



*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. 2
Save the Dates

Pg. 3
From Henry's Desk...

Pg. 4
Scholarships

Pg. 4
Condolences

Pg. 5
2013 Budget

Pg. 6
Brace Yourself

Pg. 8
Ignoring the Disabled is
the New Racism

Pg. 9
News from CVPPSG
Meetings

Pg. 9
September Elections

Pg. 10
Anesthesia

Pg. 12
Post-Polio Thoughts

Pg. 13 - Composing a
Memoire

Pg. 13 - Ads

Annual June Luncheon, June 2, 2012

Hard Shell – Bellgrade @ 12:00 Noon

11400 West Huguenot Road, Midlothian, VA 23113 - 804-464-1476

Come celebrate summer by joining us at the Hard Shell's new location. We will have a private room where we will be free to visit members at different tables. The menu will include luncheon items and dinner entrees.

Individual checks – Ample Parking

Contact Barbara Bancroft (204-1688) or Judith Moffitt (754-1067) by Friday, May 25

(The Shoppes at Bellgrade are located on Huguenot Road between Polo Parkway & Robious Road)

No July Meeting

August 4, 2012 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)

You and Your Nutrition

Marilyn Trowsell, Registered Dietitian will speak on the nutritional needs of the elderly with disabilities and address any specific problems that we might have.

No Mid-Month Lunch in June!

Wednesday, July 18, 2012

Mid-Month Lunch at 11:30

Kona Grill

11221 West Broad Street, Glen Allen 23060 (364-5660)

Located next to Whole Foods Market in the West Broad Street Village off I-64

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

Barbara Bancroft (204-1688)

By Monday, July 16th

Wednesday, August 15, 2012

Mid-Month Lunch at 11:30

Mandarin Palace

2811 Hathaway Road, Richmond (272-8020)

Located off Forest Hill Avenue in vicinity of Flowerama, 7-11 & Food Lion

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

Barbara Bancroft (204-1688)

By Monday, August 13th

Mid Month Lunches

Don't Become a Kleptomaniac; See a Doctor ...From Your Editor

Have you seen those ads about Cable versus Direct T.V.? There are several versions of them. They open with a man upset with his cable network for various reasons. In one, the man takes his frustration out by blowing off steam. He gets an eye injury and has to wear an eye patch. People then think he is tough and they chase him away and mug him. Well, you get the drift. In each ad the man's frustrations lead him to trouble. The premise is that, if he had switched from cable, he would not have encountered trouble.

So, my story is that if I had seen a doctor earlier, I would not have become a kleptomaniac. It all started in January with holiday fatigue. I took to my bed when a case of vertigo joined forces with my fatigue. How did I know that bed-rest is bad for vertigo? Should have seen the doctor! I finally saw him and he gave me a set of neck exercises. Maybe I did them too vigorously. I began to have a pain in my shoulder, bad enough to make me feel nauseated. I figured it would go away. This all developed over a series of weeks. I should have seen the doctor. Oh, wait, I did call and ask for a referral when I began to have numbness in my right pointer. Occasionally my thumb and middle finger went numb. The orthopedist suggested P.T. because he felt that I had a nerve impingement in my neck.

Now, I know that we polios need to be careful about P.T. but the fingers were now experiencing an electric shock feeling. I had to wait about 10 days to see the P.T. and everything was just getting worse. After several sessions, the pain in my shoulder eased but the fingers were still numb. However, I was feeling up to taking the train to Washington DC to meet my daughter and her friend for some sightseeing.

We had two great days. We spent the first day at the Newseum. It would take several days to do justice to this museum about the news media. The next day it turned so cold and we had planned to see the monuments. Neil at least had brought gloves and was able to keep his wheelchair driving hand warm. The two of us in wheelchairs were so happy to find we could go inside the Lincoln Memorial and get out of the cold.

All good things have to come to an end, and I returned to Union Station to wait for my train. My fingers were not doing too well

but I was happy. I wheeled around killing time and saw a bakery. The macaroons beckoned me. I put one in a bag and then added a chocolate chip cookie. It was not easy to pick them up with the paper provided since I could not feel what I was doing. The cashier asked me what I had in the bag and I told her one of each. She looked at me funny and said I had 3 cookies. I looked at her innocently and said no, I only wanted one of each and I had 2 cookies. I paid for 2 and went on my way to my train. I was riding along reading my e-reader and listening to my ancient Walkman, when I decided to eat the chocolate chip cookie. I took it out of the bag only to discover it was not an "it" but a "them". There were 2 cookies stuck together and my numb fingers could not feel the height of the cookies. I felt really terrible. I never meant to cheat the bakery. I felt guilty. I had looked so innocent when the clerk asked me how many were in the bag. I would not have started down my path of crime if I had just nipped the whole thing in the bud at the first symptom.

