

POLIO DEJA VIEW



September, October, November 2012

www.cvppsg.org

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

*Mary Ann Haske,
Editor*

Table of Contents

Pg. 1
Calendar Events

Pg. 2
From Your Editor

Pg. 3
From Henry's Desk...

Pg. 5
June Luncheon Pictorial

Pg. 6
Dump the Gump

Pg. 7
Holiday Party!

Pg. 8
Devecs, Design & Identity

Pg. 8
A Big Thank You

Pg. 9
We're Still Here!

Pg. 9
Sites Worth Seeing

Pg. 10
What Having Had Polio
Causes, Might Cause &
Doesn't Cause

Pg. 12
Note to Editors of
Newsletters

Pg. 13 - Survey Regarding
Mid-Month Lunches

Pg. 13 - Ads

September 8, 2012

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)

Being Ageless

Nancy Glenmore Tatum, a gerontologist, will discuss the therapeutic benefits of yoga for older adults and individuals with physical limitations. On a personal level, Ms. Tatum used these techniques to assist her mother, a polio survivor. (Note: the meeting date is the 2nd Saturday in order to avoid Labor Day Weekend)

October 6, 2012

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 topics that you would like to discuss

November 10, 2012

3:00 pm at Children's Hospital, 2924 Brook Road, Richmond

(Remember to come at 2:30 for refreshments and social time! Cookies provided – bring your own beverage)

The Journal of Jerry Epperson

Wallace W. "Jerry" Epperson, Jr. is one of the founders and Managing Director, Mann Armistead & Epperson, Ltd. He is a regular contributor to our newsletter. (Note: 2nd Saturday and 3:00 meeting time)

Wednesday, September 19, 2012

Mid-Month Lunch at 11:30

Cheesecake Factory

11800 W. Broad St., Henrico (Richmond) 23233 (364-4300)

Short Pump Town Center (located between Nordstrom's and Macy's)

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

Barbara Bancroft (204-1688) by Monday, September 17th

Wednesday, October 17, 2012

Mid-Month Lunch at 11:30

La Cucina Ristorante Italiano & Pizzeria

The Shoppes at Bellgrade

11400 W. Huguenot Rd., Midlothian, 23113 (378-8940)

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

Barbara Bancroft (204-1688) by Monday, October 15th

Wednesday, November 14, 2012

Mid-Month Lunch at 11:30

Feathernesters

"A Shopping and Dining Experience"

6118 Lakeside Ave., Richmond (262-7305)

Lakeside Town Center – one block south of Lewis Ginter Botanical Gardens

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

Barbara Bancroft (204-1688) by Wednesday, November 7th

Mid Month Lunches

The Joys and Perils of Travel

...From Your Editor

I just returned 2 days ago from a weekend at the “Rivah”, (that is Richmond speak for “River”), and I have decided to set aside the column I had written and create a new piece. My son-in-law, Neil, is far more disabled than I. We had a good discussion about our stay and how our disability affects our travel. I learned about roadblocks that I have not encountered. I thought it would be good to address some of those. Before I do that, I’d like to comment on a few trips I’ve taken.

Now, if you remember some of the things that I have written you will know that I have had some experiences that were totally joyful. I went by train to NYC in ’03 in the middle of a blizzard. The streets were almost empty. There were no lines in front of the Christmas windows. Cancellations were the order of the day and we were able to go to great places with no reservations. When I was stuck in a snowdrift in front of the Plaza, some men came and lifted the wheelchair out of the drift! All was good.

My husband and I took a train out of Washington to New Orleans in the 90’s. That was a little iffy only because there was a sewage smell in the bathroom in the compartment and we were stuck with that compartment. The train home was better. Our “accessible” room in New Orleans was accessed via a ramp that seemed almost perpendicular. Coming back down the ramp in the a.m. was a rather dangerous wild ride. We had them change our room. I’d rather not have grab bars, etc. than take my life in hand each day. Still, it was a great trip.

Twice we have rented houses at Nags Head. The first time was perfect. The second time, the elevator stuck between floors. It could not support the weight of me, (don’t ask), and the wheelchair. I just sat there stuck until the motor cooled. Then I pushed the down button. When I reached the ground floor I rolled out. Since I can walk a bit, I left the chair on the ground floor and rode the elevator to the living area. It was not perfect like the first house but it worked. However, if Neil had been there in early days of his illness, it would not have worked for him.

Now I no longer try and rent a house. The family has increased and multiplied and they are down there in several houses (no elevator). So, there are times I go and do driveway visiting. We might go out for a meal and then I visit in the driveway. Then Neil, Sue and I go to a motel. Not great but it is good to visit.

You get the drift. So, let’s go back to this past weekend. Neither my chair nor Neil’s chair fit through any door into the house. (I forgot my crutches but one entrance had a tiny step and a rail.) My sons helped Neil up the steps. We found chairs and pretty much spent the weekend sitting and watching everyone run around as they paddled kayaks, fished, boated, crabbed and swam. We were limited in our activities (reading) but we enjoyed the family, especially the children.

Although Neil did not have polio, he did have GBS, French Polio, and his paralysis was every bit as devastating as mine was and his recovery cannot hold a candle to the recovery I made as a child. After I returned home, I called Neil and had him tell me more. (I think it is good to remember that we are constantly changing and it might be good to look at other travel options.) I asked him to walk me through some of the preparations he and Sue make to take a big trip. This is the 3rd. summer that they have flown to National Parks since he became ill. Each year it is a tad easier but not by much. Since Sue is working, Neil is in charge of scoping out things for the trips. He

starts by finding a city near the area they wish to visit that can provide them with an accessible van. He has had good luck with “Wheelchair Getaways”. Then he looks for power chair rentals in the same city. That tends to be a bit harder as some places have scooters but they think of them as wheelchairs. Neil cannot manage a scooter because one needs the use of one’s hands. So, he has the agency send him a picture of the rental chair to make sure it is a chair! After that he investigates flights and hotels/motels.

