

POLIO DEJA VIEW



March, April, May 2013

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
A Freedom Driver
- Pg. 7
The Power of Negative
Thinking
- Pg. 7
Condolences
- Pg. 8
Trusting Parents
- Pg. 10
The Sessions
- Pg. 11
Promoting Positive
Solutions
- Pg. 12
FYI
- Pg. 13
Save the Date
- Pg. 13 - Ads

March 2, 2013

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

(Remember to come at 1:30 for refreshment and social time! Cookies provided – bring your own beverage)

How to Know if You Are Ready for an Emergency

Laura L. Southard is a Public Outreach Coordinator, Virginia Dept. of Emergency Management. She helps to provide information to the media and the public during a disaster. Her work has involved flu epidemics, earthquakes, hurricanes and tornadoes and the Virginia Tech shootings.

April 6, 2013

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

(Remember to come at 1:30 for refreshment and social time! Cookies provided – bring your own beverage)

Replacing Chaos with Clarity in Senior Housing Options

Kevin Parks, Licensed ALF Administrator, is President, Senior Housing Advisor for A Helping Hand Senior Care Services, LLC

May 4, 2013

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

(Remember to come at 1:30 for refreshment and social time! Cookies provided – bring your own beverage)

UNOS, United Network for Organ Sharing

Lisa Schaffner is the Public Relations and Marketing Director for UNOS, a national non-profit based in Richmond that matches organs from deceased donors to those on the national waiting list. For 23 years Lisa was the main news anchor for WRIC-TV8, anchoring the ABC affiliate's 4:30, 6:00 and 11:00 pm newscasts.

Wednesday, March 20, 2013

Mid-Month Lunch at 11:30

Clippers Cafe

3511 Courthouse Road, North Chesterfield, VA

Driving South on Courthouse Rd., cross Hull, turn and go north, cross Hull & it is on right. Driving on Hull, take Courthouse Rd. North & it is on right.

www.clipperscafe.com or call 804-447-4152 • Homemade Desserts are their specialty!

For a reservation, call Carol Kennedy (740-6833) or Barbara Bancroft (204-1688) by Monday, March 18th.

Wednesday, April 17, 2013

Mid-Month Lunch at 11:30

Buz and Ned's Real Barbecue

8205 W. Broad St., Richmond (Henrico), VA

Located on South Side of Broad about 1 block east of Parham (346-4227)

For a reservation, call Carol Kennedy (740-6833) or Barbara Bancroft (204-1688) by Monday, April 15th.

Wednesday, May 15, 2013

Mid-Month Lunch at 11:30

Amuse Restaurant, Virginia Museum of Fine Arts

200 North Boulevard, Richmond

Reservations must be confirmed one month in advance!

For a reservation, call Carol Kennedy (740-6833) or Barbara Bancroft (204-1688) by Monday, April 15h.

Mid Month Lunches

Complacency

...From Your Editor

When my children asked me to give them ideas for a Christmas gift for me, I said I was in great shape. I could not think of anything I needed but I would like a gift card for my Kindle or a gift of a massage. My family was a bit disgruntled because they thought I was being rather uncooperative. So, what was I? Was I totally satisfied, uncooperative or complacent? I discovered, on Christmas Day, that there were items for sale that I did not realize even existed. These were things that I would not have thought of but am so glad to have.

Christmas Eve a neighbor brought over her Hanukah cookies. While visiting, she mentioned that she and her husband loved sitting in their condo and looking over into my windows and seeing the tree and other decorations. She was the 2nd neighbor to make that comment and I was surprised because the tree was on the piano rather distant from the window. My son and daughter-in-law looked at each other and sort of giggled at the neighbor's comment. The next morning, I opened their gift and found a combination bath towel/robe garment. Tom and Chantal said that they remembered me saying that I am so tired after a shower that I would drip-dry rather than use up more energy drying with a towel. If my blinds were open, I would imagine my towel wrapped body could be quite a sight. No more would I have to struggle with a too small towel and a too large body! The garment was thick terry cloth with slits for your arms to go through if you needed to use your hands, and Velcro fastenings up the front. I could put it on wet, sit in my comfortable chair (in front of the window) and read until the robe/towel was wet and I was dry. I love it, but my complacency kept me from exploring alternatives for my non-drying life-style.

In my stocking, I found an "Extend-A-Hand". This is a miniature metal back-scratcher that telescopes out into a very long arm. It has so many uses. It can reach into tight spots where my grabber is too wide. The other day I left something on the back seat of the van. I did not want to fool with opening the ramp. I opened the driver side sliding door and pulled out the back-scratcher gadget, extended the hand and was able to pull the item over to me with no effort. (I understand that in Florida this gadget is called a "Bear Claw".) Have I been complacent or do I need to explore catalogs or sites for items for the disabled and discover what is out there?

Sue and Neil gave me a Vera Bradley duffel bag, (I have very few "name" items so I will flaunt this one). It is huge. I think I was a little surprised as I was not certain why they had selected a duffel bag. I didn't think I needed one. Well, they proceeded to talk about my journey on Amtrak up to NY to visit them. I suppose that, in their eyes, I looked like an itinerant peddler making his way down the road. If I recall correctly, I had a suitcase with a backpack zipped on it and then various items hanging from the wheelchair. Hmm...there was a charger strapped on the chair along with a neck pillow dangling, and a water bottle, a lunch bag, a brief case with my computer in it, another container with my kindle, Walkman and cd's, and a pocketbook, all hanging from the back and sides of the chair. Maybe a big duffel with all the things hanging from my chair placed inside it might be a little saner. My excuse is that I was not complacent but unaware of the sight. Maybe a picture of me would have helped. At least there were no frying pans or pots hanging down and I did not have a supply of needles and thread on me for sale.

