

POLIO DEJA VIEW



December, 2012, January, February, 2013

www.cvppsg.org

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

Mary Ann Haske,

Editor

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December 1, 2012

Annual Holiday Party & Luncheon

River Road Church, Baptist @ Noon

800 River Road, Henrico County, Corner of River Road and North Ridge Road
(Close to U of R, River Road Shopping Center and the Huguenot and Willey Bridges)
Fellowship House

(Enter from parking lot or front driveway)

Cost, \$15; Menu similar to previous years

RSVP: No later than Wednesday, November 21, 2012 to
Barbara Bancroft (204-1688) or to Judith Moffitt (754-1067)

CHINESE AUCTION:

Please bring a gift, per person, suitable for a man or woman, costing between \$10 and \$15
*A check to the CVPPSG for \$15.00 per person or the exact amount in cash is due prior to the event or on
the day of the event. Our Support Group is pleased to be able to supplement the cost of the party as well as
pay the tax & tip.*

January, 2013 – No Meeting

February 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)

General Discussion

Bring topics that you would like to discuss

Mid Month Lunches

No Mid-Month Lunch in December

Wednesday, January 16, 2013

Mid-Month Lunch at 11:30

Olive Garden

9750 Midlothian Turnpike, Richmond, VA 23235, 330-7391

For a reservation, call Carol Kennedy (740-6833) or
Barbara Bancroft (204-1688) by Monday, January 14th

Wednesday, February 20, 2013

Mid-Month Lunch at 11:30

Baker's Crust

3553 West Cary Street, Richmond, 23221

Go to: www.bakerscrust.com or call 213-0800

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

The Silent Helpers

...From Your Editor

Remember several months ago when I mentioned my PT? Well, one day he was asking me about my polio during my late teens. I told him a group of doctors literally kept me walking and enabled me to go to college. Later in the day, I began to think of all the people, silent people, who helped me and my family to weather the storm that polio brought to our lives. So, in this article, I will share the story of some of my S.H. in the hope that it will remind you of the people who made your journey easier.

Many of my Silent Helpers made my first Polio Christmas special. I have vivid memories of that holiday so this seems appropriate for this issue of the newsletter.

First, we have to examine what it was like in September 1941. Medical personnel had been called into service in anticipation of the upcoming war. Metal was scarce. People's fear of "foreigners" was rampant. So, when I was stricken with polio, my older brother was off getting his wings in the Army Air Corps. The doctor, who came here from Canada to avoid the draft, sent me home to die. We were quarantined. However, my father was considered "essential personnel" and he did not return to the quarantined house. Can you imagine the burden on my mother as the only adult in a household with illness and small children? She had to deal with an ill 4 and a half-year-old, a 2-year-old little girl and a 6 year old 1st grader. There was no television to occupy the children. I could not speak, swallow, or move. How could my mother survive?

The first morning after the quarantine sign went up, my mother heard noise in the kitchen. She went in and there was our maid. My mother told her the house was quarantined and her response was that the sign was on the front door and she had to come in the back door. She said she was there for the duration.

When my mother had to take care of the other children, she would put the telephone to my ear and my aunt or grandmother would talk to me to distract me. The neighbors would leave cooked food on the porch. They would ring the doorbell and then run off the porch. When the quarantine was lifted, my older cousin visited and painted my toe and finger nails a bright red so that there would be some color to offset the stark white of the full-body cast. I loved that.

When I was better my parents had to find a way for me to have some kind of therapy. There were no PTs left as they had signed up for service. However, there was a wonderful German woman who massaged me. Those massages were wonderful. Alas, because she was German and had a short-wave radio going at all times, my mother was very suspicious of her. Although my mother never talked about it, I sensed her uneasiness. I was too young to understand, but it seems a shame that something that felt so good had a suspicious air around it.