They mail a bath chair out to their first stop. Since they were using it this past weekend and are leaving for California in a few days, it cost \$60 to mail it so it would arrive in time. (It usually costs about \$15.) One big stumbling block for them, at first, was finding “family restrooms”. Until recently Sue had to help in a bathroom. At LAX two years ago, they had to use the airline employee’s restroom as there was no bathroom that would work for him.

Fortunately Neil is a list maker. Now that they have travelled a bit, he can almost use his old lists. He needs spoons and a strap that attaches to his hand and holds the spoon. He can’t read a real book so he has to bring an e-reader. Sue has to do the medicine packs. And the list goes on and on.

He won’t ship his good chair in the belly of the plane. That is why they rent a chair. He needs a pushchair to get him into the airport and to the gate. The first year he needed an aisle chair. Now they get seats right by the door and he can take the few steps to the seat. I asked him how he manages the restroom on the plane. He says he does not. He restricts fluids the day before the flight and the morning of the flight. The first year he had a condom-like external catheter that was connected to a bag that was strapped to his leg. Now, he just hopes he will be o.k.

Neil thinks one downer is that there is not much room for spontaneity. What happens to their reservations if they decide to stay extra days in a favorite spot?

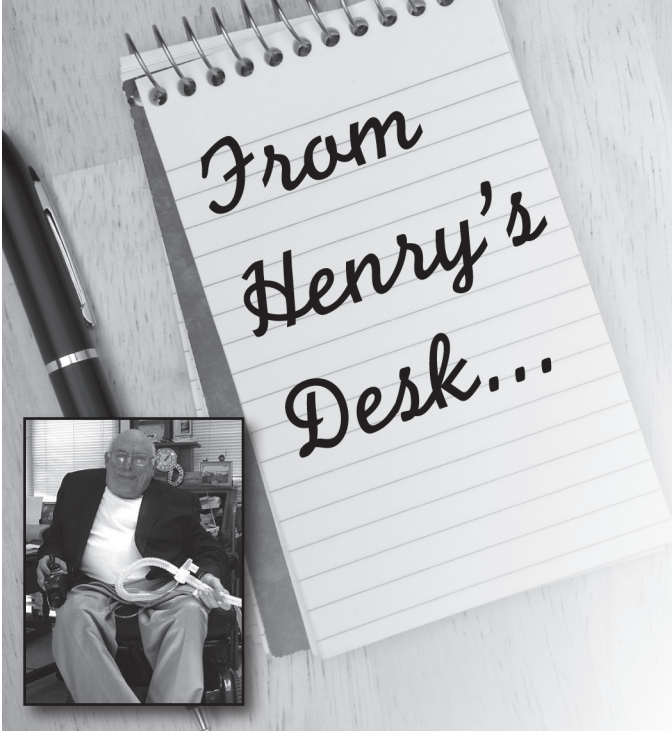
Anyone can have things go awry but when it happens to us, the disabled, it can have a huge affect.

I talked to one of our support group members and asked how he handled some of these problems. He immediately started to talk about the difficulty of using a restroom when one needs help and the person assisting is of the opposite sex. He said you just do whatever you have to do. Once, when he was still able to handle things himself, he slipped on a slippery floor. It took so long to get him back on his scooter, that he left and realized later he had been so discomobulated that he forgot to use the facility! He and his wife have had a few unsettling experiences regarding accessible restrooms.

This article is not meant to discourage travel because travel can bring great joy and renewal. There are hoops to jump through and mountains to climb and, with careful planning and a realization it might not always be easy, one can meet those challenges. I suppose I am in awe of the amazing spirit of those of us who face many obstacles and soldier on to a fullness of life.

- Mary Ann Haske

P.S. I just received a picture of Neil & Sue in Yosemite. The rental wheelchair is so huge it could hold Sue & Neil. They had to remove one arm so he could fit in the van and through doorways. I guess the agency thought, when he said he was 6’5” that that was his width!



Dependency Part II

The article that follows this brief introduction was written ten years ago. Ten years ago I had just begun using a portable ventilator 24/7. I use a bedside ventilator which I hook up to the trach tube in my tracheostomy hole every night. During the day when I am up and about I use a portable ventilator by plugging the trach hole in my neck and using a mouthpiece on the vent hose. This allows me to talk while I am up. Also in October 2003 I began using a power wheelchair that has the ability to hold my portable ventilator. I also purchased a Dodge Entervan which has a ramp that allows me to enter and exit my van whenever I go somewhere. I no longer drive, but my wife is an excellent driver. I am more dependent on my wife Brenda than at any other time in my life. Last year I fractured my right tibia while transferring from bed to wheelchair. My leg healed over time. The good news is that over the last decade I have been able to work on at least a part time basis. I can also go anywhere that is accessible to a wheelchair. Currently I work ten hours a week and my mind seems to be OK. I am still a blessed man despite the reality of being in a blessed dependency.

The rest of the story is continued on page 4

CENTRAL VIRGINIA POST-POLIO SUPPORT GROUP

Carol Kennedy, President	(804) 740-6833	Ckennedy1619@aol.com
Henry Holland, First Vice President	(804) 288-8295	Henry4FDR@aol.com
Linda VanAken, Treasurer	(804) 778-7891	ChatNLinda@aol.com
Judith Moffitt, Secretary	(804) 754-1067	Jmoffitt7114@aol.com
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.