The gift giving kept on happening. Paul and Candace gave me a felt type lap tray for my laptop. It would never have occurred to me that I should have one. Man, it beats using the kitchen tray to hold my computer. I love this thing. The computer is not slipping all around and my pens and notes stay put. It has made typing easier and conserves my energy.

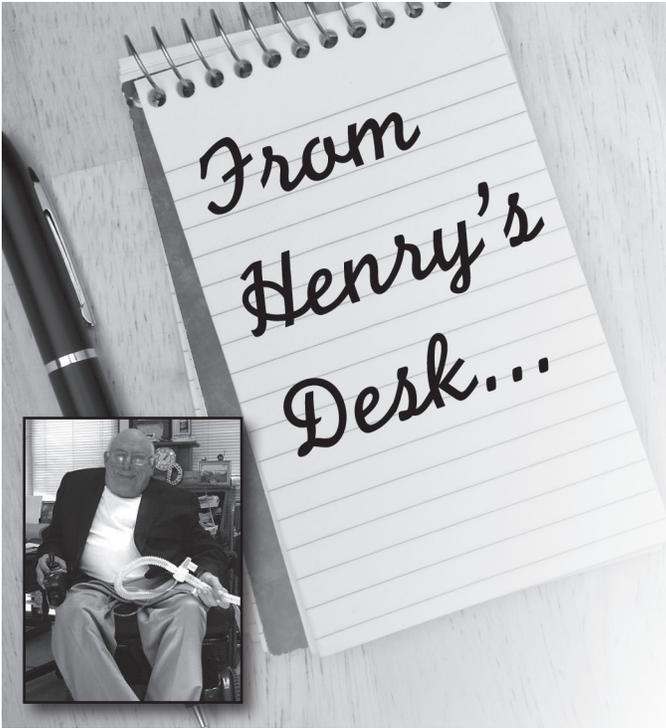
Maybe I am a bit complacent. Maybe I need to say that, though I am content, there might be products that could improve my energy level or comfort level. All of these thoughts are beginning to remind me of an experience I had in NY last fall. Now, I would swear to you that my kitchen is perfect. I can ride under the cooktop so that I can stir things on the stove safely. The same goes for the sink. I ride under it and am ready to tackle dirty pots. I have a pull out shelf that becomes a little table that I ride under and sit and prep to my heart's content. While I was in NY, Sue and Neil wanted me to go with them to a site that had a "state-of-the-art" demo home for disabled buyers. The ramp from the garage into the kitchen was great, etc. but the kitchen was fabulous! There was a continuous counter from the fridge at one end of a "u" all around to the sink at the other end of the "u". It was stainless steel so heat was not a factor. Do you know what this means? One would not have to lift a huge pot of pasta to get it to the sink. One would just slide it around. I want that! No, I need that! "That" is not possible for me because my kitchen is galley with a door at either end. Guess what else this kitchen did. One could push a button and the cabinets above the counter knelt down. One could reach all items. One could dust the top and middle shelves. If I had that I would not have to wait 'til some tall son came to visit to deal with those upper shelves. The bathrooms were fabulous. There were items all over the house that would make life easier. There were even sections designed with the needs of a disabled child addressed. My eyes were opened.

My purpose in talking about the house and kitchen is to make us aware that there are new developments in construction. If you were planning to renovate or build, it would be good to research or consult an authority. The man who built the demo house has been involved with the disabled for years. He said there are architects and builders all over the country who are very knowledgeable in improvements for the disabled.

Some new products have nothing to do with a disability but are perfect for the disabled. I saw a product the other day that can coordinate with a smart phone and is able to raise or lower the heat or air or turn on lights and other functions. So, if you are on the way home and it is very cold, you could turn up the heat in advance of arriving home. This would be great for those of us who have an issue with extreme cold.

Don't be complacent. Stay alert. If your abilities change, think of ways to make life easier. Things that can make life easier are not necessarily found in catalogs for the disabled. The able-bodied like to be comfortable, too. Happy searching!

(The designer, Daniel Szalai, CR, UDCR, has a website, www.ADALifestyles.com. If you have building questions, I think he would try and help or refer you to an architect in your area. Also, the Mobility Supercenter, which hosted our April 2012 meeting, has a demo for bathroom innovations elevators, grab bars, etc.)



“Where are the scales of justice?”

Works of fiction do not often focus on polio. Some years ago I wrote an article on *Crossing to Safety* by Wallace Stegner. In that book one of the main characters is a survivor of polio. She is an educated woman who is married to a college professor. During a trip to Italy she is looking at a work of art, which was a painting by Piero della Francesca in Arezzo Italy. The painting revealed a recently resurrected Jesus, half in and half out of the grave. There was still some of the look of death on Jesus' body. A passage from the novel described the scene.

“But I (Larry, Sally's husband) noticed that Sally stood a long time on her crutches in front of that painting propped temporarily against a frame of raw two-by-fours. She studied it soberly, with something like recognition or acknowledgment in her eyes, as if those who have been dead understand things that will never be understood by those who have only lived.”

I can identify with many interesting passages in this novel. Larry, Sally's husband, tells this story in the first person. Larry comments on the uncertainty of life with these words: “You can plan all you want to. You can lie in your morning bed and fill whole notebooks

The rest of the story is continued on page 4

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If you would like to talk with someone about Post-Polio Syndrome, you are welcome to contact the above members. If you send an e-mail, please refer to APPS@ in the subject heading.

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

Please send articles for or comments about our newsletter, as well as changes, additions or deletions for the newsletter mailing list to:

Mary Ann Haske, Newsletter Editor
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or contact me at: (804) 323-9453 or mahaske@hotmail.com

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval of the Central Virginia Post Polio Support Group.

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“Where are the scales of justice?”

