

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

December 2004 – January 2005

Carol T. Ranelli, Editor

December 4th Meeting

12:30 pm at Children's Hospital, 2924 Brook Road, Richmond

(Please note time change)

Lunch to be served at 1:00

Annual Christmas "Feast"

Catered by "Flowers on the Table"

Menu will be: Baked Ham, Roast Sirloin Tip of Beef, Garlic Mashed Potatoes with gravy, Green Beans, Cornbread Pudding, Baked Tomatoes, Caesar Salad. Rolls, Homemade Pies – Pecan, Mincemeat and "White House" Buttermilk Coffee, Hot & Iced Tea, Chilled Water

Cost: \$13.00 per person, payable at the luncheon

Please respond no later than November 30th to:

Marilyn Decker – 559-0243

Please remember to bring a gift suitable for a man or woman, costing between \$5 and \$10. We will conduct our traditional Chinese Auction again this year. Please plan on joining us for this annual holiday social.

January 8th Meeting

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

Because of the New Year Holiday, we will be meeting on the second Saturday

General Discussion

If you have concerns or questions about post-polio, please attend. Our group is a wealth of information on who, what, when and why.

Note: During the winter months, if there are questionable weather or road conditions, feel free to call an officer to check on meeting cancellation.

Mid Month PPS Group Luncheons

Because of our Christmas "Feast" and the holidays, we won't have a mid-month lunch in December.

Our January Lunch will be on Wednesday, January 19th at 11:30 at the Brio Tuscan Grille at Stony Point Fashion Park.

Please call Carol Ranelli at 794-7359 by Jan.17th to make a reservation. In case of bad weather or icy parking lots, the luncheon will be cancelled.

HAPPY HOLIDAYS TO ALL THE MEMBERS OF CENTRAL VIRGINIA POST POLIO SUPPORT GROUP

The Virginia Historical Society gets a New Scooter

If you are a fan of Virginia history, excellent exhibits and lectures, but you have had difficulty getting around at the VHS, things have just gotten easier for you.

This summer, the VHS acquired a new burgundy/red scooter with adjustable tiller and revolving seat. Just ask the friendly staff to get the key for the unit and you are on your way. The building and exhibit halls are quite accessible.

Finally, when you decide to visit, the VHS has major construction underway, so park in the back of the building. There are seven disabled parking spaces in the lot. Hope you enjoy your visit.

Gordon Kerby

Choosing to Flourish: Living a Powerful Post-Polio Life

by Linda Wheeler Donahue

Polio twisted me, shriveled me, and weakened me. It left me in the rejected pile like a heap of damaged goods. However, I amazingly triumphed over this paralyzingcrippler! No, my damaged and dead neurons did not suddenly spring into life. No miraculous surgery corrected my polio deficits. No magical elixir cured me. My astonishing victory of personal growth all took place in my mind.

My problems with body image began when I was a little girl. I remember a distinct "look" from churchgoers after the Sunday service. That look was sympathy laden. It conveyed to my parents: "How sad that you have a crippled little girl." I experienced variations of that look all through childhood and into my teen years. We, polio survivors, were stared at, looked upon with pity, ignored as though we were invisible, left out of the popular circle, and in some cases, teased and tormented. It did not take us long to make the connection between our bout with polio and social rejection.

We had to develop our own survival mechanisms. Some of us tried to cope by becoming "passers;" that is, trying to pass as able-bodied. We hid our disability as best we could. One polio survivor, who has paralysis in her arms and shoulders, told me of going to great lengths to manipulate her elementary schoolroom surroundings. She created situations that would assure she would be the last pupil remaining in the classroom. She went to all this trouble because she did not want her peers to see her struggle to put on her coat at the end of the school day. I did something similar. I sat on a bench in front of the public library and tucked my atrophied legs under the bench, pretending to be as whole and adorable as Sandra Dee! Creating a false identity comes at a great emotional expense.

Even as adults, we polio survivors realize that much of the way we view ourselves, and the world around us, is the result of negative messages ingrained in our psyche over the years. The realcrippler, for me, is not as much the polio virus, as the toxic signals I assimilated about my flawed body. I developed low self-esteem from the cumulative affect of thousands of recurring messages telling me that I was not acceptable.