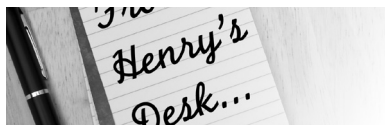
We would love to have any of our members write an article for our newsletter. It can be about your lifestyle adjustments, comments on post-polio or any subject, humorous or serious, that we may all benefit from.

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, #503, 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: Articles written by CVPPSG members may be used exactly as written provided credit is given for each article used (Ex. From Henry's Desk....). Permission for copyrighted articles must be given by the source of the article.



Cont'd from page 3

Dependency Part II

Dependency

As children we all depended on adults to provide the necessities of life. Many who had polio as children soon learned to depend on various human made devices. These devices included braces, special shoes, corsets, crutches, canes, wheelchairs, and even iron lungs. In order to achieve mobility and a sense of independence, we had to rely on many of these devices. As these devices helped us function more normally, many of us denied our dependence on these devices. However, a suddenly broken brace, crutch or wheelchair would quickly confront us with our dependence. One of the realities of Post-Polio Syndrome (PPS) is the necessity of becoming more dependent. That dependence often involves the resumption of using adaptive devices long discarded or perhaps a totally new dependence on some durable medical equipment. Many writers write best about what they know or have experienced. I will attempt to do the same.

I have worn a long leg brace on my right leg since I left the Medical College of Virginia Hospital on December 18, 1950. I never ran after polio, but I gained excellent mobility with the necessary help of my brace. Despite being constructed of steel, my brace suddenly snapped apart many times. It snapped in junior high school, high school, college, medical school, residency training, and making rounds in hospitals over the years. Each time it happened, I was reduced to an immobile or crawling state and dependent on other people to rescue me. I still wear my brace to this day. Currently I take very few steps, but those steps are impossible without my brace.

In 1968 I developed recurrent respiratory failure and had multiple hospitalizations over the next several years resulting in a permanent tracheostomy and nocturnal use of a mechanical ventilator. This treatment caused immense improvement in my daily activity. I essentially denied my dependence on my ventilator because I was otherwise functioning very well. Polio had caused scoliosis and the weakening of my respiratory muscles. I have used a ventilator every night for over thirty years. My life depends on my ventilator.

By 1991 PPS had slowed and weakened me to where I needed a scooter to conserve my daily energy and to be able to continue to function at my work. This level of dependence worked until 1996 when my fatigue level made it impossible to function at my full time work. I experienced a sense of loss at many levels. After a period of adjustment and acceptance I discovered that I could work part time in a home office and this arrangement is still working.

My latest new necessary dependence occurred a month ago. My respiratory muscles have weakened over the last several years. My pulmonary doctor recommended that I carry a second ventilator on my scooter and use it almost continuously. I have done this. My oxygen saturation is normal. Breathing is not an effort. The reality of my dependence is now considerable. I am dependent on my brace to stand, my scooter to move about my house and outside, my van with a scooter hoist to travel to other locations, one ventilator at bedside, one ventilator on my scooter, the Virginia Power Company for electric power, batteries for portable power and most importantly my wife of thirty-seven years.

My wife Brenda has always been a caretaker, but now her burden of caretaking has greatly increased. She anticipates my needs and is an unsung hero. Within our post-polio support group there are countless caretakers who are often unrecognized. Many of these caretakers are also getting older and have limited energy and muscle power. They should frequently be recognized and appreciated for their labor of love. In my judgment, Brenda is a Nobel laureate in caretaking.

How does one cope with the growing dependency of PPS? Denial is no longer a wise choice. Our return to dependencies of the past is similar to a regression, but a necessary regression and not a pathological regression. Some degree of rational thinking may help. I recognize that all humans are dependent on the natural benefits of our environment, the advantages of modern technology, the immense protection provided by vaccines, the life saving interventions of modern medicine and surgery, and the good will of our fellow humans at times of natural disasters or man made tragedies. Death is coming for everyone. Quality of life in our senior years is everyone's desire. Despite my dependencies I still have quality of life. I feel blessed. My dependencies cause me to be and feel more vulnerable, but life can often be enriched by vulnerability and even risk.

For many polio survivors the spiritual quest may be a way to cope with the uncertainty of life and the reality of dependency. For those of the Christian persuasion, the words of Jesus in Matthew (chapter 11, verses 28 to 30) speak directly to my dependence and perhaps yours: "Come to me, all of you who are tired from carrying heavy loads, and I will give you rest. Take my yoke and put it on you, and learn from me, because I am gentle and humble in spirit; and you will find rest. For the yoke I will give you is easy, and the load I will put on you is light."



Table 1, Brenda & Henry Holland, Judith Moffitt, Linda VanAken, Carol Kennedy & Helen Bunch. Center Top, Dave VanAken & Margarett Upshaw. Table 2, Joan Kerby, Betty & Jim Wright, & Jim & Caroline Wells. Table 3, Guest of Margarett Upshaw, Margarett Upshaw, Julia & Mike DeJesus, & Joe & Barbara Bancroft. Center Middle, Linda VanAken. Bottom Middle, David VanAken & Gordan Kerby. Table 4, Jack & Karen Wilson, Bonnie Atwood (Guest columnist for June Newsletter), Mary Ann Haske, & Kathy & Ed Tideberg.

JUNE LUNCHEON

Dump the Gump . . . Chapter 6

(The following is the sixth chapter of Jerry Epperson's account of his life with polio. Enjoy, the Editor)

*By Wallace W. (Jerry) Epperson, Jr.
Chapter 6*

I hated the movie "Forest Gump". The idea of running out of your leg braces just by sheer willpower was silly, or stupid, or to me, insulting. Fantasy? Of course.