Seriously, there were about 3 instances that a call to the doctor could have kept this from getting out of hand. I seemed to call the doctor too late in the game each time. I always think things will get better with time. Obviously, I am mistaken. There are a few postscripts. The shoulder pain is gone; the electrical pulse is almost gone; when it comes back I can control it with my little isometric exercises; the numbness is not as intense. Also, I really love my P.T. Well, I'll save that for another story.

A Bonus Note from the Editor...

There are two articles in this issue that deal with barriers for the disabled and for the decrease in enthusiasm for the ADA regulations. It seemed appropriate to have them appear together as one is written by a polio survivor and the other is written by a friend of the disabled. It is good to have both voices heard.

Save the Dates

Regular Monthly Meetings: Sept. 8, Oct. 6, Nov. 10 (3:00pm)

Holiday Luncheon: Dec. 1, 2012 at River Road Church Baptist



Eighty-six Days in the Wilderness

“Son, you have polio” expressed Dr. Robert Morton on Saturday morning, September 23, 1950. These words were terrifying to me at age 11 and they still convey a haunting anxiety when I think of them today. I remember every detail of that awful Saturday and what a permanent impact the poliovirus made on my life. Many times over the years I have wondered and asked myself, “Why me?” The impact of crippling polio affected my self-esteem, my self-image, and my goals in life, my personality defenses, my religious pilgrimage, and my understanding of others.

All of the synoptic gospels describe the forty days that Jesus spent in the Wilderness. During this time Jesus fasted and when he left the Wilderness he was famished. In Matthew and Luke he was tempted by the devil to eat ample bread, seek the help of angels and have dominion over the world. He resisted these temptations.

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.



Eighty-six Days in the Wilderness

Cont'd from page 3



In a polio ward crowded with children, there was sufficient bread but no angels were around and most of the children were unable to move their legs and arms or even breathe without the aid of an iron lung. The children could not even imagine dominion over anything. There was no devil to tempt the children with instant cures. Over time there was only the agonizing pain of

physical therapy and the brainwashing command of “No pain, no gain.”

I was one of the children on the polio ward at the Medical College of Virginia Hospital during the summer of 1950, Virginia's most severe polio year. I spent eighty-six days in the polio ward wilderness. I endured the pain of physical therapy, but there was some gain. Can I say there were blessings? Over time I did gain some self-esteem, saw myself and others

with different insights and perceptions and a new determination burst forth that has carried me to this hour. I have not seen or heard the voice of God, but when I least expect it, glimpses of God break into my being. It can be as simple as a sermon about a Way in the Wilderness or a story involving a broken vase or the choir singing “Christ Is Made the Sure Foundation” or a poor but grateful patient responding with a tearful smile.

During the summer of 1950 racial segregation was still the law, even in hospitals. However, on the white polio ward African American nurses were welcome and were more than willing to take the risks involved. One of them wrote the following in my notebook:

Richmond, VA

October 15, 1950

Dear Henry,

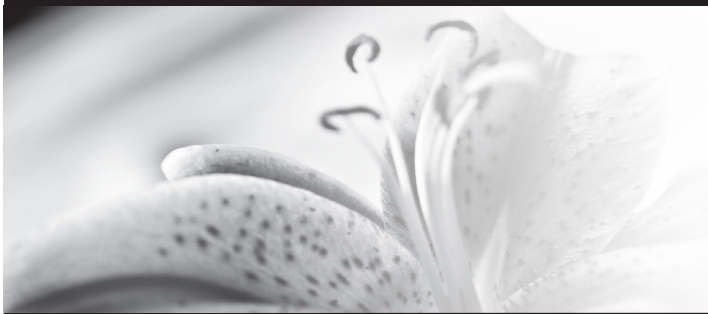
It was just you to be so pleasant at all times. Keep on keeping on.

Mrs. Therla Hall P.N.

Scholarship Funds Available!

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

CONDOLENCES



We wish to express our sympathy to the family of James C. Todd who passed away February 17, 2012.