As Christmas approached, I wanted to be able to go downtown

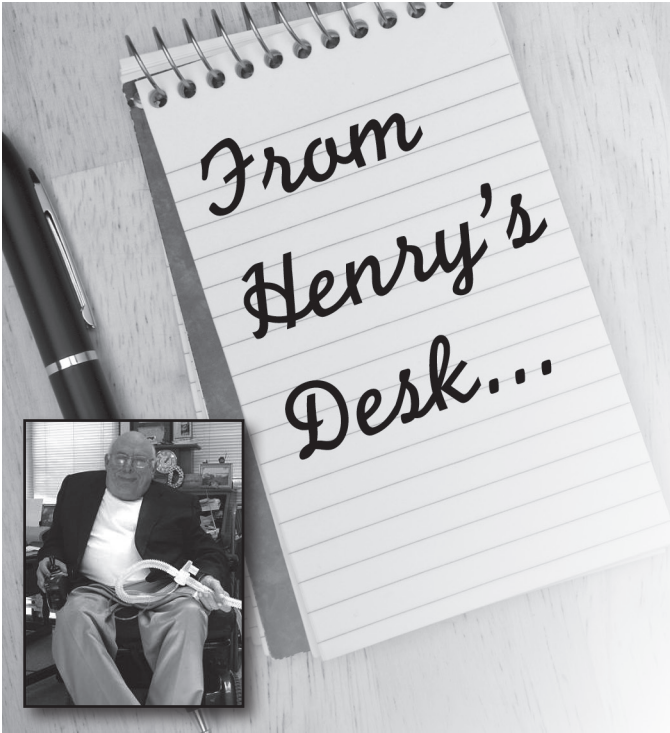
to see Santa and the windows. My mother and my aunt knew that it would not be wise to try and take me to see Santa. (The parents waiting with their children to see Santa would have been terrified that I was "catching".) I could not walk far so a wagon with the wooden sides was borrowed. I was taken to see the store windows after dinner when there would be few people present. I can still remember being in the wagon with lots of pillows and blankets and being pulled along Broad St. and Grace St. to see the wonders behind the glass. Christmas day I found a velocipede from Santa. My left leg could not reach the pedals and my Father built the left pedal up with big blocks and then tied my foot to the pedal. My right leg would push the right pedal down and I would wait for the pedal to come back up for another push. It was not easy but it was a fun way to have "homemade PT". Neighbors brought me presents. Even though I was young, it bothered me that I was receiving gifts when my brother and sister were not receiving them. (Was this the beginning of my "survivor guilt"?) I remember a wind-up Merry-Go-Round that would revolve. The horses were made of carved soaps. That started a life-long love for miniature Merry-Go-Rounds.

By late spring, I was able to play outside but I did fall frequently. One day I fell backwards and cut my head on the blades of a lawnmower. A few days later I tripped going into the house. I cut my forehead on the door. Both of these events required stitches. The doctor said to keep me in bed until both the back and front of my head were healed. I was devastated. It was like I was being punished. Then a neighbor came to visit me and brought me a scrapbook full of greeting cards collected over the years. I spent hours looking at the cards. (Don't forget there was no television or bedside radio.)

As I gained strength, I was encouraged to roller skate. Again, the right leg did all the work but sailing along certainly beat walking! Remember, when I described 1941, I said there was a shortage of metal. We are now well into 1942 and have been at war some months. Because my feet were misshapen and my toes turned up, I would cause the skates to bend and eventually brake. I needed a lot of roller skates but that was easier said than done. There were none available in the stores. Metal was used for war, not for play. Someone wrote an article about me for the local paper and I was sent old skates from garages, back porches, and basements. Those skates helped to keep me going.

Throughout the years, there were many helpers. However, I was older and could say thanks. Other than my family, I have no idea who these people were who brought "front porch food", helped my Mother care for us, gave me Christmas gifts, scrapbook, skates, wagon, massages and encouragement. I may not remember who they were but I have never forgotten their kindness to me and I am grateful that they passed through my life.

Mary Ann Haske



Looking Back

The Central Virginia Post Polio Support Group has existed for twenty-six years. I joined our group in 1991. Fifteen years ago I conducted a survey on some of the members in our group. Sixty-one members completed the survey in 1997. The results were interesting. The average age of our group was fifty-nine at the time. 70% were married, 10% widowed, 8% single and 8% divorced. Among the responders the average number of children was two. 51% had earned a college degree or higher. Almost one half of us were infected with polio in an urban environment, one-fourth in a rural area and one fourth in a small town. Two thirds of us functioned at a maximal level from 20 to 40 years after polio before Post Polio Syndrome (PPS) began causing symptoms of new motor weakness, new pain and new fatigue. Over half of us felt that PPS began in the 1980's and most of the rest after 1990. The vast majority reported that PPS symptoms were moderate to severe in causing problems in functioning. One third of us were being treated for hypertension and one half of us reported a sleep disturbance. Half of us reported problems with anxiety and/or depression. 90% of us had new motor weakness and an equal number had some

The rest of the story is continued on page 4

CENTRAL VIRGINIA POST-POLIO SUPPORT GROUP

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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
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.