His limited mental capacity and slow speech also re-enforced a stereotype that mental and physical disabilities are somehow linked, at least to some.

I doubt that I am the only handicapped person that has well-meaning people speak to me s-l-o-w-l-y as if I would have difficulty understanding normal speech. Smiling in a condescending manner, I know they are trying to be kind, but it is difficult to not be offended. I try not to be insulting or sarcastic in my replies, but sometimes I cannot help myself.

My family owned a 1969 Camaro convertible for more than thirty years. It was both kids' first car. One day in the summer I drove to the mall with the top down. I never take the last handicapped parking spot, but on this day, they were all empty so I used one.

Immediately, a lady ran over and chastised me for using a handicapped spot. I couldn't get a word in. Finally, I climbed out of the car and she saw me limp. She was quickly contrite, apologetic and explained that "handicapped people shouldn't drive convertibles". Nobody ever told me.

Another reaction is to ignore us as if we aren't there, especially if on a scooter or in a wheelchair. In line in a store or at a movie buying tickets, numerous times people have walked around me or stepped directly in front of me as if I was not there. It gets worse at Christmas. Trust me, it isn't because I am too small to see. I always speak up, often loudly, and make my presence known. Sometimes they argue; sometimes I drive over their toes.

Speaking about being on a

scooter or wheelchair, I am always amazed at how many people do not watch where they are going. It is one reason I hate crowds.

Some people who are walking and talking, either to another person or on a phone, never look down – or look forward with any degree of attention. Hundreds of times I have seen folks coming and, if no other options exist, I just stop and wait for them to run into me. Without exception, they look at me like I created the problem, but so far there have not been words.

Of course, I am not without some guilt in this regard. I have backed into displays and people, thinking I had space. Oops.

I need to use a three wheel scooter to make the sharp turns required in my home, but these can be dangerous if you are going almost any speed and turn too sharply. They do tilt and can toss the driver. They also can skid if the surface is wet or slick, too.

The largest challenge, for me, is curbs. Driving off a curb will not just throw you off, but turn the scooter over. Too often, curbs are not well marked.

At the Las Vegas furniture show in 2004 or 2005, my college roommate, Dexter, and I were leaving the Mandalay Bay to get our rental van. The cut in the curb was obvious and I drove to it, but it had a separate ramp that led down to the cut that I did not see. I was thrown off my scooter, landed on my forehead ripping my clothes, breaking my eyeglasses and my watch. The scooter ended on top of me, somehow.

It could have been worse. I landed directly in front of a bus which could have been moving.

Of course, everyone ran to help but

I needed to stay still for a moment and do an inventory to see if I had broken anything. I was stunned. For one horrible moment, I saw three Dexters.

My right knee was bloody and my forehead had a three inch square where the pavement had scraped off skin. I had abrasions on my right hand and arm and lots of bruises, but nothing was broken except my pride. I was sitting on the road while clients and strangers, including Dexter, tried to help. I was lifted by my belt onto the scooter and went to my hotel room, hurting, but nothing required an emergency room visit, thankfully. I wish they had a pill to cure embarrassment, though.

The next day, I looked like (and felt like) the bus had hit me but life went on and I survived. I also slowed down a bit.

The Americans with Disabilities Act mandates that cities put in ramps and cuts but too often they do not look at the angles, especially if it is on a steep hill, and these can be dangerous. Also, some of the automobile ramps that are cut into sidewalks are too steep for scooters or wheelchairs to cross without tipping. In my predicament, if I tilt to the right I can stick out my right leg and catch myself. Unfortunately, if I tilt to my left, I just fall over just like Arte Johnson on his tiny tricycle on "Laugh In". (Young people, ask your parents.)

There is one block in downtown Boston that has no cuts at all. Somehow it was forgotten. Fortunately, I didn't have clients on that block, I just had to pass it to get to others. The only choice in these situations is to drive on the street which usually is not as dangerous as it sounds.

Please, if you see a scooter on the street, it isn't because they want to be there.

HEAR YE!! HEAR YE!!

COME ONE! COME ALL!
Saturday, December 1, 2012

HOLIDAY PARTY

RIVER ROAD CHURCH, BAPTIST

THE LUNCHEON

Another tasty buffet presented by Morrissey's Catering
The menu has not been finalized, but we will have a variety of superb dishes
Cost will be comparable to previous years
Luncheon service will begin at 12 Noon
Assistance will be provided

The Location

River Road Church, Baptist
800 River Road, Henrico County, Corner of River Road and North Ridge Road
Close to U of R, River Road Shopping Center and the Huguenot Bridge and the Willey Bridge

Fellowship House

Closest to Ridge Road
Lots of parking
Side entrance door
Elevator leads to the main hall
Driveway at front entrance with parking
Handicapped ramp to the front door

Chinese Auction – Gift Exchange

Each person brings a gift
Gift valued between \$10 - \$15

Reservations

Call Barbara Bancroft (204-1688) or Judith Moffitt (754-1067)
To save your place at the table, call by November 21, 2012

Devices, Design and Identity

Audrey King, Toronto, Canada
(king.aj@rogers.com)

When a caveman stuck a tree branch through the middle of two large flat stones, seated his curious body on that branch and launched himself from a hilltop, the very first wheelchair, possibly the very first Paralympian, was born.

From the 6th century, we find the earliest pictograph of a wheelchair incised in stone on a Chinese sarcophagus. In the 15th century, Leonardo da Vinci designed the earliest known prototype for a self-propelled vehicle. One hundred years later, King Philip II of Spain is reported to have used an elaborate rolling chair to get around, which King Louis XIV of France later re-created and dubbed his very own "roulette."