Now I want to tell you how I banished those old malignant messages and replaced them with positive, self-affirming thoughts. It involves me telling you something I am not proud of. All of my life growing up and as a young adult, I avoided people with disabilities. I did not want to acknowledge that I was, indeed, part of that branded population. I am ashamed to say I did not want to lower myself by associating with people with even more stigmatized disabilities. Well, the stroke of irony is this: not until I embraced other individuals with disabilities, could I heal myself.

In 1985, I experienced a life-changing event that led me down a new path. I signed up to attend a conference in Hartford, Connecticut geared to women with disabilities. One image that remains with me even today is the shocking sight of all sorts of mobility devices everywhere in the hotel lobby. There were women in manual chairs, powerchairs, on crutches, on ventilators, pushing walkers, and wielding canes. My emotions went in two opposite directions. One

feeling was: "I'm home at last," contrasted with the reverse feeling: "Oh no! What am I doing here?"

The next image that warms my heart to recall is seeing Shelley Teed for the first time. Here was a strikingly attractive, thirty-something woman with bright smiling eyes and a mass of curly hair going this way and that. Born with spina bifida, she skillfully used a neon bright powerchair. Her tiny legs and feet protruded straight in front of her, and most telling of all, she dressed them in fuzzy **RED** socks.

Her commanding voice had a theatrical tenor as she projected instructions to various people on how to arrange the room, where to line up the presenters, etc. Shelley was a take-charge person, and what amazed me most was how comfortable she was in her own skin! She whisked around the conference rooms with utter confidence.

I was enthralled. I met my "roll" model for sure. I wanted to be as enlightened and as freed as Shelley Teed. Over the next years, Shelley and I became fast friends. I often think that if I had only met someone like Shelley in my formative years, my self-image may have been very different. Growing up, I never knew anyone who had polio, in fact I never knew any other disabled kids. All I had to inform my psychological struggle were the false messages of Madison Avenue. A "Shelley" in my life at that time, would have gone a long way toward eclipsing the shallow ideals put forth by the mainstream media.

Inspired by Shelley and the other dynamic disabled women at the conference, I decided to become an activist for disability rights. I did a complete 180-degree turn-about, from evading people with disabilities to seeking them out! I found that when I united with other people with disabilities, enduring bonds of friendship strengthened me. In addition, becoming a disability advocate is making the world a better place. When we join forces with other individuals with disabilities, we affirm each other; we gain strength, comfort, power, and healing. Where do you find others with disabilities? Join a local advocacy group; share your gifts at your nearest independent living center; volunteer at a rehabilitation hospital. By joining the disability culture, you will find you are free as never before to be the real you.

When I bonded with other people with disabilities, I learned to reject a lifetime of negative inner self-talk as false and shallow. I opened myself to new, positive thought patterns and began to redefine who I am and what I stand for. I realized that consumerist-driven, stereotypical images of "attractive" are oppressive lies. I bathed in the healing notion that I am OK just as I am, complete with atrophied legs and polio weakened body. When you accept yourself, you project confidence. Society respects you because self-acceptance is stunningly attractive, and something able-bodied people are unaccustomed to seeing in someone who is disabled. Other peoples' positive responses to you will help you shed a burden you may have carried for decades.

Let me give you an example of this newfound acceptance with my post office story. As a person with an obvious disability, I can never be anonymous, invisible. I am always conspicuous, always the center of attention. Therefore, it was with a certain amount of dread one day that I loaded some packages in my van for a trip to the local post office. Why the dread? Because I get tired of being Exhibit A. Because I do not always feel like being the world's disability educator to little children. Because I sometimes just want to blend in.

I pulled into the handicap-parking slot, lowered my ramp, and disembarked. I am sure I was quite an interesting sight with my scooter platform loaded with packages. Well, I decided to make this a positive experience! I held my head up, forced a little smile, and drove into the building. All eyes were on me, or so it always seems. This day, I know I gave an image of self-confidence. The postal employees were very pleasant and welcoming and I left the post office with a happy feeling. Nothing was different about the building, about the workers, about the way I drove my scooter . . . no, the thing that was different was something within me, it was my attitude. I felt approval; I even felt admired. I know I can never really be a nameless, faceless person in a crowd. Therefore, I have decided to make the best of my celebrity!

We polio survivors grew up being told to always be brave, be good soldiers, and "never *ever* feel sorry for yourself." Moreover, being the good soldiers that we were, we obeyed. Now I am here to respectfully disagree with that advice. I think it is perfectly OK to grieve your disability, to mourn your losses; in fact, it will help free your spirit.