2013 Budget

Income/Expense Budgets Jan. 2013 to Dec. 2013

Revenues

Gifts, grants, or donations	
Dues (Mar. – Aug.)	\$1,400.00
Donations (Mar. – Aug.) (come with Dues checks.)	\$1,300.00
United Way receipts	\$550.00
Advertising in Newsletter	\$850.00
Memorial donations	\$ _
	Total Income <u>\$4,100.00</u>

Expenses

Newsletter Printing	\$1,300.00
Postage	\$400.00
Gifts, grants (Children’s Hosp., Nat’l PPS)	\$200.00
Fund Raising expense	\$100.00
Speakers gifts	\$100.00
Professional fees (Bank acct, Web Master	\$250.00
Meeting expenses	\$200.00
Lunches & Xmas Party	\$1,000.00
Misc	\$500.00
	Total Expenses projected <u>\$4,050.00</u>

The Social Committee is funded by our Brown Bag Auctions

Brace Yourself . . . Chapter 5

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

*By Wallace W. (Jerry) Epperson, Jr.
Chapter 5*

In addition to the paralyzed left leg, other clear evidence of my polio were hammertoes on my right foot, as the tendons tightened and made the toes go into a permanent claw-like position. Since the toes do not touch down normally, this reduces balance, especially forward and backwards. It also results in corns and calluses, and extreme difficulty breaking in new shoes.

The tendons drawing up had two other obvious affects: very high arches in both feet, and tight heel cords so when relaxed, the foot points down, not at a 90° angle to the leg, as is normal. This lends to the foot dragging as I pull it forward to take a step.

My father was well over six feet tall and I would have been as well, instead of just six foot. Both legs were shortened by the polio, and I ended up with my right leg being about an inch and a half shorter than my left. Of course, this added to my limp.

From the waist up, my body is proportioned to be six foot four. My legs are more appropriate for someone five foot seven or eight. In apparel terms, I am long-waisted, and in trousers, a long-rise. Just to round out the picture, my arms are an ape-like thirty-seven inches, an impossible-to-find arm length in normal shirts.

I was taught to walk wearing a long leg brace on my paralyzed left leg and a below the knee brace on the right. These required truly hideous high-top shoes and crutches. The high-top shoes and braces were to help keep my feet at the normal ninety degree angle, and not allow them to drop as they do when relaxed.

The left brace curved under my buttocks so I would "sit" into the brace, which supported me with two metal rails

on either side of the leg. A leather pad at my knee, secured by leather straps kept my leg straight (not bending) when walking. Several leather covered metal bands behind the leg kept the leg from bending backwards – always a danger since there are no muscles to prevent it. If I were to stand without this brace and put weight on the leg, it would bend backwards (hyper-extend) and break. Ouch.

Both braces had pegs on the bottom that snapped into the heels of my shoes. On occasion these would pop out, sometimes creating a gradual fall. Because I could feel this, usually I let myself down gently into a seat or onto the floor.

When you think about it, the foot bends at the ankle, not the heel, so these type braces caused pain across the top of the foot over time and with use. Later, the braces were modified to have an ankle joint which helped greatly. These had a screw and bolt that would fall out regularly, and I could usually feel it and fall gently or ask for help to a seat. I have spent hours looking for those special #!%# screws. After a while, you learned to hate this type of problem.

As I grew into being a teenager, I was allowed to walk without the half brace on my right leg, and to wear more normal looking shoes, not the ugly high-tops. (Yeah!) Although others probably did not notice, this was a big deal to me.

Also, after years of my weight going onto my left knee, I asked that the brace be modified with straps above and below the knee, and the removal of the pad on the kneecap. The knee had become hyper-sensitive to the touch after years of pressure.

Because of the polio, my feet never grew normally. As an adult, I wear a size four shoe on my left foot and a size six on my right. For a six footer, shoe sizes of ten to twelve would be more normal. Once again, this affected my balance greatly.

Imagine standing on a brace which you cannot control other than to put weight on it, and on a very small foot with dysfunctional toes. Just standing still is a chore without something to lean on, at least a cane.

Consider walking. To take a step, I swing the left leg forward using my hip. Because the foot is held at a 90° angle, the left foot always lands on the rear edge of the heel, not on the full foot as normal. On a wet or slick surface, this just slides forward and "BAM" you have fallen.

To go down stairs, you swing the left leg out, and bend the right knee until you sense the left foot is on the lower stair. Then you can gently lift the right foot and lower it to the next stair. Each stair requires this same process because the left leg cannot be bent.

On the rare occasion, the metal rails on the brace would snap and throw me into a fall. Once or twice, the broken metal would rip into the flesh of the leg, a nasty occurrence.

Early in my work at Scott & Stringfellow, my brace snapped suddenly just below the knee, throwing me into a row of file cabinets. Books and "stuff" on top of the cabinets went everywhere, and I ended up in a pile on the floor. The crash brought folks in from around the firm. All you can do is laugh it off, and ask someone to go to my car and get the emergency crutches.

