have programs that will educate new members. Yet, we don't want to bore the long-term members to death. Our Chairman does a great job of balancing out needs. For our August meeting, Frances Thomas hit a home run. If laughter is the best medicine, then we all left feeling better than when we came into the meeting.

Our speaker was Harvey Hudson of Harvey Hudson's Passing Parade. Harvey has been heard on Richmond radio and TV for over 60 years. I was enchanted by his dapper appearance. . He sported a cap of cream color that looked like an old-fashioned driving cap. His rose color jacket, pink shirt and tie with stripes of rose, pink and orchid, looked striking with his cream colored trousers. If I had not known better, I would have thought I had come on to a movie set. Harvey had a pixie quality and a twinkle in his eye.

Our members came with an expectation of hearing a bit about Harvey's life, of being asked questions about Richmond, and of taking home a prize. (The prizes ranged from bags of fabulous Hanover tomatoes and bags of melons to USPS Stamps and gift cards. That would have been a nice afternoon. However, it was so much better than that.

We learned that Harvey Hudson was the youngest radio announcer in the entire US when he began his career. He is also the oldest as his career just keeps going. (He can be heard on WLEE 990 AM every Saturday, live, from 9-11 AM.) This gentleman with a sweet, flirtatious air charmed us with his stories about his career and his beloved wife. He met various stage and screen personalities when they came to Richmond and had friends in all aspects of radio, TV and screen. It would appear that he had adventures with everyone he met.

When he began to ask questions, I think we were just trying to get the right answers so we could win a prize. Although we learned a lot about Richmond, we learned even more about our members (who will remain anonymous) by the questions they knew how to answer. When one person knew the best parking, make-out spot in Richmond, eyebrows were raised. (Bosher's Dam) Then another knew the favorite drink at such hot spots as The Tantilla Gardens. (Sloe Gin Fizz) Shocking! Guess who they are!

Thanks, Frances, for arranging such a fun afternoon.....

Your Editor's Musings.....

DUHH! What Was I Thinking?

I guess the reality is that I wasn't thinking. I was doing what I have always done, adjusting subconsciously to my body. This past spring, I realized I was getting weaker and weaker. I was in more pain and life was harder. I think for me to make sense of this, I have to look at my life and some of my reactions.

I accepted early on that I would have troubles. When I fell, while pregnant, in the OB's office, I laughed it off and said I always fell. Within minutes, he had me sitting with an Orthopedic Dr. who prescribed a leg brace. (The old fashioned kind) Then, after the baby came, he performed surgery on my left leg.

Seven to eight years later, I found tears were running down my face when I took my children for walks. I just kept on walking and ignoring the fact that I was in pain. One day, a woman driving past slammed on her brakes, jumped out of her car and came over to offer me, and the groceries I was carrying, some

assistance. I did not know what she meant until she pointed out that I could hardly walk. She drove me home. That's when I had my second leg surgery.

I am telling these anecdotes to illustrate how powerful DENIAL is in my makeup. I'm fine, I'm always fine. In the 80's I read about PPS and actually went to be evaluated as I had been experiencing weakness. I was told I was fine and to keep on exercising. So, I did so with a vengeance. Each year I had to bike fewer miles, do fewer laps, and lift lighter weights. By the time I sort help again, I had hit the wall. I was told to rest for 3 months, use a power chair to get around and take care of myself by pacing my activities. I lived in a big ranch house in a rural area in Maryland. My friends came in and began to rearrange everything so that I could function from a wheelchair. I have to chuckle as I can still hear my husband calling from the next room that no one should touch the music cabinet. As he was yelling that I was watching my friends move the music cabinet. I mean these friends were on a tear. For five years I managed very well in that house and became stronger.

Then we moved to Richmond to a large apartment. We had the kitchen done over so I could cook from my chair. We widened a few doorways. It was not perfect but it was not so bad either. However, my trunk was becoming weaker and I was put in a tilt power chair. It was a great chair but it was huge. I felt like Lily Tomlin playing the part of Edith Ann in the great big rocking chair. I could no longer do as many chores from the new chair. Tooling around in the kitchen was not easy. Consequently, I did not use the chair for everything like I did in the past.

Well, this spring when my chair was seven years old and rather rickety, I was fitted for a new chair. The new chair arrived this summer. IT WAS WONDERFUL! In those seven years someone learned how to make the chair smaller, make the charger petite and lightweight and make the chair able to turn in tight spots. All of a sudden, I could go everywhere in my condo in the chair, even the walk-in closet. Cooking was a breeze. And, before I knew it, my pain was WAY less and my fatigue was WAY less. Why didn't it occur to me that my life was not working for me? First off, I did not have a clue that there was this adorable little chair available. If I had known how great an improvement this would have been for me, I would never have waited so long.