The devices we, as polio survivors, use and the environments in which we use them define us. Centuries old stigmatized notions of people "confined to" a wheelchair explain why it is often so difficult for people to accept the freedom that comes with using one, especially a model with power.

It can be said "we have come a long way." In today's world we have wheelchairs that tilt, recline, stand up, climb stairs and go at incredible speeds. But, I have found that a state-of-the-art

Olympic driven wheelchair – swifter, higher, stronger – can force me into identities I don't want.

While leaning forward to check out a "universally accessible" bathroom sink design at a Toronto design exhibition, my wheelchair tilt control got stuck under the sink and could not be reached. All of a sudden I found myself tilting relentlessly upwards – swifter, higher, stronger - prying the sink off the wall with my knees. To escape, I quickly reversed my chair, at which point the sink came off of the wall, shattering into a vast sea of millions of ceramic shards. My preferred identity is not that of a demolition expert; my mobility device seemed to prove otherwise.

More often than not, good design encompasses simplicity, ease-of-use and uncluttered-ness. It also involves consideration of the environment in which such devices are used.

A merchandise display rack packed tightly together in high-end clothing stores did not interface happily with my power wheelchair. The result was a totally "seized-up" chair, stalled between the racks. The only clue to the problem was a \$500 price tag dangling from the spokes, still attached to the cuff of a silk Giorgio Armani blouse. Poor design can result in embarrassment all the way up the chain of command from

an innocent shopper to a chief manager humiliated and on his knees trying to release both parties snippet by snippet.

In today's world, it is gratifying to see more and more people out and about in our communities using all kinds of mobility devices. I meet elderly people proudly driving shiny red scooters like the latest fashion in golf carts, telling me how far they have gone, or about a particular park with awesome accessible paving and water fountains.

People with walkers stop and ask, "Should I get a scooter or power wheelchair? What are the pros and cons of each?" Not so very long ago such strangers would have deliberately been walking on the other side of the street.

Yes, perceptions about people once "confined" to wheelchairs are changing, thanks to our increasing visibility and involvement in the not-always-designed-for-us world. Let's just keep on rolling.

Audrey King, MA (Psychology) is a Toronto artist, author and advocate who worked with children and youth with disabilities for 30 years. She is currently involved in teaching, research and consultation.

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

A Big Thank You ○○○○○○○○○○○○○○○○○○○

Linda VanAken was thanked and honored at our June Luncheon. She has served as our Treasurer for 12 years. Linda has kept our finances in order, organized our budget, sent out dues letters, kept track of address changes and handled many of the duties concerning our retreats. She has done all of this with a smile.

Linda was presented with an engraved crystal vase and flowers. President Carol Kennedy made the presentation.

WE'RE STILL HERE! ... AND WE VOTE!

**WE'RE
STILL
HERE!**

October 7-13, 2012
www.post-polio.org

It sounds a little threatening, doesn't it?

Not voting or expressing our opinions about our countries' policies can threaten us. We must vote, knowing that in some countries polio survivors can't.

People with disabilities are of all political persuasions. Some are liberal, some are conservative. A few of my post-polio friends are libertarians. Many others declare their independent status to be sure politicians of one party or another won't take our collective support for granted or just write us off.

How you vote is your decision and yours alone.

But, how do we know what we hear in a sound bite or read on the Internet is true? Who does the talking-head expert really represent? Will one party cut Medicare more than another? How will the candidates' ideas affect those with pre-existing conditions?

It is up to each of us to vote, armed with the confidence that our selections are based on facts and that they represent our personal philosophies. Our choice will help determine who will be the decision makers about our future quality of life as polio survivors and as citizens of the world.

Take the time to search for information from reputable non-partisan groups. For example, in the United States, Factcheck.

org carefully analyzes claims made by candidates and elected officials. The League of Women voters (www.vote411.org) focuses on registering people to vote and to educating voters about national, state and local elections.

Polio survivor Justin Dart used to remind us: "Vote as if your life depends on it. Because it does." PHI agrees and strongly encourages you to be involved in the process in your country.

We want to help you take action.

The August issue of Post-Polio Health will include an eye-catching form letter that you can mail to your sitting legislators and hopeful candidates. It will inform them about polio and its survivors and enumerate the major issues facing the post-polio population worldwide.

Help us create the list. What is your greatest concern? What issues should we list to educate our legislators about our needs? Send them to info@post-polio.org or call 314-534-0475 by July 2, 2012.

You will be able to add your personal message and let the people in power know that WE'RE STILL HERE! Watch www.post-polio.org and the PHI MEMBERSHIP MEMO for updates.

Joan L. Headley, Executive Director, PHI

Reprinted from Post-Polio Health (formerly called Polio Network News) with permission of Post-Polio Health International (www.post-polio.org). Any further reproduction must have permission from copyright holder.

"Sites" Worth Seeing & Visiting

News From down Under:

"Polio Australia Incorporated" (www.polioaustralia.org.au) suggests viewing an article that highlights the late effects of polio. One needs to go to the "Chain of Protection" website and click on "Adult immunization – the weak link". (www.chainofprotection.org) This 13 minute video discusses polio and is also an excellent article regarding the importance of adults staying current regarding their inoculations.

News from Post-Polio Health:

The summer issue of Post-Polio Health will not arrive in time for us to include the form letter mentioned in the piece "We're still Here!...And We Vote!". This letter can be mailed to your sitting legislators and hopeful candidates. (See Article) You can access the letter by going to www.post-polio.org and downloading it. It will be available later in the summer in the Summer 2012, Vol. 28, Number 3 Issue. If you don't find it the first time you look, keep trying.