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form of fatigue. 80% of us were dealing with pain. 70% of us reported some form of cognitive problem, usually word finding difficulties. 18% of us were still working full time and 10% of us were working part time. The rest of us were disabled from working or retired.

Fifteen years have passed and hopefully we are wiser as well as being older. Most of us have made necessary adjustments in our lives to live more comfortably with PPS. Sadly some of our members are absent from us because of death from natural causes such as cardiovascular disease and cancer. PPS and aging are not a good match as one can complicate the other. As we grow older we have risks of falling and PPS can contribute to falling. The difficulties in accomplishing the activities of daily living have become more challenging and risky. Often we require the help of loved ones or hired care workers in order to function on a day-to-day basis.

At this stage in life some of us reflect on those blessings we have received and hopefully those ways in which we have been a blessing to others. In an article I wrote some years ago, I compared our aging fate as dying gladiators. The image of the dying gladiator comes from the poet Lord Byron in his long poem Childe Harold. The lines read:

I see before me the Gladiator lie:
He leans upon his hand -- his manly brow
Consents to death, but conquers agony,
And his droop'd head sinks gradually low --
And through his side the last drops, ebbing slow
From the red gash, fall heavy, one by one,
Like the first of a thunder-shower; and now
The arena swims around him -- he is gone,
Ere ceased the inhuman shout which hail'd the wretch who won.

He heard it, but he heeded not -- his eyes
Were with his heart, and that was far away:
He reck'd not of the life he lost nor prize,
But where his rude hut by the Danube lay,
There were his young barbarians all at play,
There was their Dacian mother -- he, their sire,
Butcher'd to make a Roman holiday --
All this rush'd with his blood -- Shall he expire
And unavenged? -- Arise! ye Goths, and glut your ire!

Looking Back

The article concludes with my words:

Do you feel at times like the dying gladiator? So many of us fought the polio gladiator early in our lives and often came away victorious or at least came away stronger despite residual wounds of the battle. Those wounds might have been shorter or curved limbs that limped, limbs wrapped in steel and other atrophies and curves marking our fight with the polio gladiator. For many two score of years passed or even more time elapsed and another polio gladiator engaged us in another, but different battle. This time we were no longer young. We tried many of the battle tactics of the past, but usually these tactics only added to our misery and suffering. We did learn new tactics and became wiser. We conserved our energy and put it to better use. We formed alliances with other survivors of the polio gladiator and together we found that we were stronger in a cognitive, emotional and spiritual sense. We found that often what we had experienced as individuals was almost universal with the experiences of other survivors of the polio gladiator. For many of us our eyes are with our hearts and minds in our experiences of battles fought long ago and battles fought only yesterday. Are we still dying after a long struggle with the polio gladiator and do we expire unavenged. No, we keep arising every time we tell our stories to each other and to the world

FYI...

Are you unable to cook all your meals either permanently or for a small period of time?

Check out: momsmeals.com, or call: 866-971-6667

I have not tried it but it looks inviting.

I recently took Amtrak and LIRR to Long Island, NY. It had been 9 years since I used Amtrak with my wheelchair. This time I went alone and I was very impressed with the smoothness of my journey. Improvements have been made. One tip is to get a train that originates in the city from which you are leaving. That makes for less congestion and less stress.

A Freedom Driver . . . Chapter 7

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

*By Wallace W. (Jerry) Epperson, Jr.
Chapter 7*

I have never considered myself a studmuffin, as hard as that is to believe.

Like many, I have had problems with self-esteem. Because of my limp, scars and weight, on a scale of 1 to 10 (like Bo Derek when she was a "10"), my body image is a 1.0 or lower.

I am no high intellect either, but when I apply myself, I think my intelligence would qualify for a 7.0 to 7.5. This is offset, however, by sub-average common sense. I am too willing to accept what I am told is the truth and I am gullible in believing others' sob stories. I would put my common sense at a 4.0.

Growing up, I always had a girlfriend. Unfortunately, they never knew they were my girlfriends.

My first crush was on Nancy Rist, a tall lovely girl in my class. In the second grade, I found a plastic ring in a box of Cracker Jacks with a red cut "stone". It looked good to a seven year old. It took all my gumption to give the ring to her. It was a big deal in my mind. I have no idea if she kept it or threw it away.