Other times the lock on the knee of the brace would not catch so when I would stand, the left leg would bend and, again, create a fall. This was fairly common, and more embarrassing than harmful.

Walking was not a mindless task. There were times my mind would wander or I would be talking, and forget to throw my left leg forward, causing an immediate tumble, face first. This never fails to impress clients, as it did when taking an out-of-town visitor to lunch. I fell crossing the street, too.

Obviously I never could run, although this was challenged years later. My work

required a lot of air travel and I would have to race as fast as I could to keep up with the mob exiting planes. I noticed that at the top of the ramp, I was often breathless and nearly faint. Soon, I realized that while trying to remember to swing my leg, hold onto a briefcase and cane, I was forgetting to breathe. I know it sounds impossible, but it's true.

One last thought on the brace. A new brace did not adjust to your leg – your leg had to adjust to the brace. Until the skin would toughen where the brace touched and rubbed, there was bruising and sometimes broken skin. In the 1950's and 1960's, it was suggested you use a "horse salve" to toughen your skin where it was rubbed by the brace. It had been developed to help horse's skins under saddles. In the 1970's, I was told that over many years of use, the "horse salve" made the skin thinner and more likely to tear. Lucky me.

Walking with an obvious limp honestly never bothered me. Unless it was pointed out to me, or I had a fall or a challenge getting around, I forgot about it. When I was allowed to walk without the right leg brace and the crutches, it was easy to forget about the limp doing everyday activities. Locking and unlocking the brace to sit or stand was automatic, and somehow my brain adapted to my head moving side to side as I walked, without losing focus.

You get used to children asking "What's wrong with him, Mommy?" and even some good-natured teasing. I remember friends mimicking my limp, looking to me more like the grandfather in "The Real McCoy's", who also had a limp. His looked more like he had a rock in his shoe, at least to me.

I would try to make light of it when I could. I told people that on Halloween, I limped on the opposite leg so no one could recognize me. I was also tempted to dress up as Igor, Dr. Frankenstein's assistant, on Halloween but dragging my leg didn't appeal to me. Even so, my feelings would get hurt on occasion. I still remember Mrs. Lenz, my friend Larry's mother, telling me she didn't want me sitting on her sofa because I

just flopped down. Truthfully, with only one knee that worked, when I unlocked my brace I had a difficult time gently lowering myself into a seat. She was right – I just didn't like to hear it.

Much of my life was spent going to doctors. While Dr. Herbert Park was my primary polio doctor in Richmond, I had a Dr. Good in Warm Springs. Of course, I had a general practitioner, a dentist that met every requirement for a horror film, and my eye doctor, Dr. Burton. In addition, there were visits to the Powell's "brace shop" for the braces, crutches and the special mis-matched shoes (i.e. they were different sizes) that had to be fitted onto the brace. They also needed other adaptations like massive arch supports and steel shanks. The people at Powell's became like family to me over the decades.

By the way, it is difficult to be 100% reliant upon things mechanical that wear or break. The best plans can be ruined by a broken strap, a lost screw or worse. Even today, scooters and handicapped accessible ramp-vans dictate my life. I rarely get angry at people, but I lose my temper with things easily.

One bright spot growing up was my physical therapist, Mrs. Crawley, from Blackstone. My legs and trunk had to be stretched regularly after my nearly a year in Warm Springs to keep the tendons from contracting, perhaps requiring additional surgery. I would lay on our kitchen table on a sheet, in my underwear, and she would twist my legs in different ways, making certain they had full flexibility, bending my knees then straightening the legs fully, and then she would work on my ticklish feet, especially under the arches where tendons had been repaired. She would stretch the six or seven incisions, and then massage my muscles to keep them loose.

The massage was tricky. My left leg is just flesh, no muscles, so it had no resistance and is easily bruised or hurt. In flexing, it must be held gently or it would just fall off the table.

In sharp contrast, my right leg was doing the work of two, and it was extremely muscular. To keep it stretched

and flexible was a chore, and a lot of work.

Mrs. Crawley also worked on my back and especially on my left side where a major tendon transplant had occurred and left a scar from my groin to my hip bone.

She visited me weekly from when I was ten to until I was well into high school. Her daughter, maybe six or eight years older than me, learned from her and actually did some of my physical therapy toward the end.

This hour and a half visit made Mrs. Crawley a very special friend and confidant. We could talk about things that I could never discuss with my parents.