Cont'd from page 3

with schemes and intentions. But within a single afternoon, within hours or minutes, everything you plan and everything you have fought to make yourself can be undone as a slug is undone when salt is poured on him. And right up to the moment when you find yourself dissolving into foam you can still believe you are doing fine.” This sounds a bit like the process of PPS. Many of us have “fought” to be contributors and not burdens to our individual worlds, only now to feel undone by the “salt” of PPS.

Near the end of the novel, Larry writes of his observations upon living his adult life with his polio-disabled wife.

“One of the peculiarities of polio is that its victims, once they have recovered from the virus and settled down to whatever muscular control it has left them, live a sort of charmed life. Crippled as they are, they are rarely ill, they are surprisingly tough and durable, they astonish their sound companions with their capacity to endure. But that is not forever. There comes a time in the life of every such patient when the whole system---muscles, organs, bones, joints---begins to fall apart all at once, like the wonderful one hoss-shay. Every polio patient is warned to expect that time, every polio family lives with the foretold doom waiting for it at some unknown but expected time in the future. One learns to live with it by turning away from it, by not looking. And yet on occasion one is aware of an intense, furtive watchfulness, and the victim, the doomed one, must surely have just as often the vulnerable sense of being watched.”

In my mind, the above paragraph is describing PPS. The author of this novel, Wallace Stegner, lived from 1909 to 1993. *Crossing to Safety* was published in 1987, around the time PPS was being identified as an entity.

More recently I read a novel entitled *Nemesis* by Philip Roth. This novel was published in 2010. The story is about a twenty-three old young man named Eugene “Bucky” Cantor who lived in a Jewish neighborhood in Newark, New Jersey. The story follows the polio epidemic during the summer of 1944 in New Jersey. Cantor grew up in the neighborhood where the story evolves. He was the Phys Ed teacher at the local school and in the summer of 1944 he was the director of the local neighborhood. His mother had died during his childbirth and his father had embezzled money and went to prison. Bucky was raised by his maternal grandparents in a third floor apartment. Bucky had poor eyesight and wore thick glasses. As a result he was ineligible to serve in the military during World War II. He felt guilty about this as many of his best friends were in Europe.

Then polio hits the neighborhood and one by one some of the boys that come to the playground contract polio including two that die. Bucky goes to visit the father of one of the deceased boys and the following conversation occurs.

Where are the scales of justice?” the poor man asked.

I don't know, Mr. Michaels.’

“Why does tragedy always strike down the people who least deserve it?”

“I don't know the answer” Mr. Cantor replied.

“Why not me instead of him?”

Mr. Cantor has no response at all to such a question He could only shrug.

“A boy - tragedy strikes a boy, the cruelty of it!” Mr. Michaels said, pounding the arm of his chair with his open hand. “The meaninglessness of it! A terrible disease drops from the sky and somebody is dead overnight. A child, no less!”

Bucky has a girlfriend who is a daughter of a local Jewish physician. The young lady is working at a summer camp in Pennsylvania. She communicates to Bucky that there is a job opening at the camp because one of the male counselors has been drafted. She begs him to take the job to escape the risk of contracting polio. With ambivalence he accepts the job and goes to western Pennsylvania. The tragedy of the story is that one of the young boys at the camp contracts polio and then others. Bucky concludes that he is a carrier of polio. Eventually Bucky contracts polio. Unlike most polio victims he does not possess the will to fight and try to overcome the resultant paralysis of one side of his body. He rejects the love of his girlfriend despite her declarations that she loves him and his disability does not frighten her or change her love for him.

In my opinion this is not an uplifting polio story but it does reveal feelings that many of us felt to some extent. It describes the fear of polio, the random selection of victims, the guilt that can be associated with being a victim and some theological issues. I highly recommend this novel and I emphasize the fact that the story is fiction as there was no polio epidemic in Newark in 1944.

References:

Crossing to Safety by Wallace Stegner. Penguin Books. New York. 1987, pp. 274-275, 201, 288, 336

Nemesis by Philip Roth, Vintage Books, New York, New York, 2010, page 48.

A Freedom Driver . . . ChapterS 8, 9 & 10

(The following are the eighth, ninth, and tenth chapters of Jerry Epperson's account of his life with polio. Enjoy, the Editor)

By Wallace W. (Jerry) Epperson, Jr.

Chapter 8 – “Not a Jock”

Sports were clearly not in my future but my father loved to play golf or watch it on television. Of course, those were the days when Arnold Palmer was the king, and everyone's favorite.

My father told me there used to be a “Putt-Putt” like miniature golf course somewhere in Victoria but it closed years ago. Somehow he was able to get four or five of the very old wood-shafted clubs - all putters - and brought them home.

The home we moved into in the late 1950's was on two large lots, both of which sloped down gradually from 13th Street to the alley. The Lucy's, its former owners, had grown large 8-foot privacy hedges in the yard behind the house that also divided the lot next door in half side-to-side. In the front of the side yard was a massive hemlock tree, taller than the house, and a shorter, broad hemlock, about 10 feet high and thirty feet wide. Someone had cut out a cave-like area inside this lower hemlock.

In the side yard was a long clothes line with metal poles, and in the yard behind the house was a rock-lined cement gold fish pond about twelve feet by five feet, with several wooden boxes in the pond that grew lily pads and flowers. It was quite lovely. To the west side of it was my mother's flower garden with roses and a seemingly endless supply of Japanese beetles.

When my father got the old golf clubs, several of us built a backyard golf course using clay flowerpots for the holes. Looking back, it was quite creative, using the hedges as both a boundary and also a vertical hazard requiring you to hit over them. The fishpond was also a great

natural hazard as were the hemlocks. We had par 3, 4 and 5 holes.

Most of the time, we used plastic golf balls that would not go very far plus they would not break windows. On occasion, we would get a real golf ball or two that usually ended up getting hit into the neighbor's yards. We never heard glass break, fortunately.

The golf course became popular with friends visiting regularly. Over time, we got some additional old clubs including a 9-iron to help get over the hedges, and more plastic golf balls because we were always losing them in the hedges or in others' yards.