If you cannot be outstanding in sports, a policeman, fireman or some other brave person, you have to have other hero fantasies. I remember imagining saving Nancy Rist from her house on fire, because my braced leg would help me walk through fire to save her.

Of course, all the boys liked Nancy and I realized we were never going to be a couple. Besides, I knew that I would end up marrying Anne, the girl that I grew up with next door, then across the street after we moved.

In grade school, I was told I was off-

key in a class song, so I never sang again. For more obvious reasons, I never danced, knowing I would look pathetic. This added to my feeling like less than a great catch for the local girls.

Before I got my driver's license, my older sister would allow me to occasionally take a "date" with her to the movies, usually Elvis flicks like Blue Hawaii or G.I. Blues. I took Nancy Rist a couple of times, although I don't know how I got the nerve to ask her. I think I held her hand.

In grade school, we had dances, but my role was playing records. I had a decent record collection and enjoyed being there. Truthfully, I still have a decent record collection (but no one plays records any more).

When in high school, my friends and I would go to dances in South Hill, Blackstone and at the Old Mill in Farmville. Away from Victoria, I occasionally told the girls my bad leg was a Vietnam War wound. I could pull it off if they were not very bright, partly because I always looked older. When I was thirteen, I was already shaving and some friends would have me go into stores in Crewe and Blackstone to buy beer. I did not drink, but I almost always bought the beer. One told me it was because I looked 18 or 21, but another told me the store clerk would never think a crippled kid would lie about his age.

Getting my driver's license at 15 was a true rite of passage, allowing me freedom. In the first week, I was in an accident. I was turning left and a school teacher, Mrs. Hart, was pulling out of a gas station diagonally across the street. She was looking back down the lane she was pulling into, and I was looking up the street where I was going. We hit head-on at low speed. Mrs. Hart hit her head on the rear view mirror and was bleeding. I

was fine but shocked. It had happened so quickly.

My father and the town police arrived. The policeman said that neither of us broke the law and both had used turn signals. He called it "equal fault" with no tickets necessary.

I was upset, and just wanted to go home. Dad made me drive, and even made me drive the next night to a dance in South Hill. It was my first time to drive others anywhere, and can still remember how the right headlights were pointing up because of the accident. It was strange.

Dad told me that he had been taught if you were thrown off a horse, you had to get right back on, or you would be scared to ride. That's why he made me drive. Thank heavens he did.

Unfortunately, when I was added to my family's auto insurance I was arbitrarily put on the extremely expensive "assigned risk" coverage, perhaps four times the cost of regular insurance, which was already high for a teenage male. We learned this was because I had a "restricted" license requiring me to drive only vehicles with an automatic transmission for obvious reasons.

Dad spoke to our local agent, and he rode with us to Richmond to see if they would allow me regular insurance. The agent in Richmond saw my grades, had me walk, discuss my disability, and drive a short way. I was very nervous but, thankfully, he agreed and I was given regular insurance. We probably could not afford the assigned risk rate, so my freedom was at risk.

I still remember the trip more for an accident we saw first hand. Going north on Route 360 just before the Appomattox River bridge (where Amelia and Chesterfield Counties meet), we were behind a station wagon when a fast moving truck passed on the left.

The station wagon drifted towards the left lane and the truck blasted his horn. The driver over-reacted and the wagon swerved right, then left, and then drove off the right shoulder just before the bridge. The drop was probably twenty feet, with mud and water at the bottom. The station wagon ended on its right side well off the road.

Dad pulled over and he and the local agent, Mr. Gallion, ran down to help. Others stopped as well and soon the state troopers and ambulances were all around us. I felt helpless because there was no way I could climb down the steep hill to the wreck.

The wagon had six elderly nuns going to Richmond, and they were all hurt to some degree. All were brought up on stretchers but were alive.

To me, the suddenness of the accident was a real lesson, and it made me a better driver. That, plus not drinking and driving my parents very slow four-door Chevy kept me from racing like some others my age.

My first dates driving were double dates, often with Eddie DuPriest from across the street who was a year younger. I cannot explain why, but my earliest dates were girls one or two years older than me. Somehow I was more comfortable with them.

Later, I dated an assortment of girls from my school but I never felt any romantic attraction. Some were very attractive and even cheerleaders or majorettes, but not special to me. Most of these were one or two years younger.