News from the Middle East:

Google "C.I.A. Vaccine Ruse" and discover articles from The New York Times, CNN.com, POLITICO.com and World-Time Magazine to read about the Ruse and the War on Polio.

News from CNN

Go to http://www.cnn.com/2012/07/27/health/polio-eradication-efforts/index.html?hpt=hp_c3 and read their account of "Why Polio Hasn't Gone Away, an interesting account of the past and future of polio.

What Having Had Polio Causes, Might Cause and Does Not Cause



*Marny K. Eulberg,
MD,
Family Practice,
Denver, Colorado*

Introduction: As time has elapsed since the major poliomyelitis epidemics ended, following the widespread introduction of the polio vaccines, persons affected by polio, their families and their healthcare providers seem to have less and less clear understanding about what symptoms are caused by polio, which are associated with polio and which are not. Many healthcare providers in practice today have had little experience or training in the care of polio survivors, and they studied the basic pathology that the polio virus causes years ago.

Organizations, such as Post-Polio Health International, which exist to provide information to polio survivors, are frequently asked questions about various symptoms and the relationship to the acute polio. Post-polio groups and expert professionals have indicated that many individuals have been given incorrect or confusing information.

Attributing symptoms or changes in functioning to one's previous polio when the symptom is, in fact, due to a disease or condition that should be treated by an entirely different medical regime than polio/post-polio is not only not helpful but may be dangerous. Polio clinics can help with symptoms that are polio related and can help a person sort out what is and is not related to polio. The primary care physician can treat the non-polio related symptoms, and can also manage polio-related symptoms with guidance from knowledgeable post-polio professionals.

The intent of this article is to provide basic information about what the polio virus does to the human body and to provide a general framework to guide patients, families and healthcare providers as they encounter new symptoms and try to understand them. Often a symptom can be caused by many different mechanisms and sometimes even by a combination of factors.

This article is not meant to be all-inclusive and list every possible cause/disease but to discuss the most common and most frequent conditions. As polio survivors age, especially as they approach the second half of their lives, other medical issues can emerge that may make it difficult to determine exactly what is causing what. Polio survivors should inform their healthcare providers about their prior history of polio because it can directly or indirectly affect their current medical condition.

What does the polio virus do (pathology)?

The diseases that were called "infantile paralysis", acute poliomyelitis or acute polio encephalomyelitis, or simply "polio" were all caused by one of the three polio viruses (type 1, type 2 and type 3). The exact virus causing a person's disease can now be identified in the laboratory but each of the viruses can cause a similar pattern of disease when they infect an individual. As used here, polio virus or virus refers to one or more of the three polio viruses

The virus causes a "flu-like" illness with nausea/vomiting/diarrhea, a fever and perhaps a headache and muscle aches, and, in a small percentage of individuals, varying degrees of paralysis. The majority of persons infected with the virus had only the flu-like illness, did not develop any paralysis and were thereafter immune to that virus.

Less than 5 percent of all individuals that were infected with the virus

developed paralysis of muscles ranging from a few muscles to nearly all the muscles of their body; some people died as a result of the infection. The virus circulates in the cerebrospinal fluid all around the brain and up and down the spinal cord. In the spinal cord, the virus attacked the anterior horn cells (the nerve cells that go out to the muscle and tell the muscle what to do) but did not affect the nerves that go back to the spinal cord with messages about touch, pain, temperature sensation or position sense (where the body part is in space, i.e., "is my foot on the floor or in midair? Or is my foot on a flat surface or a slanted surface?")

The polio virus primarily affected nerves leading to voluntary muscles. Those are muscles that you can control with thought, such as, "I think I'll point with my right index finger." This may include the muscles involved in taking a deep breath, in swallowing, of the face, of the trunk and abdomen and the limbs. There is a lack of consensus among medical professionals about how much the polio virus affected non-voluntary muscles such as those in the bladder or gastrointestinal tract. The polio virus did not seem to cause permanent damage to the heart (cardiac) muscle.

What symptoms/signs are likely related to polio (primary effects)?

Atrophy (muscle wasting). The "skinny arm" or "skinny leg" is a result of the muscle or part of the muscle not getting the message from the nerve that it should contract or move. Related to this is the possible shortening of the limb. In a growing child, bone grows as a result of the muscle pull on it and/or weight bearing. Therefore, many who contracted polio as a growing child may have one arm or leg or foot that is shorter and smaller than the non-affected/less affected limb.

New weakness. In the more than 40 percent of polio survivors who develop post-polio syndrome, increasing muscle weakness

in muscles previously affected or new weakness in muscles that were thought not to have been affected is one of the defining features of the condition.

Loss/absence of reflexes at a joint. For example, when the healthcare provider hits your knee with the reflex hammer and it does not “kick” out. But rarely, a polio survivor may have an exaggerated response or hyperactive reflex.

Muscle fatigue/decreased endurance. When a muscle does not have a full supply of “motor units” it may still be able to function for a limited number of repetitions but it “wears out” sooner. The person may be able to “sprint” but could not run a mile and certainly not a marathon.

Muscular pain. Polio survivors generally describe this as an “achy, burning or sore feeling.” It is thought to be due to overuse of the muscle(s) in the area. Individuals who had acute polio when they were old enough to remember the event say it feels similar to the muscle pain that occurred with the acute polio. Others describe it differently, but polio-related muscular pain is rarely sharp and stabbing.

Biomechanical problems. These are problems related to abnormal positions of a limb around a joint, e.g., one leg being shorter than the other or abnormal curvature(s) of the spine. This can cause mechanical low back pain, increase the likelihood of “wear and tear” arthritis in a joint or a chronic tendonitis/bursitis or even nerve compression problems.