Playing backyard golf was probably the closest thing to exercise that I ever got as a pre-teen.

In the ninth grade, I began to manage the various high school sports teams, eventually including the football, basketball and track teams. The only other sport was baseball in a small school like ours. Once I got my driver's license I could drive players to the games (when we didn't use a school bus) and some of the players home after school.

It was fun most of the time, but early in one basketball season, I followed a new coach to Bluestone High School in neighboring Mecklenburg County. There were three carloads of players and soon we were lost. Our short caravan pulled into a full parking lot next to a new school and its gymnasium. We were nearly late for the 8 p.m. game, so we rushed out of our cars, got the two large trunks that had our uniforms and supplies, and we ran into the front doors of the school gym.

The shouting and noise inside suddenly went silent, as we saw we had showed up at a black high school. Players on the court, cheerleaders and fans all stared at us and we stared back. The new coach ordered us back to our cars.

This was 1963 or 1964 before our

schools integrated, and soon we were in our cars. A crowd had followed us outside and was laughing at us. We sat and waited for our coach who was getting instructions to Bluestone. I don't remember being scared, but we were very uncomfortable.

We got to our game on time but we were the source of jokes for quite a while.

I vaguely remember going to the local black school once for some sort of football practice. The Victoria High School football field was adequate with some red clay bald spots, but the black high school's field had large rocks in the field that you could trip over, or fall on and get hurt. Several black players watched us, and explained the rocks were a “home team advantage” because their players knew where the rocks were.

Managing the various teams allowed me to earn an athletic letter and join the “Monogram Club”. I got a letter jacket in the school colors, maroon and gray, similar to the VPI colors. In fact, our cheerleaders used several of the VPI cheers, too, for some reason.

There was a required initiation to get into the Monogram Club that involved mud and verbal humiliation but some authority figure decided that I could not do the initiation. Why? I have no idea.

I also never took physical education. I understood why I could not run or do the exercises, but I did not take the classes, either. Why? Who knows? I always assumed it was the polio, for some reason.

Each of these made me feel both different and excluded, although I know it was well intended.

One last thought about my exposure to the black community. I had almost no exposure to any other ethnicities in Victoria. Our high school Spanish teacher was a lady a local farmer had met and married when overseas in World War II. I didn't take Spanish, but I guess she

was our only “Hispanic”.

On our four-block Main Street business district, one storefront had a “five and dime” store run by a Jewish man and his mother. I never went there and I never met them, but I remembered friends that went there for the penny candy.

In high school, we had two Muslim teachers (math and physics) who were teaching in our rural school while working on degrees at Arkansas State, I think. The men were cousins, and were married. Both were good teachers and had great senses of humor. To raise money one weekend, the two had a car wash. They washed Mom’s car and offered to wax it, too. When I returned they had waxed it – including the windows – not knowing better. The windshield never was completely clear after that, as Dad noticed repeatedly. I wish I could remember where they were from.

As far back as I can remember, a wonderful black lady, Jeannette, was helping me with exercises, stretching and other polio-related things. She didn’t live with us, but would be at my home many days helping me, Mom or babysitting me when Mom had to go somewhere. I remember seeing her downtown one-day, meeting her children and being surprised. Somehow I thought we were her family. As I got older, we saw her less often, and by the time I was in college, I saw her rarely. Whenever I saw her, even as an adult, we would hug and catch up. She was closer to me than most of my relatives.

Another memory growing up was “Uncle Charlie”, an older black man that would always come to our back door. I never understood why. Even when you encouraged him to come into the den door like everyone did, he said “no sir”. I wondered why he said “sir” to me, too.

No one came in through our front door, ever, which led into our seldom-used living room. It was the only door we ever locked for some reason.

Uncle Charlie would help Dad around the house with various work, although sometimes he just needed some cash and Dad always helped him, if he could. He was a warm, friendly man who showed me how to paint, drive a nail and use a drill. He must not have done a good job because I am horrible doing those things today.

Every summer, Dad and Uncle Charlie would repair and paint an old wooden bench in our backyard. Eventually it got so rickety that no one could sit on it. When Dad finally got rid of it was one of the rare times I saw him cry. Mom told me that Dad and his father (who died the year I was born) built that bench together and it was very special to him.

I remember going to see Uncle Charlie when he was sick, taking him food, and driving him to his doctor a couple of times. Dad and Uncle Charlie could talk for hours and were friends. I am pretty sure Uncle Charlie knew Dad’s father, too.

In the mid-1960’s in the middle of our schools being integrated, there were some protest marches at our county courthouse. In a photo in our local weekly newspaper, Uncle Charlie was on the front row of the protesters. Dad was upset, and surprised because he always treated Uncle Charlie like family.

I don’t think I ever saw Uncle Charlie again. Until I saw that photo, I never knew Uncle Charlie’s last name. It was Hatcher.

I miss Jeannette and Uncle Charlie. I’d love to see them again.

By the way, I only knew of one Catholic family in Victoria, the O’Brien’s. They had to drive to either Blackstone or Richmond to go to church, I remember. The O’Brien family was very well liked, and the son, Michael, was a year younger than me. I only have one memory of Mr. O’Brien. A carload of my guy friends and I somehow got to the county fair in Chase City, about 20 miles away. The Jaycees or some other men’s club

sponsored it, and it had lots of rides and games to win prizes. It also had a girly “Hoochie Koochie” show with the girls dancing outside in harem outfits between shows. The four or five of us watched from a distance and eventually got enough combined nerve to buy tickets to go in. We were all under age, but we thought it was worth it.

As the girls finished their brief dance to loud music on the stage, we got in line with many other men to pay our dollar to get in. We were about three or four back from the front of the line when the man selling tickets stood up, and Mr. O’Brien took his place. Oh no! What if he wouldn’t let us in or, worse, told our parents?