I was nearly 50 before I found another physical therapist as good as Mrs. Crawley. Too many could not handle the gentle needs of the paralyzed leg and the workout the good leg needed, without doing more harm than good.

By the way, lying on our kitchen table in my underwear getting bent in every way possible never slowed the traffic flow through our home. There were my friends, my mother's friends and neighbors, and even some of my sister's friends, all of whom would drop by for a visit or some food. This seemed true everywhere I went for treatment. At hospitals or physical therapists, privacy was minimal. Where they had the curtains that would be pulled shut for privacy, they seldom were. There was no privacy at all in Warm Springs. I still remember the doctors bringing by patients and others, who knows who, to see my scars and learn how I was being treated. This is tough on a kid.

One last example, if I may. I had just returned home from surgery, a treatment or whatever, but I could not walk. In bed, I was forced to use a bed pan – never a popular choice – and while so engaged, a flock of my friends came in the house to see me and my mother said to my horror, "go on back – he's in his room".

I challenge anyone to display any dignity on a bed pan.

Ignoring the Disabled is the New Racism

By Bonnie Atwood

I get a lot of invitations, and some of them infuriate me.

Recently was invited to a cocktail party sponsored by a professional association. A few days later, I went to a college alumni event. The mixer was to be upstairs in an upscale Richmond restaurant. The alumni gathering was also upstairs, on a fun rooftop balcony looking over Shockoe Bottom. What's not to like? Both parties were in splendid restaurants. I have dined at both, and I highly recommend them. Glittery, glamorous, grilled chicken on little sticks, drinks, laughs, business cards.

The problem is this: You can't attend unless you can climb the steps. Groups ignore accessibility much of the time. (In fairness the college alumni association told me it will be more mindful in the future, and for that I am very appreciative.) But just recently, I have received three more such invitations – one from a hobby club supposedly open to the public, and two from social-justice organizations! Mind you, these are good people, and good associations

I anticipate some personal questions Here are the answers.

No, I do not have a disability. I can walk, run and skip. Sometimes I bypass the elevator and choose to walk up steps.

Yes, I adore old architecture. I think a beautiful old building is a work of God. I appreciate it more than I do a tree or a painting. I support the Historic Richmond Foundation and send letters asking that old buildings be saved from wrecking balls. I like it that structures are grandfathered into code, and I don't demand major modifications.

Yes, I know how hard it is to plan events. I've done a lot of them, and I've made some mistakes that I don't want to repeat. You have to plan around holidays, weather, money, everything.

Somebody always complains about something, even the free food.

I used to be able to enjoy myself, blissfully unaware of accessibility. It didn't cross my mind. It was not until I attended some events at which good friends had to sit apart from the crowd that I noticed. When I did notice, I felt absolutely mortified. I don't expect people to remodel their houses and make them all accessible. A lot of houses have staircases, small doors and so forth and people should be able to live and entertain as best they can within their budget and preferences. If you do choose to make your private party accessible, you can find local companies that can supply temporary ramps, or even wheelchair accessible bathrooms.

Accessibility is not a radical idea. Holding a big or public event in a venue that is not wheelchair-accessible is the same thing as holding an event at a "whites only" club. In the latter case, you're excluding African-Americans – an exclusion that most people today find appalling. When leaving out people with disabilities, planners think it's permissible so long as none of the members use wheelchairs.

But white people used to say the same thing about African-American people, or any minority for that matter. That's what a lot of people said when they went to their swimming pools and Scout troop and PTAs. They said, "But we don't have to accommodate those people. They are not members." Well, it's small wonder they are not members. Their application forms were preempted before they were even filled out. The mega-message was that people just expected to be surrounded by people much like themselves.

Exclusion of people with disabilities is not usually done with hate. Sometimes it is prejudice, sometimes fear and pity. Most of the time, it's probably merely an oversight – but the resulting exclusion is still the same. These practices are

persisting, and after a while, such oversights become less and less tolerable – if not by the person excluded, then often by his friends and family. As with any kind of discrimination, history will judge these faux pas harshly. In the human rights field, what is embarrassment today becomes shame tomorrow.

These are solvable problems. But the solutions have to include respect. Including people who have to enter through the back door, or go through the kitchen or be carried in, or plugged in through videoconferencing is just not enough. That's like telling Rosa Parks that there are perfectly good seats just a couple of rows back.

Bonnie Atwood lives in Richmond. Contact her at BonAtwood@verizon.net.

(The above article is reprinted, with permission, from the Richmond Times Dispatch, Thursday, July 21, 2011. We appreciate the RTD and the author, Bonnie Atwood for giving their consent. Any further reproduction must be done with their consent.)