Many of us were polio guinea pigs when we were children. We had to display our bodies to groups of male doctors in the interest of "medical education" all without our consent. We may have been asked to strip, walk back and forth in front of complete strangers, and subject our limbs to manual manipulation to determine flexibility. Often we were treated as inanimate objects and talked about as though we were not in the room.

I have begun an initiative with The Polio Outreach of Connecticut in which I invite members to "tell your polio story." This is a kind of truth telling exercise that I feel will liberate and bond. There are two almost opposite benefits from having people share their disability stories. The first is that many people felt they alone had these feelings and struggles. It was a tremendously positive, affirming thing to hear others express similar feelings. When you address hurts that you never fully acknowledged before, you transform inner realities.

When you tell your polio story, you get a chance to grieve your losses. What was that word? Grieve? We are not supposed to feel sorry for ourselves! However, grieving is necessary and healthy. This is a neglected emotional process; often our feelings are "stuffed" because able-bodied folks among our family and friends do not want to hear that we suffer, that we have losses, that our life is often difficult and painful. I encourage you to grieve your loss as healthy and natural and do not feel you must present a false front of "my disability is no big deal" or "it doesn't bother me."

Relive the all-important teenage years and confront the pain. Take time to confide in a close friend or try writing journal entries about your teen experiences. This is a way of allowing the memory to surface in your psyche. Then in the light of day, you can embrace what is good about the memory and eradicate what is hurtful. A profound release from heartache happens when you give way to grief. You face it, process it, discard it, and replace it.

In counseling sessions with people with disabilities, we deal a lot with issues of sorrow over loss of body function. In post-polio syndrome, these losses are gradual over time. Our PPS trail is not a clearly defined path with road signs along the way. It is largely leading us to an unknown destination, and that unknown is anxiety producing.

The great thinkers and philosophers tell us that happiness is a choice; we can choose to be happy. I am here to tell you that I know that to be true! All those old negative messages can be erased and taped over with good, strong, positive transmissions. In psychological terms, this process is called cognitive restructuring. I call it choosing to flourish.

Living a powerful post-polio life means you are thankful for simple things. You take comfort in ordinary events, often taken for granted, that millions of people upon the earth can only dream about: a full refrigerator; clean running water; a soft, warm bed; a long hot shower. When you choose to flourish, you will be released from fear, worry, and self-doubt. Like me that day at the post office, you can decide to start every day with optimism. When you rejoice in each new day, you empty your heart of pain and your mind of worry. You choose to flourish.

Did life with polio weaken your sense of worth along with your muscles? You can improve your level of self-esteem at any stage in life. One way to gain confidence is by simply practicing confidence. Visualize yourself as a proud, confident person. If you act self-assured, you will soon *become* self-assured. Choose to flourish.

An important way to live your own powerful post-polio life is by adopting the habits of a healthy lifestyle: good nutrition, helping others, laughing out loud every day, taking time with your grooming, and surrounding yourself with positive people . . . all are immensely important. Live a life of high aesthetics. Invite music, books, gardening, art, travel, color, and whimsy into your life. Choose to flourish.

A secret of life is not what happens to you, but what you do with what happens to you. All the resources you need to start living life to the fullest are right there within you. You make hundreds of decisions every day . . . choices abound in your life. You can choose to be bitter and angry or happy and filled with a love of life. If you fill your life with goodness and love of others, you chase away the fog of fear and self-doubt. Happiness is a choice; choose to flourish!

When I opened this essay, I said that polio twisted me, shriveled me, and weakened me. These statements were all true, but I was describing what polio did to my self-confidence. I learned that by changing my mind I could embrace my life with joy and acceptance. I could choose to flourish . . . and so can you.



About the Author

Linda Wheeler Donahue, Professor Emeritus of Humanities, is a polio survivor, writer, and speaker.

She is President of ***The Polio Outreach of Connecticut*** and is a frequent presenter at conferences, focusing on the social/emotional complexities of disability. Choosing to flourish remains her ongoing objective.

Linda's essays on subjects of disability dignity, positive thinking, and living with the aftermath of polio have been published worldwide. She welcomes feedback and can be reached at LinOnnLine@aol.com.