The line kept moving and soon each of us sheepishly handed our dollar to Mr. O’Brien and went in the tent. We got to see women the age of our mothers and teachers undress. Yes, we enjoyed it and were the envy of our friends back in school. Mr. O’Brien never ratted us out, thank heavens.

Growing up in this small town, with minimal exposure to other ethnicities has been very useful to me, I think. I never experienced the negative influences that exist too often in larger communities. It has certainly helped as I have gotten to know so many others world wide in my work.

Chapter 9 *“The Power of Negative Thinking”*

I have never been inclined to smoke or drink. My father did both.

Dad was a great guy, no doubt, for as long as I can remember he was elected to be the union representative handling all the local railroad men’s union work. He spent hours pecking away on his old manual typewriter or on the phone arguing for other men’s rights and claims. These were complex issues, complicated by the 1959 merger when the family-run Virginian Railway was acquired by the Norfolk & Western. The union agreements that resulted from the merger were unusual, since the same union represented both railroads and favored the surviving N & W to the detriment of the Virginian railroad men.

Dad smoked regularly, but dropped cigarettes for a pipe late in life.

Many of the railroad men drank regularly. Dad was also a veteran and active in the VFW (Veterans of Foreign Wars), which also had a lot of drinkers. Simply, put my father could not hold his liquor. Not even just a little.

My mother was vigorously against his drinking and her compromise was to let Dad keep a bottle in the pantry off our kitchen. In the evenings, Dad would go into the pantry and stand and drink and he sometimes ended up drunk during the meal. Really drunk. Face in the dinner

plate drunk.

I grew up with my sister, mother and I scared that we could not get Dad awake when the railroad gave him a “call”, the one-hour notice to show up at the yard office. Missing a call could get you fired.

About every six or eight weeks, we would get a phone call and have to get Dad at the VFW Hall or elsewhere, because he was too drunk to drive home. We would have to get a neighbor to go get him because Dad had usually taken our car.

His drinking resulted in arguments with Mom getting upset and Dad saying he was not good enough for her. Sadly, I blamed Dad’s drinking on my being such a disappointment to him. Today, I know that was not true, but to a child, it was very real.

Seeing him like this taught me not to drink. Not drinking in high school was unusual for a guy. At UVA it made you a very small minority.

I always told others that I didn’t drink because of my balance, and that would have been a good reason. It just wasn’t true.

I was always afraid that if I started drinking, I would not stop, and would be the same unpleasant drunk my father became. I didn’t hate Dad for drinking; I just didn’t want to be like him.

By the way, when Dad retired, he stopped drinking. Go figure.

Another negative influence that helped

me was my high school principal, Mr. Thweatt. We never got along for some reason, even though his son was in my class and we got along fine.

Mr. Thweatt was a VPI grad and before becoming principal, he taught “shop”, a course I did not take.

Every high school senior had a closed-door visit with Mr. Thweatt in the weeks before graduation. Mine did not go well. In blunt terms, he told me despite good grades and good SAT scores (the best in my small class of 51 students), I was foolish for going to UVA and I would end up embarrassing myself and flunking out. He told me there was no way I would graduate from UVA so I should change schools. He implied that my family background with no one going to college would show in my results.

I don’t remember exactly how I responded but I was not very respectful, and I think I called him a glorified shop teacher.

Needless to say, he did not come to my graduation in Charlottesville four years later, although I should have thanked him for making me so angry that I did not want him to be proven correct. Was that his idea in saying what he did? No. I think he was just a jerk.

I saw him decades later at a restaurant. I spoke to his wonderful wife but was terse to him. He was not happy to see me, either.

Articles continue on page 8

CONDOLENCES



We wish to express our sympathy to Sarah and the entire family of Martin Eugene Maples who passed away on December 8, 2012

Chapter 10 *“Trusting Parents”*

My mother was the great stay-at-home Mom, so typical from the 1950's sit-coms on television. A former Miss Crewe (Virginia), her life was devoted to Dad, Nancy and me, and when my grandmother (Mom's mother) came to live with us, it seemed like Mom had trouble letting my grandmother do any chores around the house. She did let her wash the dishes.

My grandmother, Julia Kelley, was an orphan. She and her brother, my uncle Harold Flanagan, were raised in an orphanage in South Carolina, just south of Gastonia, North Carolina.

She had a sister, Mabel, who was very strong willed and lived in Charlotte, North Carolina. Visits from Aunt Mabel were always traumatic – everyone was scared of her, and she was very critical of most things. Visits to Charlotte were always dreaded as well because Aunt Mabel would always show off the church she was active in and her perfect house. In college, for some reason Grandma, my girlfriend, Kathy, and I had a meal at Aunt Mabel's. She had fixed her specialty, squash casserole. I hate squash.

Aunt Mabel served each of our plates, giving generous helpings. The other food looked good. I decided to force down the squash so I could relax and enjoy the other dishes. Just as I finished the last bit of the horrible gruel, Aunt Mabel's face lit up and she said “I am so glad you love my special dish!” and she scooped an even larger serving onto my plate. I didn't dare look at Kathy – we would both crack up.

In Gastonia, Grandma had two elderly, “old maid” relatives that lived together. Both were delightful.

My grandmother was an RN and would be called on by family often to go for weeks at a time to take care of whoever needed care. I felt others took advantage of her because I never heard her decline anyone who called. Of course, her life

was dedicated to others, and that also included me and I had my various polio-related surgeries – and other ailments from broken limbs to having my tonsils and appendix removed.

She was a tiny, soft -spoken lady who never learned how to drive or write a check. My grandfather, “Pop”, always took care of her. Like my father, he was a railroad man who lived in Crewe, about 16 miles from Victoria, until he was transferred to Suffolk.