I met a girl from Kenbridge who played basketball, and we dated once. It was a disaster. We had absolutely nothing in common, had a bad dinner at a restaurant in Blackstone, and I was stopped by a town policeman for going 45 in a 35 mph zone. I didn't get a ticket but I was mortified. Even the movie was so bad we left early. That date set a standard (for her and me) that no future date could ever fail to exceed.

At a dance in Blackstone, I met an attractive, talkative girl and dated her several times, including taking her to my prom. Although very pretty, I sensed she did not date often and she appreciated my attention. We became good friends but nothing romantic. Of course, being a guy, I had to tell my friends what a great date she was. We did kiss but there was no spark.

To be as honest as possible, I was scared of all of these girls, afraid I would embarrass myself, and confident that they could not have any interest in a crippled kid.

All of this re-enforced my belief that I had to get away from Victoria to create a new identity with more confidence. It wasn't Victoria's fault, I just wanted a new universe to explore. Plus, Victoria had few employment opportunities. Actually, no employment opportunities for me.

The few kids from Victoria to go to college usually went to VPI. Ever since going to Charlottesville for eye surgery, I wanted to go to UVA. Few had gone there from Victoria, and even fewer had graduated. Monty Ingram, who was a year ahead of me at Victoria High School also planned to go to UVA so we started wearing ties to class, just like the UVA students did. Trust me, no one else wore ties in our high school in 1964-1966.

Even as a junior in high school, I felt plans to go to UVA made me different and gave me a bit more confidence. It also gave me yet another incentive to get better grades.

Dad had told me often that I could not work on the railroad, or in tobacco, or in the factories like others. I had to have a good education. Thank heavens he drilled that into me.

CONDOLENCES



We wish to express our sympathy
to the family of
Marshall E. Howard
who passed away September 15, 2012

Ask Dr. Maynard

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Question: I am now 76, had polio when I was 4. Since post-polio syndrome (PPS) hit me, I needed a leg brace and walk with two canes. I can never remember a day without pain, but now it seems to have spread all over my body, not just my legs. My question is: How do you feel about the pain patch, Duragesic, 12mcg to start. My internist feels that this will help. I would just like to get an OK from someone who has experience in treating PPS.

A: Pain control in people with post-polio problems is highly individualized because there is no one source of pain. I would NOT endorse the use of a Duragesic patch (fentanyl transdermal system) for long-existing pain in a person with PPS because I think it is a “dead end” in regard to long lasting relief from pain. It is probably safe but can lead to dependency and less tolerance and awareness of pain that it is helpful to be aware of (so the pains can be “honored and have actions taken on.”)

I would definitely have a comprehensive evaluation by a “post-polio expert or clinic” before trying to merely “suppress your awareness of pain” by using a Duragesic patch. There are many alternatives. Maybe “giving up” regular walking and using a scooter for usual mobility would lead to a major reduction in pain levels. A thorough evaluation may tell you that and/or other alternatives.

PHI’s Post-Polio Directory (www.post-polio.org/net/pdirhm.html) of clinical resources for post-polio survivors can help you locate regional options for an evaluation by a post-polio rehabilitation and pain control physician, preferably a specialist in Physical Medicine and Rehabilitation.

Good luck in finding help and relief.

Question: I had paralytic polio 64 years ago at the age of 13 months. My left leg had major paralysis and a small amount to my right leg. I always walked with a severe limp. I was diagnosed 25 years ago with PPS as I was developing new weakness in my legs. Four years ago, swallowing began to bother me and also volume when blowing breath. In the past two years, my left fingers have “clawed,” and now my tongue muscles are weak causing speech problems as are my vocal cords somewhat. I recently saw a neurologist who thinks I have ALS. Do you know of any cases of people with PPS and ALS?

A: Yes, I know of people who are post-polio survivors who have developed ALS. The majority expert opinion on this subject is that polio people are not more likely to develop ALS than other people, but the diagnosis of ALS, as opposed to, Progressive Post-Polio Amyotrophy (Post-Polio Syndrome) is very difficult and at times impossible to distinguish with certainty. Given you have had some slow progressive weakness problems for over 25 years, your condition sounds more like a post-polio condition mimicking ALS. Unfortunately there is no definitive test for either diagnosis. Given how severe your new symptoms have become, you may be an appropriate candidate to try one of the more aggressive new treatments for progressive post-polio weakness, such as intravenous immunoglobulin therapy as shown to be helpful by researchers at the Karolinska Institute in Sweden. (See IVIg Update, this issue.) I suggest you consult with the neurologist who diagnosed you and together pursue possible new treatment options to slow down progression of symptoms.