NEWS FROM CVPPSG MEETINGS

Be Prepared, That's the Boy Scouts' Marching Song

At the February meeting our group's topic for discussion was "The Relationship Between Caregiver and Partner". The first members to share were those who had no partner. They immediately listed the people in their lives who helped them. They were well aware of how vulnerable they are and are very grateful for any and all help. They are cognizant of expressing their gratitude. These friends are called upon to help with Xmas decorating, with putting away and taking out seasonal clothes, with transportation and with just being supportive.

Then we heard from the members who have a partner who serves at times as a caregiver. It appeared that the partner might be taken for granted. The discussion centered on the importance

of open dialogue and the importance of affirming the caregiver.

We segued into what would happen if the caregiver was taken ill or had to be away. What became apparent is that the couples had not really processed that thought and had not made contingency plans. The partner of one of our couples actually had an incident where the caregiver became ill. Since the "polio" spouse did not drive and they did not have an up-to-date list of friends to call, they put off medical help. The rest of the meeting we discussed the danger of being too complacent and the importance of preparing together for the unexpected.

I am going to take this one step further. We did not discuss this at our meeting, but I think it deserves being

mentioned. I live in a high-rise condo building. Although it is not a building for "seniors", it does have a large senior population. Recently, we had several residents, who are singles, become suddenly very ill. What is to become of their pets? No contingency plan! Fortunately, other residents pitched in to help. However, one person has been helping by walking a dog for a few months. That seems excessive to me. So, I am going to add another item for the Post-Polio community to consider. Not only is it important to have caregivers/friends/partners in our lives that assist us and plan with us for unforeseen events, but we also need to plan for the care of our pets. That brings us back to the title of this piece...Be Prepared.

Fun Was Had by ALL



In March we gathered together with bag lunches in tow to play board games. Who says we can't have a fun, happy second childhood? Dessert was provided by a few of the Board Members. This group loves a good brownie or cookie. There was a lot of laughter as we settled into two groups and chose games. Some played Mexican Train Dominoes and others played Phase Ten. There was a trivia game played toward the end. Fortunately, the powers that be know that we are an extremely competitive group and let it be known there would be no grand prize winners. However, they did draw names and award gift cards.

Field Trip

In April, we took a field trip to the Mobility Supercenter, an establishment that sells adapted vehicles. Many of us have used them in the past. However, they recently moved to a much larger space and have expanded their concept. I guess one could call it one stop shopping. Need grab bars, a ceiling/tracking lift, or an accessible shower? They can sell you the components and furnish you with a contractor to do the work. Want your ramp lubricated and your van inspected? They will soon be able to do both in one easy trip. I say easy because their waiting area is especially nice. It is a grand space. While we listened to a presentation, we enjoyed popcorn, cookies, fruit and beverages. Yes, a fun time was had by all in April too!

September Elections

In preparation for the coming elections, a nominating committee has been formed.

If you are interested in running for a seat on the board or if you wish to nominate someone, please contact one of the following people:

Carol Ranelli 804-794-7359

Fay Garnett 804-740-2422

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

Anesthesia Use in Polio Survivors: What's New?

Selma H. Calmes, MD, Chairman and Professor (retired), Anesthesiology Department, Olive View/UCLA Medical Center, Sylmar, California, shcmd@ucla.edu

Do we know anything new about anesthesia for polio survivors? By reviewing reports in medical journals we find that in the last two years, 2008-2010, there were five case reports (each about a single post-polio patient having anesthesia) in the medical literature and one study of a group. We will look at useful aspects of these cases and also comment on two other aspects of anesthesia care that are important.



Selma H. Calmes, MD, is a polio survivor and a member of PHI's board of directors.

Three of the five case reports were about regional anesthesia (RA). Regional anesthesia means that a local anesthesia drug, such as lidocaine, is injected to numb nerves in the back (spinal or epidural) or other body locations such as arms or legs (various nerve blocks). It is very safe and is preferred to general anesthesia, because it blocks the pain signals coming from the surgery site to the

brain. This is very favorable for patients' well-being. However, some operations can't be done with regional anesthesia. It is often technically hard to do RA in post-polio patients with scoliosis, especially if Harrington rods are present.

There is a new tool to help place RA: portable ultrasound (US) devices that help anesthesiologist find exactly where to administer the anesthesia drug. This technique is now commonly used in the United States, especially in teaching hospitals. One of the five cases was the first to report using US to place a spinal anesthetic in a post-polio patient with Harrington rods. Another case of regional anesthesia involved severe scoliosis and reported using a computed tomography (CT) scan to look at a post-polio patient's back anatomy before trying spinal anesthesia. Both techniques helped the anesthesiologists know where to place the needle for local anesthesia successfully and easily. The third case report on regional anesthesia was about a nerve block of the leg for postoperative pain relief after surgery on that leg.