Pop always made a big fuss over me. I remember when a new town reservoir was being dug off the road to Burkeville. Pop drove my father and me out to the reservoir, still under construction, and he drove down onto the bottom. I thought it was so great to ride around what would be deep underwater in only hours.

For some reason, flashlights fascinated me as a child. Dad got upset with me more than once for borrowing his railroad lantern to play with. He had to have it with him at work, and hated to have to search for it. Seeing this once, on his next visit Pop brought me seven different flashlights, all different sizes and colors. I loved them.

Pop passed away when I was eight. To this day, I still feel like I am more like Pop than any other relative.

Many years after Pop died, my grandmother got an unexpected letter. It explained that because the taxes had not been paid on a building lot in Kitty Hawk, North Carolina, it had been sold at auction, the taxes paid, and the remainder was included in a modest check. Grandma never knew Pop had bought the property, probably to retire there.

Since she did not drive, when I got my license, I drove Grandma to visit relatives like Pop's sister-in-law, Olive, in Crewe or other relatives in Rice, Lynchburg, and North Carolina. I remember driving her somewhere in the rain, hitting the brakes too hard, skidding and sliding, ending up turned around facing the wrong way. Another passenger would have been

scared but Grandma just said “Wheee! That was fun!”.

Grandma spent her time in her room upstairs watching television – she liked some soap operas and “Guy Lombardo” music – or at the end of the kitchen table sipping coffee, or in our seldom used living room in her rocker looking out the picture window. Sometimes, she made quilts, often as gifts. She passed away in 1982, and is still missed.

Dad's work on the railroad required him to overnight in Norfolk or Roanoke, so when he got home, he wanted my mother's home cooking. Her barbeque chicken, pot roast, fried chicken, and other dishes were excellent, often served with a pear salad, homemade rolls, and desserts like a lop-sided chocolate cake, chocolate or coconut pie or my favorite, brown sugar chess. We also had home-churned ice cream in the summer. Mom's bread was even better when our neighbor, June Hazlewood, would give us some of her country butter that she made a couple times a year.

I never thought of us as rich or poor. Dad had a good job and seemed to do well. The only time I remember money worries were when either the railroad men or the coal miners went on strike. Both would close down the railroad, sometimes for weeks at a time. We were fortunate, because Dad had a dear friend, Billy Millican, who owned a regional refrigerated trucking line. Billy would always let Dad drive a truck if the railroad wasn't running.

When Dad was home, we could not have sandwiches, Italian food or anything canned or frozen like the often-advertised “TV dinners”. Those were served when Dad was out and I still like Chef Boy-ar-Dee. Meals were always served in the kitchen unless we had “company”, then we would use the dining room.

The dining room had an old chandelier that was at best dim in a dark room. It was one of several quirks about our old brick house. The tin roof always leaked, the furnace – once coal fired then

converted to oil – always needed repair, and the front porch floor planks warped frequently. The plumbing made loud noises but as I heard frequently, “if you fix one thing, everything else breaks”.

Until I was a teenager, I stayed downstairs in a small bedroom, behind my parent’s bedroom. Going upstairs or into the basement was a challenge for me.

Most importantly, our home had lots of room, and all I needed was the first floor. We were blessed to have it.

When at home, Dad was a deacon in our church, loved to play golf at a 9-hole course that about 20 of the railroad men constructed themselves on a farm just outside of town, or go hunting. My golf was horrible because of my balance, and Dad only took me hunting once in the woods off the Burkeville road. It was memorable because we ran into Roy Clark of “Hee Haw” fame on television, who grew up in nearby Meherrin. We sat, ate Vienna sausages from a can and crackers, and talked. We never fired a shot.

Dad loved country music – including “Hee Haw”, the Grand Ole Opry, and occasionally we would travel to “Maggie Valley” in the mountains of North Carolina to listen to the music.

As a typical kid, I loved rock and roll, learning it from listening to my sister and her friends, and watching American Bandstand. I had a drum set, and while not very good, I did play briefly with a small band in Fredericksburg at a college hangout. At least I could sit while playing.

Unlike most of my friends whose parents were strict with their driving, I cannot remember my parents refusing me use of the family car. It was probably because of my polio, because they saw the car as giving me freedom.

Because of this and my not drinking, it seemed like I was always driving groups to events and dances. Carloads of us would go to carnivals and fairs, dances

at South Hill, Farmville or Blackstone, or several times to see James Brown and his Fabulous Flames at the Richmond Mosque. What a great show.

There were the usual teenage adventures. One night at a dance in South Hill, one of my friends got drunk and passed out. Driving home, other friends stuck his head out the rear window trying to wake him, and somehow he slipped and nearly fell out the window at 50 mph. They desperately held on to his legs until I could stop the car. We went to the town reservoir, threw him in the water and he eventually woke up enough to go home.

Another July 4th, we had a dance at the Community Center in Victoria. One of my friends had a visiting cousin from New Jersey who had some “cherry bomb” firecrackers. Driving around he would light one, throw it out and watch the reaction of the car behind us when it exploded. Being nighttime, you could see the bright light as they exploded under the following car. It was a hoot until he was having trouble lighting one of the firecrackers and rolled up the window. He lit it, and forgetting the window was up, bounced it off the glass onto the floor of the back seat. I slammed on the brakes, slid to a stop and we all fell out of the car doors as the bomb exploded. Smoke and little pieces of black paper filled the car, as the car behind us drove by laughing.

The cousin continued to throw cherry bombs. Going up Main Street approaching the town’s only stoplight, he tossed a cherry bomb under a parked car. Unfortunately, this idiot did not see it was a police car with Trooper Mac Edmundson in it.

We were stopped immediately and got a very strong lecture. I drove the New Jersey cousin home and never saw him again.