Now the question that I have to ask myself is, "Will I continue to be oblivious to the changes my body is experiencing?" I hope that this has been a "light-bulb" moment. As I feel stronger, am I going to forget how bad it can be? I hope not. I went to pump gas today at a station that is not easy to do from a wheel-chair. The island for the pumps is not right. I stood-up, realized my legs were shaky, to say the least, and called an attendant over to pump the gas. I am hoping that

that is a good omen. If not, I hope my polio friends and others will say to me, "Duhhhhh, what are you thinking?"

REMEMBER TO WHISPER "THANKS"

This past weekend, while I was watching tributes to Ted Kennedy, my thoughts went to a time in the 90's when I went with members from my Delaware PPS Group to a Congressional hearing in Washington. I was offered a ticket to the hearing room and I felt privileged to watch Newt Gingrich and Ted Kennedy fight for a bill that would allow Medicaid patients to receive nursing care in their homes rather than have to live in a nursing home. The room was filled with people with disabilities and their relatives. The whole process was very moving.

In 1999, I demonstrated at the Supreme Court Building when the court was considering the legality of that bill. At that time, I was privileged to hear Justin Dart, the "Father" of ADA speak. (Justin Dart, who contracted polio in 1948 when he was 18, was a wheelchair-bound heir to Walgreen Drugs.) When I heard Justin speak, he had on his signature cowboy hat and boots. He was a Texan to the core.

When I was living in Maryland, I was privileged to hear Hugh Gallagher speak at Washington Hospital and at Washington College in Chestertown, Maryland. (Our PPS Group had had Hugh speak but that was before I moved to Richmond.)

All of these memories came back to me as I watched Ted Kennedy's funeral on TV. These men had one thing in common. They all worked tirelessly for the passage of the ADA. This is not about politics. This is about men who saw a need and gave their all to see that the need was met. When you pull into a handicap parking space or use a curb cut or have a door swing open automatically, pause and whisper a "thanks" to these men who made it possible for us to go through life with fewer barriers.

Mary Ann Haske

RETREAT PROGRAM CHANGE

There is a change in the program for our Tenth Annual Fall Retreat. Our afternoon program, scheduled for 2:00, will be a presentation entitled "Improv Your Life" by Dave Gau and Katie Holcomb. This interactive presentation will combine improvisation and the principles that make us all improvisers. By the end of the hour presentation, everyone will be laughing, and feeling light hearted.

INFORMATION FROM THE DEPT. OF SOCIAL SERVICES

An online Medicaid application is now available on [Virginia Easy Access \(http://www.easyaccess.virginia.gov/\)](http://www.easyaccess.virginia.gov/), a Web site designed to help seniors and adults with disabilities find information and services to meet their long-term support needs. The online application was designed and developed in a collaborative effort among the Virginia Department for the Aging, the Virginia Department of Social Services and the Virginia Department of Medical Assistance Services. VDA Commissioner Linda Nablo, VDSS Commissioner Anthony Conyers Jr. and DMAS Director Patrick Finnerty made the announcement.

The online application makes it easier for seniors, individuals with disabilities and their families to apply for Medicaid services using a new streamlined application that is shorter, easier to understand and can be submitted online to local departments of social services.

"The new online application will be extremely beneficial to elderly and disabled citizens of the Commonwealth - especially those who lack mobility or have transportation issues - in ensuring that they have access to the medical services they need to improve their overall quality of life," said VDSS Director of Benefit Programs Tom Steinhauser.

Individuals and families can complete the application at their convenience, 24 hours a day, in the comfort of their homes. Once the applicant electronically completes the form and hits "send," the local department of social services will receive automated notice that a new application for Medicaid has been submitted, and the process to determine eligibility can begin.

This new online application will also allow many local private and public agencies to assist individuals and families complete the form. The electronic Medicaid application is an important step toward a larger effort to streamline Virginia's long-term support system.

There are approximately 235,000 low-income seniors and individuals with disabilities in Virginia — 17 percent of whom also meet the eligibility requirements for Medicaid-funded long-term care services — who can benefit from the new application.

The project was funded by the Productivity Investment Fund (PIF), a collaborative effort of the Secretaries of Administration, Finance and Technology. The mission of the PIF is to partner with Virginia agencies to identify, catalyze and implement innovative solutions which enable a simpler and more effective government for the benefit of the citizens of the Commonwealth

Did you know?...

....Rx Information from Jenny

PROBIOTICS

A growing number of products with probiotics are being promoted to improve GI function and immunity.

Probiotics contain strains of "friendly" gut bacteria...(ex: *Bifidobacterium*, *Lactobacillus*, *Saccharomyces*, and others).

The idea is to recolonize the gut with good bacteria and crowd out harmful ones. They might also stimulate the immune system.

Some probiotics are more beneficial for certain conditions.