“Polio cold” leg or arm. There are several theories about what causes it, but it is real! Generally the person doesn’t perceive the limb as feeling as cold as it feels when it is touched. It occurs when the environment is cold – such as in winter or in an air-conditioned room. Unless the person has other reasons such as poor arterial circulation from diabetic vascular disease or severe hardening of the arteries that causes poor blood flow in the arteries, “polio cold” leg or arm will not cause delayed healing of fractures or injuries. It is mostly an inconvenience to the individual and his/her bed partner.

Some problems with breathing. These include decreased ability to move enough

air in and out to get ample oxygen into the lungs or to exhale enough carbon dioxide due to new respiratory muscle weakness or from residual muscle weakness from the initial polio. Medically this is called “restrictive lung disease.” Problems include “remembering” to take a breath or to take enough breaths per minute. This is broadly called sleep apnea (central apnea). Paralysis of some muscles of the throat can also cause intermittent blockage of the air passages in the throat, which may also be termed sleep apnea (obstructive).

Certain problems with swallowing. These can cause choking while swallowing, especially thin liquids such as water, and sometimes some of the swallowed material will go into the lungs instead of down into the stomach causing a pneumonia known as aspiration pneumonia. Some people lose weight and have difficulty maintaining adequate nutrition because eating is so time consuming or difficult. (Note: Many people over age 50 have other problems unrelated to polio that can cause problems swallowing. Various tests can determine the exact cause of the dysphagia.)

Osteoporosis/osteopenia. Weight bearing exercise is necessary for bone to become and remain strong. In persons who had paralytic polio the affected limb(s) may have bone that has less than the normal mineral (calcium) content. The terms osteoporosis and osteopenia refer to decreased amount of normal bone tissue; osteoporosis is more severe than osteopenia. These conditions can mean the bone is more “brittle” and may break more easily than normal bone. (Generalized osteoporosis/osteopenia can also occur in certain medical conditions and with increasing age and is usually not related to polio.)

What symptoms/signs may be related to polio (secondary effects)?

Increased wear and tear on joints including osteoarthritis, tendonitis tendon tears, bursitis. When a person has a weak limb, the unaffected or lesser affected leg or arm does more work to compensate, and weakness from polio can lead to arthritis problems in the good limb as well. People who use their arms in place of their legs (crutch walkers, users of canes, manual wheelchair users) put more stress on the

joints of the upper extremities than someone who has normal use of their legs, and this can result in damage to cartilage, tendons and ligaments in the wrists, elbows and shoulders.

Nerve compression. Carpal tunnel syndrome can be caused/aggravated by pressure on the heel of the hand and palm from crutches and canes or from propelling a manual wheelchair. Other nerves may also be compressed by abnormal positions of joints and of the vertebrae in the spine. Symptoms of nerve compression are usually a numbness or tingling, an “electric shock” sensation and sometimes progressive weakness in the area of the body supplied by the particular nerve that is being pinched.

Increased respiratory problems from increasing curvature of the spine resulting in less room for the lungs and internal organs.

Fatigue from increased energy expenditure. Walking with an abnormal gait, use of crutches and propelling a manual wheelchair all require more energy than unimpeded walking. For example, walking with a locked knee can use up 20 percent more energy than walking with an unlocked knee, and walking with two crutches can burn up to twice as much energy as a non-disabled person would use walking the same distance.

Headaches. These can be “muscle contraction” headaches that may be caused by chronic overuse of neck muscles, unusual use of neck muscles when doing daily tasks or related to abnormal positions of the neck from muscle imbalance or scoliosis. Headaches, especially upon awakening, can be from inadequate ventilation (breathing) overnight that may be due to respiratory muscle weakness and/or sleep apnea that may or may not be connected to prior polio.

Emotional issues. These can include post-traumatic stress disorder associated with hospitalizations and medical procedures and/or teasing by childhood peers or dysfunctional family interactions with the person who contracted polio.

Continued on Page 12

What Having Had Polio Causes, Might Cause and Does Not Cause ... Cont.

What symptoms may be compounded by having had polio (tertiary effects)?

High blood pressure and/or coronary heart disease aggravated by weight gain and decreased exercise that were related to limitations imposed by polio.

Weight gain (including overweight and obesity) linked to decreased exercise/activity. Significant obesity, can, of itself, lead to obstructive sleep apnea and restrictive lung disease plus other problems including diabetes, osteoarthritis of hips and knees, etc.

Diabetes, in susceptible individuals, related to decreased activity and/or weight gain.

Skin breakdown, or pressure sores, from prolonged sitting without shifting position, from sleeping in one position due to difficulty turning in bed or from poorly fitting supportive devices (corsets, braces).

Situational depression associated with decreased functioning and independence.

More important than establishing the relationship between a condition and prior polio is finding a treatment or solution for the medical problem. Post-polio experts agree that in most instances the management or treatment plan for the secondary and/or tertiary problems are the same as for people who did not have polio.

What symptoms/signs are NOT related to polio?

Tremor of arm, leg or head especially when that body part is at rest.

Problems with “sense organs” – vision hearing, taste, smell.

Seizures

Allergies to medicines or to things in the environment.

Dizziness or vertigo (“the room spinning”).

Sharp, shooting pains or severe burning pain with numbness.

Generally, polio does not cause numbness, but nerve compression can result from abnormal positions around a joint or from crutch/cane walking or propelling a manual wheelchair and cause these symptoms.

Inability to know the position of a part of the body or where it is in space (decreased proprioception).

Food getting stuck in the lower esophagus (in the mid-chest or lower).

Abdominal pain or diarrhea.

Cancer of any kind.

Liver disease.

Kidney disease.

Most infectious diseases, except perhaps pneumonia in a person with a weak cough or who has swallowing problems and is “aspirating” food into their lungs.