There are many rehabilitation strategies to minimize risks from the swallowing and breathing problems and to maintain function and quality of life.

Also, please see Swallowing Difficulty and The Late Effects of Polio (Vol. 26, No. 3) and New Swallowing Problems in Aging Polio Survivors (Vol. 12, No. 1)

IVIg Update

(Joan L. Headley, Executive Director, Post-Polio Health International, St. Louis, Missouri, director@post-polio.org)

Currently, the most talked about treatment for a subgroup of polio survivors is IVIg (intravenous immunoglobulin), a blood product that is administered intravenously. Opinions vary from “the most promising treatment in years” to “very doubtful it will prove to be of benefit.”

The March 27, 2012 issue (Vol. 78, No. 13; 1009-1015) of *Neurology* featured “Evidence-based guideline: Intravenous immunoglobulin in the treatment of neuromuscular disorders.” The article, a Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology, can be accessed at www.neurology.org/content/78/13/1009.Full.html

The recommendation for post-polio syndrome is that “Evidence is insufficient to support or refute IVIg use in the routine treatment of postpolio syndrome.” They further note “There is presently no effective treatment for postpolio syndrome.”

The subcommittee based its comments on the review of two Class 1 studies that evaluated IVIg efficacy in patients with postpolio syndrome. (Neurology defines a Class 1 study as a randomized controlled clinical trial of the intervention of interest with masked or objective outcome assessment, in a representative population. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences.)

Their conclusion was that “one Class 1 study (Gonzalez) showed a significant difference, but the difference was not clinically important for IVIg use on the most affected muscle in postpolio syndrome. One underpowered Class 1 study (Farbu) showed an effect of IVIg for pain in postpolio syndrome but no effect on strength or fatigue.

Dr. Kristian Borg, Professor and chair, Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institute, Stockholm, Sweden, author on the Gonzalez study and numerous articles, tells PHI that “at the moment we are analyzing data from an open clinical study with IVIg treatment trying to determine which patients are responders.

“Preliminary data suggest that they are characterized by age below 65 years, paresis in the lower extremities and no concomitant disorders, as well as low quality of life for the SF-36 subdomains of vitality and pain. These individuals are in ongoing studies to receive IVIg treatments to help determine who will benefit from the treatment.”

All experts agree that post-polio syndrome is not just one problem that will be solved by one answer. As for IVIg, it is too early to tout or dismiss the benefits. More research needs to be done, published and duplicated.

MORE on www.post-poli.org

For more about IVIg. See:

Intravenous Immunoglobulin Treatment for Improving Muscle Strength

Post-Polio Health, (Vol. 22, No. 2) 2006

Recent experience Using Immunoglobulin to Treat Post-Polio Syndrome

Post-Polio Health, (Vol. 26, No. 3) 2006

More About IVIg, Post-Polio Health, (Vol. 23, No. 2) 2007

References

Gonzalez H, Sunnerhagen KS, Sjoberg I, et al. Intravenous immunoglobulin for post-polio syndrome: A randomized controlled trial. *Lancet Neurol* 2006; 5: 493-500

Farbu E, Redand T, Vik-mo E, et al. Post-polio patients treated with intravenous immunoglobulin: A double-blinded randomized controlled pilot study. *Eur J Neurol* 2007; 14: 60-65.

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Two Child-Eye Views of Polio Parents

Two Child-Eye Views of Polio Parents featured at Annual PNNJ Conference

Two children who grew up with polio-survivor parents were the luncheon speakers at the Polio Network of New Jersey's 21st Annual Conference, "Polio and Post-Polio: a Family Affair", on April 16. Kimya Jackson and George Swain shared their special experiences of "Life with a Polio Parent".



KIMYAI JACKSON: POLIO AND POST-POLIO FROM A DAUGHTER'S PERSPECTIVE

"I don't see a handicap when I look at my mom; I don't see disability," said Kimya Jackson, daughter of polio survivor and Polio Network of New Jersey board member Edwina Jackson, as she began her talk.

Kimya, a second-grade teacher and mother of two, described how she believed from an early age that she had to be her mother's protector. She asked us to picture a cool Fall evening in 1979, when she was five or six years old. She and her mother were walking to the entrance of her grandmother's apartment when her mother fell. "It was the very first time I had ever seen my mother fall," Kimya explained. "There were some people around who laughed at her and no one helped. I remember calling out 'Help my Mom' and I began to cry. And on that day, I knew I had to be her protector."