Irritable bowel syndrome (IBS) Try *Align* (*Bifidobacterium infantis*) for abdominal pain and bloating due to IBS...or *VSL#3* (*Bifidobacterium/Lactobacillus/Strep thermophilus*) for bloating with diarrhea-predominant IBS.

Ulcerative colitis *VSL#3* should help maintain remission of ulcerative colitis.

Antibiotic-associated diarrhea *Culturelle* (*Lactobacillus GG*), *DanActive* (*Lactobacillus/Strep thermophilus*), or *Florastor* (*Saccharomyces boulardii*) should help prevent diarrhea from antibiotics.

Take the probiotic during antibiotic treatment and up to a week afterwards for best results.

Also, take the probiotic 2 hours AFTER each antibiotic dose...so the probiotic is more likely to survive.

Constipation. *Activia* (*Bifidobacterium*) seems to decrease gut transit time (helps food to be digested faster) and *Yakult* (*Lactobacillus casei*) might help soften stools...but they're not proven to prevent constipation.

Respiratory tract infections. Preliminary evidence suggests a specific combo of *Lactobacillus* and *Bifidobacterium* (*Howaru Protect*) decreases respiratory symptoms and antibiotic use in preschoolers.

However, this combo product won't be available until 2010.

Probiotics are usually safe and well tolerated. However, immunocompromised patients (those having a weakened immune system due to certain diseases or treatments) should play it safe and avoid them.

Be sure not to confuse PRObiotics with PREbiotics. Prebiotics are sugars or carbohydrates that encourage the growth of good bacteria in the gut.

Call me if you have any questions!
Jenny Aveson (804) 730-9498.

From Henry's Desk.....

Tell Your Story

For the last fifteen years I have attempted to write a column or essay on some subject related to Post Polio Syndrome (PPS) or a life with polio in almost every issue of the Deja View. On my computer hard drive I have stored eighty-three articles which if you divide that number by fifteen (years), the answer is 5.5. The Deja View is published six times a year and almost every issue has some missive by this author. Some of my articles originate as inspirations or I get a clue from something someone says or writes to me. In reviewing my articles I have noticed that on several occasions I have encouraged polio survivors to write their stories. This article is an effort to get readers to begin that task. I have started writing my story, but I admit it is a laborious undertaking. Your story might be equally laborious or maybe it will take less time. If you feel you cannot write it yourself, perhaps someone of the younger generation would be willing to listen to your story and write it down for you. I have learned that this method of getting an oral history can be most effective with other groups. It works very well for veterans of World War II and for Holocaust survivors. Compared to those two events polio did not kill as many people, but polio did mark and distinguish us in a way that should not be forgotten. At least within the Central Virginia Post Polio Support Group we could attempt to collect some histories of our experience with polio and PPS. If you have no one to write your history, I am willing to listen and do it for you. Below is a suggested outline to use, but you are certainly encouraged to write it with your own emphasis and narrative style. I would encourage writing in the first person.

Write about identifying data such as birth date, sex, and place of birth.

When and where did you contract acute polio and how old were you.

Describe whether it was a city, rural or a small town (less than 25,000 people)

Describe how you probably contracted polio.

Describe all the details of your acute polio illness such as early symptoms, who made the diagnosis, and memories of being hospitalized in isolation and thereafter in a hospital.

Identify the hospital's name and location. If you remember, write about when you were admitted and memories related to admission and when you were discharged. Also, describe when you learned that you had polio and who told you.

If you remember names of doctors, nurses, physical therapists or others, write about them, the good and the bad.

Write about other patients you remember at the time.

Describe in as much detail as you recall about the damage to your body during acute polio.

Describe your condition when you left the hospital and whether you used any orthotic devices upon discharge.

Describe the makeup of your family at the time you had polio and what impact polio had on your family at that time and even later.

Following acute polio describe that time period when you functioned at your maximum physical capacity after polio; even if you feel you had completely recovered. During this

good time period, describe what you could do and not do. After maximum recovery did you still need some assistive devices such as braces, special shoes, crutches or even wheel chairs?

If you had visible signs of polio, describe them and how that made you feel.

Write about your successes and failures in life that had anything to do with polio. For example did polio help or hinder you in pursuing an education? Did it help or hinder you in getting a job or having a career. If you were a home maker, did it cause problems for you in that activity? Did it have an impact on your life in other personal ways, such as marriage or having children?

Describe the challenges that you met and those that you were unable to accomplish.

Write about your religious faith if it was a factor in living with polio past and present.

Of course you should write about PPS and its impact on your life. You can follow some of the same factors in describing your life with PPS; the onset, the progression and the new limitations.

From your life with polio and PPS, what words of wisdom would you like to offer?

I strongly encourage all polio survivors to make an effort to write your story. The generations that will follow you should know of your unique experience. Let me know if I can be of any help.

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