From Henry's Desk:

The Time Line of Polio and Post-Polio Syndrome

The Central Virginia Post-Polio Support Group was honored to have Dr. Lauro Halstead spend two days with us in mid September at our annual Retreat at Camp Easter Seal East in rural Caroline County, VA. Dr. Halstead is a polio survivor, physician and recognized expert on PPS. His PPS clinic is at the National Rehabilitation Hospital in Washington, D.C. He has written many articles about PPS and a book about living with PPS as well as being a frequent speaker around the country on various aspects of PPS. At the Retreat we all learned that Dr. Halstead has a keen wit and a good sense of humor. His spoken presentation to our group focused on his pilgrimage with PPS. He had a power point presentation in which he demonstrated his life adjustments in living with PPS. For example he uses a scooter at work, uses several pillows to get comfortable in his bed, takes a short nap daily in his office and has made many individually unique adjustments as have most of us.

He had created a graph for himself that charted over time the significant events that have occurred since he began having symptoms of PPS. This is a worthwhile endeavor for all of us to do. The typical pathogenesis of polio and PPS usually reads something like the following course. Most of us had acute polio before the development of the Salk vaccine in 1955, almost a half a century ago. After surviving acute polio we were left with varying degrees of muscle weakness and muscle strength. Some were fortunate enough to recover all of their muscle function and others had to use assistive devices such as braces, crutches, canes, wheelchairs and in some cases, iron lungs. Most of us had thirty to forty years of stable functioning before the onset of Post-Polio Syndrome. For some PPS has been a rapidly progressive reality and for others it has been a slowly progressive condition. For a growing smaller percentage PPS has not occurred.

To demonstrate how a Polio/PPS time line can be done, I will do my own.

Birth__# 1 Acute
Polio

L #2 good function
e with leg brace

v #3 pneumonia
e (#4) respiratory failure
l & tracheostomy

of #5 onset of
PPS-scooter

f #6 brain
u fatigue
n #7 vent 24/7
c power w/c
t
i
o
n

1939 #1 1950 #2 1960 #3 1967 #4 1970 #5 1990-91 #6 1996 #7 2002-04

On the vertical plane of this graph is a measurement of the level of my functioning. The greatest level of functioning was prior to polio. My level of function is estimated by the height of events on the vertical plane. On the horizontal plane are the significant years of my life with polio and PPS. From birth to age eleven my functioning was essentially active and normal. In 1950 I had acute paralytic polio (#1) causing weakness from the neck down with the right side being more severe. I had to use a long leg brace on my right leg. I maintained a steady physical function (#2) with my maximum functioning occurring around 1960. This improved level of functioning continued until 1967 when I contracted pneumonia (#3) during my hospital rotating internship. I essentially recovered but had to have a tracheostomy performed in 1970 and had to use a ventilator at night to prevent recurrent respiratory failure (#4). I remained stable for twenty more years until the onset of gradual leg weakness and general fatigue in 1990. In 1991 I had a CT brain scan, attended my first post-polio support group meeting, diagnosed myself with PPS and got a scooter and a van with a hoist to carry the scooter (#5). This step resulted in an immense saving of energy and I was able to continue practicing including daily hospital rounds. In 1996 the onset of debilitating fatigue (#6) began on June 21. I was hospitalized and underwent lots of tests with no unusual findings. I moved my office home and continued to practice part time. Over the next six years my muscles continued to weaken as did my respiratory muscles. In June 2002, my oxygen saturation levels were dropping below 88% and I was advised to use a ventilator 24/7. I began doing this by carrying a heavy battery on my scooter along with a heavy vent. In March 2003 I was able to get a Newport ventilator which has an internal rechargeable battery and the entire vent weighs only 17 lb. This was a tremendous advantage in mobility and reduction of weight to carry. In October 2003 I acquired a Jazzy power wheelchair and purchased a Dodge Caravan Entervan (electric fold down ramp). All of these necessary adjustments were not inexpensive, but the advantages gained made the cost a worthy investment.

None of us know how long we will live with PPS, but the preservation and maintenance of a good quality of life does a lot to improve one's mood and provide some peace of mind. I did not share all of this information to prove any particular point, but rather to demonstrate how each of you could do a similar Time Line of Polio and PPS graph for yourself. It may help one better understand the various struggles and necessary adjustments one has to make in order to live longer and more comfortably with PPS. Do you own Time Line graph and share it with others when an opportunity presents itself. I just did it with you, the reader.