Skin rashes, but unrelieved pressure on areas of the skin can cause skin breakdown and redness.

Diabetes, but weight gain and decreased activity often worsen blood sugar control in persons with other risk factors for diabetes.

Hardening of the arteries (atherosclerosis) in the heart, legs, neck, brain, although lifestyle changes induced by polio may increase the likelihood of developing this when added to other risk factors.

Marny K. Eulberg, MD, is a polio survivor who has worn a brace for more than 30 years. She is a family physician who founded a post-polio clinic in 1985 and has seen more than 1,500 polio survivors. Eulberg was named “Colorado Family physician of the Year” by the Colorado Academy of Family Physicians in 2005. She is a member of the PHI Board of Directors and serves as Secretary. Eulberg can be reached at Post-Polio Clinic, St. Anthony North Family Medicine Center, 8510 Bryant St. Westminster, Colorado 80031, 720- 321-8180.

Reprinted from Post-Polio Health (formerly called Polio Network News) with permission of Post-Polio Health International (www.post-polio.org) Any further reproduction must have permission from copyright holder.

Note to Editors of Newsletters

In the section of our newsletter where we list our officers, we have a paragraph at the bottom of the page regarding copying of articles. We say that anything written by one of our Central VA Post-Polio Group members may be used exactly as written provided credit is given for each article used. (Ex.” From Henry’s Desk”). Then we go on to state that permission for copyrighted articles must be given by the SOURCE OF THE ARTICLE in order for that article to be used. I was very chagrined when I opened a newsletter recently and there were pages scanned and used with “Polio Deja View” clearly in sight at the top of the pages. Now, I don’t know if permission

was sought from Post-Polio Health to reprint, but I do have my doubts. I take copyrights very seriously and I often have to forego using something because I can’t gain permission. However, Post-Polio Health is very generous in giving permission and just e-mail them at: info@post-polio.org and you should be okay. If you need help with this because you are a new editor, feel free to call me at 804-323-9453 or e-mail me at mahaske@hotmail.com. I remember how confusing it was when I took on this job and I would be happy to help another editor navigate the system.

Mary Ann Haske, Editor

Survey Regarding Mid-Month Lunches

We, the Board, have noticed that attendance at the mid-month lunches seems to fluxuate a good bit. We were wondering if there were particular reasons for this. If you have any ideas, we would like to hear them. We can come up with a few reasons, but they may not be relevant. We really need to hear from you. Some of our ideas are:

- The economy*
- Held too frequently*
- The location*
- Did not put in day-planner so forgot*
- Same old crowd*

We need feedback. If there is no interest, we need to know that. President Carol Kennedy has agreed to take calls about the lunches. (740-6833 or ckennedy1619@aol.com)

THANKS FOR ALL THE SUPPORT

Powell Orthotics & Prosthetics *"Providing a Lifetime of Care" Since 1932*

New Location

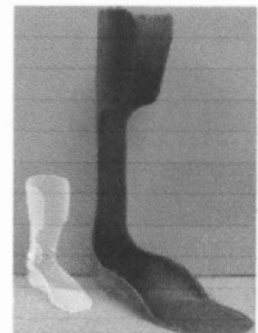
2034 Dabney Rd. Suite C
Richmond, Va

(804) 649-9043

2374 Jefferson Hwy, 102
Waynesboro, Va.

(540) 942-9545

- Custom Knee / Ankle Orthosis
- Lightweight Artificial Limbs
- Corsets & Body Jackets
- Surgical Garments & Stockings
- Custom Molded Shoes
- Rx Arch Supports
- Shoe Modifications & Build-Ups



www.powelloandp.com

**WE DELIVER RIGHT TO YOUR HOME
PROMPT, COURTEOUS SERVICE - 24 HOURS A DAY**



**GAIN INDEPENDENCE WITH STYLE
COME TEST DRIVE ONE TODAY!**
ACHC Accredited

SALES AND RENTAL

- Wheelchairs (custom, power, manual)
- Lift Chairs
- Scooters
- Walkers, Canes & Rollators
- Hospital Equipment
- Oxygen
- CPAP
- HomeFill™ Products
- Full line of Respiratory Products
- Full line of Orthopedic Products
- Pediatric & Adult Rehab Equip
- Bathroom Safety Products
- Nutritional Support-sales
- Incontinence Products-sales

RICHMOND
2277 Dabney Rd. (804) 353-7703
(800) 494-9378




D.P. Stairlift Company
Personal Mobility Products

Complete Mobile Service
Stairway Lifts, Door Openers,
Portable Ramps and Modular Ramp
Systems

Grab bars - installed,
Wheelchair/Scooter Lifts for Vehicles
Repair of Wheelchairs, Scooters, Lift
Chairs and More

**Over 20 Years Experience &
Free Estimates**

Dale Yeatts, President
Phone: 804-763-1100
Toll Free: 877-990-1100
FAX: 804-744-1626
E-mail: stairsbgone@aol.com



Mobility products for your home, auto, and lifestyle

Mobility supercenter

WHEELCHAIR ACCESSIBLE VEHICLES (WAV)



We Service What We Sell • Factory Trained Technicians



Porch Lifts



Custom Seating



Stair Lifts



PORTABLE CEILING LIFTS



CEILING LIFTS



DRIVING AIDS



ELEVATORS

Mobility supercenter
Mobility products for your home, auto and lifestyle

Come See the New Mobility Supercenter!
Tour our new facility
Drive in Service Bay and Customer Lounge
with free popcorn and drinks.

7450 Midlothian Turnpike
North Chesterfield
Virginia 23225

804-231-7774 • www.mobilitysupercenter.com