Kimya carried that protective role with her while at the same time enjoying the kind of mother-daughter activities that all young girls appreciate. She recalled for us a number of times when the fact that polio had left one of her mother's legs smaller than the other caused some

unanticipated problems. Like practicing how to walk on high heels. It just didn't work when one of her mother's shoes was size 7 and the other a size 9, when one had a lift in it and the other didn't. The result, Kimya said, is that she never learned to walk in heels and has, instead, a wardrobe of flats. "It's not a bad thing, she said laughing, "Because I always find stylish ones."

Her Mother's "Protector"

Then there was the time back when Kimya enjoyed roller skating a lot and her mom decided she wanted to try. "My mother wanted to try everything," Kimya explained. "It was a very interesting experience. Because her right leg was affected by polio, that didn't work out so well." Then she illustrated how as one leg went in one direction, the other went in the opposite. "We were in our basement, and as her protector, I had to go help her," Kimya explained. "We both fell and had a great laugh."

"I never saw my Mom as a handicapped person; so whenever I did something, I wanted her to do it too," Kimya said. There was a popular dance everyone in her school knew how to do except for her. "I came home and told my Mom about it and she had no problem about doing it. So much so that she'd come to school when we had a dance and she would show me up by doing the dance with my friends. Needless to say, I had to practice and do the dance just as well."

Soul-Searching

Researching a high school biology class research paper on polio was a soul-searching experience for Kimya. "I had to realize that my Mom was different and maybe could not do what other parents could. It affected my thinking about my Mom and the things we were able to do together. It didn't change

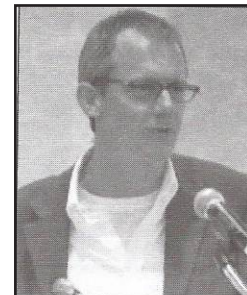
what we did or how, but I had to become very mindful of different things."

"My Mom probably didn't know this, but as a child, I was very angry with the fact that she had contracted this virus," Kimya said. "Because she's such a great person and this is not something she deserves. She told me she had had to stay in the children's hospital away from family and friends for a long time, had to wear braces."

"Made me stronger"

In summing up, Kimya said, "However, getting beyond the anger, her having polio has made me a stronger person. My mother had three adversities: first, being a woman; second, being African-American, and third being handicapped. What I learned from her is that if she can do it, I have to be one step better because I have one less adversity. "

"So, where she bought a house at 30, I had to buy a house at 29." (Kimya helped to build the Habitat for Humanity home she lives in with her two children in Newark.) "Where she went to college, I had to go all the way through." (Kimya has a bachelor's degree, completed a master's degree this spring, and is now working on a doctorate.) "My Mom showed me that I have to be strong and cannot let adversity get me down."



GEORGE SWAIN: POLIO – A FAMILIAR SHADOW THAT CHANGES OVER TIME

"My mother, who serves as an incredible model for me, has

always stood up to whatever challenge she has in front of her, and I think it has probably made her a stronger person,"

said George Swain, son of Joan Swain, PNNJ vice president.

It's hard for me to separate my mother from polio since the two have always been connected in my life," said George, the head of a Middle School in New York and father of two. "As a child, I never really saw it as a disability. I saw it as something particularly challenging to my mother. I don't think I had any idea of how much strength she needed to compensate for things that were difficult for her.

Being a helper

"My sister and I learned from a very early age that being a helper was a really important part of how a family works. We realized that we had some really important jobs in the house. Those jobs included going grocery shopping, pushing the cart around the aisles, lifting heavy things, bringing in the groceries."

"My early memories are of a very strong and determined person, and these memories also include somebody who was out gardening in the yard, cooking, driving a car, taking me all the places I needed to go as a child. Even getting in and out of pools and lakes to swim. Something that didn't occur to me was how difficult it would be to get from that place to the car. It might have taken her a bit longer. Maybe I had to stand around and hold some crutches or stabilize her a bit. But she could do it.

A more empathetic person

"My mother was really active and engaged. She wrote a weekly column for a local newspaper, worked on the board of a local library, and then began to work full time and built a career. What didn't occur to me as a child was how people had to overcome difficulties, like she and you who had polio had to overcome. You have all the challenges the rest of us have and then a couple more." Looking back at the effect polio had on his life, George said, "Polio wasn't a huge part of my childhood. However, it's made me a more empathetic person."