I was embarrassed one Sunday morning by a large red mark on my cheek that was difficult to explain. I dated a tall, nice girl a couple of times. Driving home one night from another date, I saw this girl

walking beside the “gravel piles” just outside of town. I stopped and she got in, crying and upset. She had been on a date with a friend of mine who had tried inappropriate things so she climbed out of the car and was walking home. Listening to her talk, I turned to say something and she slapped me harder I have ever been hit. She yelled, “How could you let me go out with him? I thought we were friends!” I was dumbfounded, and explained that I never dated him so I didn’t know.

I loved to drive. I still do. In Victoria we had to go twenty to forty miles just to see a movie. I knew every car type, and made many plastic car models. When the new cars were introduced each fall, it was a huge deal and everyone went to see the new models. As small as Victoria was, it had Chevrolet, Ford, Pontiac and Plymouth dealerships.

One week before the new cars were in the dealer showrooms, Dad took me to Mr. Smithson’s farm and hidden in his barn were four of the new 1957 Chevrolets. I got to see them before everyone else. The auto industry lost a lot when new car excitement disappeared.

In my opinion, being able to drive is a great equalizer to the disabled. We can at least drive anywhere we want even if we cannot walk there. Conversely, losing the ability to drive is a huge problem. My vehicle is so important to my sense of freedom that even when I traveled for work, I always rented a car. I needed access to that vehicle everywhere I went.

“The Sessions” – Polio and Sex on the Big Silver Screen

William Stothers, San Diego, California

wstothers@cox.net

Hollywood has a history of portraying people with disabilities as objects of pity, inspirational “supercrips” or embittered villains. So going to see a film about a man with a disability seeking to lose his virginity sets alarm bells clanging. “The Sessions” puts those expectant fears to rest.

Beyond “disability correctness,” however, for polio survivors this film stirs deep memories of our own growing up experience.

Based on the writings and life of Mark O’Brien, a poet and writer who had polio and spent most of his time in an iron lung, the R-rated film is an engaging, often lighthearted, portrayal of a 38-year-old severely disabled man who lives independently in an apartment in Berkeley, California. Mark manages his personal care attendants, gets out into the community on a gurney, and writes poetry in addition to essays and articles for several publications.

He’s no wallflower or shut-in, but, like all of us, he has his self-doubts and struggles. He yearns for love and intimacy. He falls for Amanda, one of his personal assistants. Finally, he screws up his nerve to tell her he loves her. Pause. For while Amanda cares a lot for Mark, “love” and all that that means frightens her off. Mark is left feeling his old sense of low self-worth and shame.

I’m sure many of us with disabilities have felt the sting of hearing “I really like you, but...only as a friend,” or words to that effect. I can relate.

Deeply distressed, Mark, who is a devout Catholic, consults his priest about his desire to experience sex. He wants permission to follow his therapist’s urging to hire a sex surrogate. After some dramatic reflection, the priest says he thinks God will give him a pass on having sex outside of marriage. “Go for it,” he says.

The film follows Mark’s halting journey with sex surrogate Cheryl. Sensitively played by actor John Hawkes, Mark stumbles and is awkward in his first encounters with Cheryl, who has her own learning curve but is very matter-of-fact and professional.

In their first session, Cheryl asks Mark: “Do you have any area of unusual sensitivity? Any parts of your body you don’t want me to touch?”

Mark responds, “I have normal sensitivity all over. It’s just that my muscles don’t work. You can touch me anywhere.”

That’s polio for you.

You’ve got to see “The Sessions” for yourself to see how it plays out. But the context of the film is pretty realistic in showing that a polio survivor with a significant disability can live a remarkably normal life and experience mature feelings of real intimacy and love.

Kathi Wolfe, a writer and poet herself who has a disability, writes: “... it was with Mark as it has been and will continue to be for so many of us: joy, pain, hurt, pleasure, humor, shyness and chutzpah are indelibly intertwined in life. Keats spoke of what he called ‘negative capability’ – of the poet being capable of being ‘in uncertainties, mysteries, (and) doubts....’”

In reviewing the film, long-time disability advocate and scholar Anthony Tusler said, “O’Brien was one of those polios [sic] that used his intellect and sense of humor to connect with the wider world. We’ve known many of them, and most are now gone. I’m not sure what it is about polios. One theory of mine is they gained confidence in who they were in the open wards and the polio camps of the 50s. They found their disabled brothers and sisters early on, and they changed the world.... [They refused to believe it was okay to exclude their disabled brothers and sisters, their community, from life, liberty, and the pursuit of happiness.]”

The reaction among people with disabilities has been overwhelmingly positive. People embrace the honesty and matter-of-factness of how disability, especially polio, is portrayed.

The credit goes to Ben Lewin, the screenwriter and director who is a polio survivor. He has said that he wanted Mark to be depicted as a human being who could, like all of us, be at times, “a jerk.” The cast, Hawkes as Mark, Helen Hunt as Cheryl and William H. Macy as the priest, is spectacular, and bring the great script to vibrant life.

“The Sessions” is now in theaters across the country and in Canada. Go see it. I would be surprised if it doesn’t unlock some memories, both good and uncomfortable. It did for me.

Bill Stothers is a long time editor and consultant on media and disability policy. He edited *Mainstream*, a national advocacy and lifestyle magazine for people with disabilities and major newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post-Polio Health International and currently serves as its Chair.

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

Promoting Positive Solutions



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

Question: I found out I had polio when I was 55 years old. My Mother's explanation was that "the doctor told me not to tell anyone." Can you help me understand why this was told to parents?

Response from Stephanie T. Machell, PsyD:

Your experience is not an unusual one. I've had many clients who didn't remember having had polio and were never told that they did. While there can be many reasons for this, what your mother was told by the doctor points to one of them: the stigma attached to polio and those affected by it.

At that time, polio was viewed much as HIV/AIDS is now. Polio survivors and their families were often shunned, even after the risk of contagion was past. Polio was considered to be highly and indiscriminately contagious (think closed swimming pools and movie theatres), and the polio survivor and his or her family were often viewed as dangerous.