The group study was from Brazil and reported on 123 patients having 162 operations, mostly orthopedic surgery. Mean patient age was young – 35 years, and only three patients had serious medical diseases in addition to having had polio. Regional anesthesia was used for 64 percent of patients. No significant anesthesia complications occurred. These patients were followed for 22 months postoperatively, and there was no change in neurologic status.

This study documents that young post-polio patients do well during anesthesia, especially with RA. However, American patients are much older, in their 70s and 80s, and so also have diseases of aging, such as heart disease, diabetes and hypertension, all significant for anesthesia risk. Often, these diseases of aging are much more important than any post-polio issues. So, we still need a large

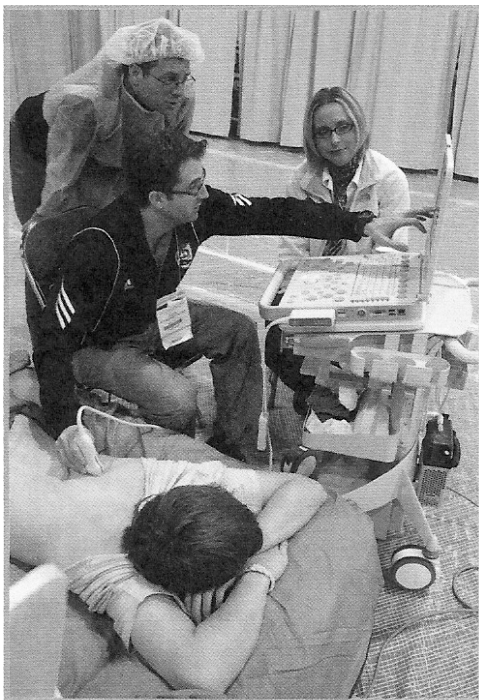
group study of the U.S. polio population during anesthesia.

What do we learn from these reports? First, this is increasing evidence that RA can be safely used in post-polio patients. And, so far, there is no evidence that PPS gets worse after RA. (This had been a concern after inflammatory proteins were found in the spinal fluid of some post-polio patients.) Technical difficulties can be overcome by using US or CT imaging. Also, regional anesthesia can safely be used for postop pain relief. So polio patients can experience the many benefits of modern anesthesia care!

The importance of two other aspects of anesthesia care for post-polio patients is becoming clearer: the need for preoperative pulmonary function tests and sleep apnea issues. Respiratory muscle function gets worse as we age, especially for those who had polio. It is important to know what a particular patient's pulmonary status is before most operations, especially upper abdominal or chest operations. This is measured with pulmonary function tests (PFTs) by a pulmonary physician. Those who used iron lungs should definitely have preop PFTs, because they seem to be at high risk for postop respiratory failure. Lung function should be optimized by treating any infection, controlling bronchospasm and assisting coughing before high-risk patient have major surgery and a pulmonologist needs to be involved in the postop care.

Sleep apnea is common in post-polio patients, and many need CPAP/BiPAP devices. Sleep apnea is well-documented to be a risk factor for anesthesia incident, both at the beginning of anesthesia and, especially, at the end of the case as patients begin to breathe on their own. Useful guidelines are in place to improve safety during anesthesia. Patients with sleep apnea, especially those on CPAP/BiPAP, should let the surgeons know this early in the surgery scheduling process, so they

can alert everyone on the surgical team. Patients should bring their CPAP devices to hospital and, after the breathing tube is removed, CPAP should begin. This requires someone to set up the machine, usually a respiratory therapist. If regional anesthesia is used, the CPAP device can even be used during the procedure, although not all anesthesiologists are comfortable with this.



Anesthesiologists at their annual meeting learn how to use ultrasound to place a nerve block of the arm or shoulder.

Photo by Steve Donisch courtesy of the American Society of Anesthesiologists

Should we make any changes in the present recommendations for anesthesia for polio survivors? Regional anesthesia appears to be safe for post-polio patients, and the benefits – in terms of pain relief and anesthesia safety – are worth a possible small risk. So, the recommendations stand as is. It is essential to realize that the recommendations are not based on actual data; there is no significant data yet about how polio patients actually do during anesthesia. See the sidebar for other resources about anesthesia.