George spoke about his own experience with rehabilitation and disability as the result of a bicycle accident a year ago that left him with 25 broken bones. "I knew I was going to come back to full strength – broken bones heal themselves," he said. "It made me understand a little bit more what it must have been like before the polio vaccine for people who contracted polio and had no idea if they were going to be able to walk again."

Three insights George named that he received from his rehab experience. 1. The world looks different from a chair; and the world is not built for people to move around in chairs. 2. It's very frustrating to depend on other people for everything. And 3. Through hard work it's possible to make incredible progress. (Not for polio survivors though, whose mantra is "Conserve to Preserve!")

"Think, Pair, Share"

To conclude his talk, George suggested we participate in a "Think, Pair, Share" game with others at our tables. The idea is for a polio survivor to pair up with someone who has not had polio. Then they ask each other the following questions.

1. What is your first memory of polio?
2. What is your first memory of post-polio?

3a. What is something you would like people to know about post-polio? (for the polio survivor).

3b. What is something you would like to know about polio? (for the person without polio).

Afterward, several parent/children admitted they had never before talked to each other about polio and had benefited from the opportunity. This informal game is a good way for families to start an overdue conversation about polio and post-polio syndrome.

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Tiny Tim Redux

William Stothers, San Diego, Ca.

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It's that time of year. Leaving aside the contrived frenzy to spend, spend, spend, this is a traditional time for giving thanks and sharing, a time of reflection and appreciation.

But I feel conflicted.

Several years ago, I wrote a column for the season entitled "I hate Tiny Tim." I wrote that Dickens' Tiny Tim "helps shape some of society's most cherished attitudes – charity and pity for poor little Tiny Tim and people like him." Tiny Tim, plucky, sweet and inspirational, tugs at the public heart. He has become Disabled Everyone in popular culture. He is Jerry's Kids. He is me.

Society idealizes this sentimental image of disability as a pitiful child in desperate need of help. People feel better when they give a few bucks or a little toy for a kid with a disability.

The problem is: not all people with disabilities are children, but we all tend to be treated as if we are.

When I'm in stores and malls this time of year, I get a lot of smiles meant for Tiny Tim. How do I know? Well, I am a middle-aged and balding adult in a power wheelchair and people, mostly women, flash those smiles at me.

Not the kind of smiles most men would hope for from a woman, nor the neutral courtesy smile exchanged by strangers passing on the sidewalk, but that particular precious smile that mixes compassion, condescension and pity. It's withering to the person on the receiving end.

But, I would not say that I "hate" such occurrences now. Perhaps I have matured.

The "smiles" still happen and there is no question, though, that they constitute a strong challenge to my sense of self. But these days, when I look at my reflection in the morning mirror, I think about who I really am, and I confess. I tell myself: "I'm so beautiful!"

And it's true.

Sure. I'm as flawed as the next person, but still I have a load of positives. Not only have I survived as a person with a significant disability, but I have thrived. Pushed and encouraged by people who believed in me, I worked hard to get an advanced education.

I wheeled myself into a career in the newspaper business, a career in which I succeeded and which I loved. I'm also a husband, a friend, a colleague, a responsible voting-taxpaying-citizen who tries to volunteer for public service.

Sure, having a disability is an important – and sometimes difficult – part of my life, but it is only a part. Often it is humbling. But it should never be humiliating.

I have a great ability to adapt and solve problems, and that is far more meaningful. I embraced and joined the emerging disability rights movement, forging strong, enduring relationships with others.

And as a result of that work, I have influenced a wide range of non-disabled people and the community in which I live.

I am not a person who needs to be taken care of by others. And, I am not totally independent, either. I am interdependent, receiving and giving though a myriad of relationships. Just like everybody.

So as I encounter those stinging smiles and looks this year, I will remind myself that I am not just a "Tiny Tim." I am not diminished by disability. I am a whole person, and I am filled with appreciation for all that I am. I give thanks for all the relationships with people who make my life so chaotically rich and fulfilling.

God bless them everyone.

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

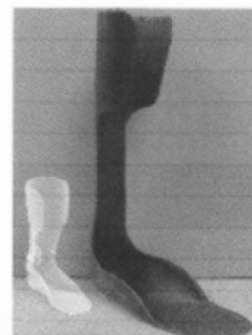
newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post-Polio Health International and currently serves as its Chair.

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

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