I have heard stories of homes being burned by neighbors and of doctors and dentists whose practices closed because patients were afraid of being infected by a parent who might be carrying the disease. These beliefs persist in many who lived through the epidemics. For example, a few years ago, I was told by a well-educated person that it was a miracle that my brother and I didn't catch our father's polio. (The person making this statement knew that I was born two years afterwards. My brother was born six years later!)

Apart from fear of contagion, there was fear of disability itself. In the mid-20th century, and even now, many people subscribed to the moral model of disability, in which the person who has the disability (and by extension his or her family) must have done something to deserve this fate. The polio survivor would be viewed as morally flawed or bad, and the possibility that such badness could be as contagious as polio itself makes others reluctant to associate with "carriers."

It is also possible that the doctor was trying to be helpful. If you recovered well enough that you had no need to be aware

that you had had polio, you were most likely able to "pass" as non-disabled. Your lack of knowledge that you were a polio survivor would have helped you to pass. Because children with disabilities often were excluded from schools and other opportunities, this might have been seen as positive. And because it was widely believed that children would suffer no ill effects and might actually benefit emotionally by not being told about their polio experience, parents were often advised not to discuss polio with their children, even those old enough to remember what had happened.

Your parents' own shame and guilt over what happened to you may also have factored into their willingness to go along with what the doctor advised. Because of the way polio was viewed, parents often had these feelings when their children were afflicted. They may have felt responsible for your polio because of something they allowed you to do, or for something they failed to do (like not vaccinating you soon enough if the vaccine was available). The doctor's message would have reinforced their shame and guilt, further reinforcing the secrecy around what happened.



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

Question: I am 66 and widowed for five years. My wife was highly attuned to my needs with polio. We had a loving relationship for 25 years. I am anxious about dating again, specifically meeting and trusting someone and also relying on someone again with my disability. My wife had a heart of gold and it's hard to imagine anyone being able to replace her.

Response from Rhoda Olkin, PhD:

First, I am sorry about the loss of your obviously beloved wife; my condolences. And second, I can relate to your trepidations about dating again – it is not easy as an older person, nor as a person with a disability. (I happen to fit both of these descriptions.) But rest assured, it is not easy

Article continued on page 12

Promoting Positive Solutions Continued

for those without disabilities either! You have to know that nothing replaces 25 years of building a loving and trusting relationship one that started when you were younger. Thus, it is important as you date that you not be looking for the same things that you found in your wife. You were in your mid-30s when you married her, and what you wanted and needed then are probably different from what you want and need now. Additionally, the life tasks and goals we have in our 30s, 40s and 50s are different than our life tasks in our 60s and beyond.

I would suggest you begin by making a list of what is important to you now, individually, as a 66-year-old man. Second, what would you like in a partner? Is it to live with someone or to see someone on weekends, to have someone to watch movies with but then go home, for sexual encounters or for snuggling in the middle of the night, for intimate chats or occasional dinners?

Third, look hard at the items on this list. I cannot help but wonder if some of the things you want are about basic assistance or security as a person with a disability. Are you worried you might fall and no one will there to help you? Do you have trouble with daily household tasks? Do you get fatigued and want someone else to do some of the driving?

I understand the fragility some of us polio survivors feel about living independently, especially as we age. But as you look for a partner, make sure you are not really looking for an assistant. Partners provide assistance because they have a meaningful history and years of love to fortify their assistance. New partners do not bring this to the table and shouldn't be expected to.

So basic assistance needs have to be met other ways. For example, start a phone buddy system of someone to check in on you (and you on that person). If at all possible, hire someone to do laundry, clean, grocery shop; outsource whatever you can afford.

At any age, we do better at dating if we have confidence in ourselves and our ability to be alone. From this position of strength, go find a partner. And love can come at any time, at any age. It won't be like the last time, but it can still be rewarding, fulfilling and special.

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FYI...

There have been 3 films over the past 12 months that deal with polio or paralysis. In case you missed them in the theatre, you can get them on DVD now or very soon. "The Sessions" will be released on DVD February 12, 2013. (See review in this newsletter.) The date is pending for DVD release of "Hyde Park on the Hudson". (FDR) "The Intouchables" DVD was released January 15, 2013 and will be released for Netflix March 4, 2013. (Active life of paralyzed man.) I don't remember any time that there were several major films dealing with polio or paralysis released in so short of a time frame. Kudos to the motion picture industry!

You may wonder why there are 3 chapters from Jerry Epperson in this issue. Well, we had published all but 6. I am feeling much weaker and more fatigued. I have decided that, in the interest of my health, the next issue will be my last. I wanted to complete all his work and decided to put 3 chapters in this issue and 3 in the next. (I will address my "retirement" in the June issue. This is a recent decision and it will take time to address the complications of my stepping down.)

Our November 2012 speaker was quite the raconteur. Jerry Epperson not only brought delightful treats to our meeting but also delivered delightful tales about his life. If he is on our agenda in the future, give yourself a great afternoon by attending.

All who attended enjoyed our Holiday Lunch and Chinese Auction. It is always fun to discover what was this year's hot-ticket item.

NOTE WELL: the RSVP for the April lunch at Buz and Ned's and for the Amuse Restaurant is on the same date, April 15th. When you call Carol or Barbara, make sure that you make it clear that you are responding to one date or two.

Suggestion: Save this issue so that you have all pertinent dates.

Save the Date

What?
June Luncheon

When?
Saturday June 1, 2013 @ 12 Noon

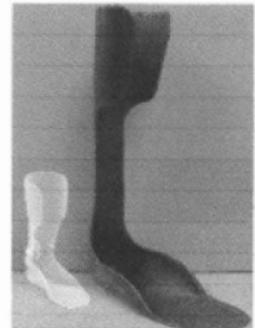
Where?
The Hard Shell
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(Menu will be available at the March meeting)

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