For more information on anesthesia:

Recommendations: www.post-polio.org/edu/hpros/sum-anes.html

Anesthesia update. Separating fact from fear: www.post-polio.org/net/10thConfAnesthesiaCalmes.pdf

Sleep apnea issues: www.post-polio.org/edu/pphnews/pph22-1.html

Lambert DA et al. Postpolio syndrome and anesthesia,

Anesthesiology 2005;103:638-644

(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.)

Post-Polio Thoughts THAT OLD FEELING

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

It got their attention—our friend Mac wheeling along in his power chair, lugging three two-by-fours and a standard toilet stool into the City Council meeting.

He'd been there before, our friend Mac, and had made no headway trying to describe why the city government building restrooms made it impossible for people like him in wheelchairs to use those facilities.

This night he showed them. Plopped down his two-by-fours to square off the dimensions of a stall, arranged the toilet stool in the center, and proceeded to demonstrate, tastefully, why this does not work—and then made clear what needed to be done. By the end of Mac's show, he had a unanimous vote for change, and the city government building had accessible restrooms within weeks.

Lesson One in Making the ADA Work For You.

But that was 20 years ago. Enthusiasm ran high among those of us with disabilities back then. We saw a world of freedom beckoning. Suddenly there were buildings we could get into, pathways we could sail through, reachable drinking fountains. We spread the word, touted the universal importance of accessibility. We talked with city planning directors, property owners, parents watching children frolic in the park. We shared our vision, and it became theirs. We showed them how—and why. What spectacular results!

But time marched on. As with other initiatives to great social change, after outstanding bursts of accomplishment, efforts began to wane, and today public response to the ADA remains “a work in progress.”

A local polio survivor serves on a committee dealing with housing units being built in a retirement community. “Management” tells her they want to comply with ADA regulations. Only, apparently, not too often—a pitiful one in fifty of the independent living apartments currently under construction is accessible. Could they possibly believe that those of us with disabilities cannot also be independent?

They say budget concerns cause ADA cuts; they can adapt later if they need to. Besides, they say, people are turned off by apartments that look as if the purchasers, themselves, might be disabled some day.

Indeed, the retirement village's resort-like ads project, through appealing photos, the image of a mecca for active aging folks. The relatively affluent. The non-disabled. Nary a wheelchair, scooter, or walker in sight. Can it be this describes the typical retiree?

Who are “the disabled,” anyway? Our fathers, putting up with debilitating arthritis all these years? Niece Amy, living with MS since she was 35? Beloved Uncle Ralph, using a walker after recovery from a stroke? Our sweet old neighbor, still baking cookies as she did when we

were kids, in spite of her frequent need for oxygen? Thousands of veterans returning home scarred and maimed from defending us in wars? These people couldn't possibly be independent?

Surely we have not become so outrageously biased as to suggest relegating them all to an invisible society. Who today would be offended by the sight of a wheelchair? A brace? An artificial limb? Are there actually those who do not accept people who are disabled as viable members of a community?

Let's find out. Get people's attention again. Let's remind them of the tune they danced to twenty years ago when they began to embrace the ADA. The kindness in their hearts. The way they felt when they made room for one more imperfect soul in their world. Let's start shouting from the rooftops as we did before. Only this time the message is: WE'RE STILL HERE!

Let's see how it goes. I'm betting on us.

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

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

Composing a Memoire

(A friend of our treasurer, Linda VanAken, sent her this note about writing one's memoire. We thought it might be helpful to all of you out there with writer's block who need a jumpstart.)

“Yesterday I went to my PPS monthly meeting. One of our members talked about how he has been writing his memoirs over the years. He became interested in doing this through a writing class that he's been taking for the past 10 years. His teacher stresses it is best to write about snippets of your life rather than getting bogged down by starting at the beginning. Our speaker has done precisely that and has accumulated quite a portfolio of his writings. He has quite a story to tell, being very severely affected by polio. He said the hardest and most important thing to do is organize these snippets in a way that you can easily find them as they really can stack up over the years. I hope he eventually puts them in book form and publishes them as they are very interesting.”

From a friend of Linda

THANKS FOR ALL THE SUPPORT

Powell Orthotics & Prosthetics

“Providing a Lifetime of Care” Since 1932

New Location

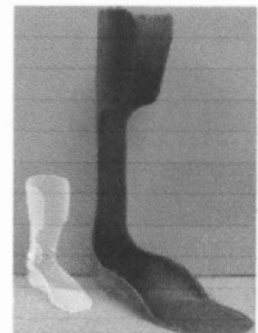
2034 Dabney Rd. Suite C
Richmond, Va

(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