

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

December 2003 - January 2004

Carol T. Ranelli, Editor

December 6th Meeting

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

(Please note time change)

Main Auditorium

Lunch to be served at 1:00

Annual Christmas Luncheon

Menu will be:

Three types of Quiche: shrimp, bacon & swiss, spinach, basil & tomato; ham biscuits, fresh mixed greens salad, pumpkin mini-muffins & rolls, fresh cut fruit assortment. Dessert will be mini cream puffs, lemon bars, raspberry cheesecake bars and brownies. Beverages to include coffee, iced tea or lemonade.

Cost will be \$14.00 per person, payable at luncheon

Please respond no later than November 30th to:

Frances Thomas - 804-550-7590

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 10th 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.

From Henry's Desk by *Henry Holland*

Christmas Memories and Polio

Christmas is a time of family togetherness, generous gift giving, joyful times with friends, and an element of fantasy and for many a time of religious renewal. In my first decade of life my family consisted of three generations with six adults and myself living in a two-story stucco house in the north side of Richmond. The house was almost a cube with four rooms downstairs, four bedrooms upstairs and one bathroom. Every morning everyone used that same bathroom and I rarely remember having to wait in line to get into that bathroom. There was a basement, which had a coal bin at the rear end where the coal was stored near the coal furnace that had to be attended to several times a day. The burning coal heated the water that sent steam to the radiators located in every room of the house and usually provided cozy heat. Of course the addition of homemade quilts helped insure warmth at night.

Until I was nine years old I slept in the same large bed with my grandparents and I never felt crowded. When an uncle and aunt married in 1948, I was allowed to get my own room. My earliest Christmas memory was during World War II in 1943 when I was four years old. My Uncle Stokely was in the U. S. Army and he came home for Christmas and brought an Army buddy named Ray Chappell with him. Somehow these young men had found a Lionel electric train and bought it for me. Electric trains and other metal toys were hard to find during W.W. II. This was a simple electric train with a black engine, coal tender, boxcar, flatcar and a caboose. The train ran on O-27 gauge track and was a marvel to watch. The adults seem to enjoy it as much as I did.

After the war on another Christmas about 1948, Santa Claus brought me a larger electric train. This train engine was marked as a Pennsylvania Railroad model. This engine had a realistic sounding train whistle and after dropping a little white pellet in the smoke stack, it would puff out smoke like a real steam engine. During the Christmas of 1949 I received a new Roadmaster bicycle. This was a twenty-six inch bike that had only one speed, but actually would go any speed that I could make it go. It had a speedometer on the handlebars and I could visualize just how fast I was going. I rode that bike almost every day until September 17, 1950 when I contracted polio. I spent the next three months in the Medical College of Virginia (MCV) Hospital polio wards. I spent Halloween and Thanksgiving on those same wards. I was convinced that I would spend Christmas on the polio ward on 5 West of MCV Hospital. I was resigned to it. This was a painful time as many of my new friends who were fellow patients were being discharged almost daily during December. I had just started walking slowly with two leg braces and crutches by mid December. Daily, I had been going across the street by means of a tunnel constructed during the Civil War to Old Memorial Hospital where the physical therapy department was located. With determination I had learned to laboriously and slowly climb steps. This was dangerous despite my success, but apparently this was a significant milestone in my rehab.

Because on Friday, December 15, my doctor (Dr. R. D. Butterworth) told me that I might be discharged before Christmas. This was exhilarating news and I could hardly believe it. On Monday morning my discharge became a reality. I remember getting dressed in regular clothes, strapping on my two new long leg braces and walking slowly down the hallway of MCV 5 West to the elevator rotunda. Other patients said goodbye and wished me well and many of the nurses fondly said their farewells. When I got to my home on North Avenue in the north side of Richmond I knew that I was facing the six steps to get into my house. I climbed those steps in a backward fashion as I had been taught by the physical therapists. Over the next week I fully enjoyed the preparation for Christmas Day. My grandmother used some old family recipes to make Christmas special coconut cake, fruitcake and eggnog. My peer friends in the neighborhood came by to see me and seemed to accept me despite my leg braces. I was thrilled to once again enjoy the decoration of the Christmas tree, especially the miniature snow village under the tree. That Christmas was a very joyous Christmas. I received many additions to my electric trains and this interest in electric trains lasted through my teen years and provided a pleasure that did not require running or a lot of movement. It also helped me understand the mechanisms of electricity.

When I reflect back on that Christmas of 1950 I know at the time that I had no idea how I would face and largely overcome the challenges that I had to face. My short-term goals were to get back to school with my peers, to learn to ride my Roadmaster bicycle again and to find ways to get around in a barrier rich world. I do know that my experience with polio was a major inspirational influence in directing my life goals toward a medical career. I also think that polio caused me to take my religious faith more seriously and to continue to study the scriptures to this day.

Many Christmas seasons have followed that one in 1950 and many have focused on the joy found in helping to provide Santa Claus for my children and grandchildren. Each Christmas has also enriched my belief in the wonder and mystery of the meaning of Christmas as found in the Gospels of Matthew and Luke. For somewhat illogical reasons I have also realized that my polio experience has mysteriously enriched my life. In the company of other polio survivors and PPS survivors I am among those who bear witness to a whole generation of polio survivors who usually persevered in silence and rarely shared much about their lives with polio, the greatcrippler of children. In my current state of health I am delighted to be alive and in my right mind. I can even state that my life with polio has been a unique gift that I did not choose, but am now grateful for the pilgrimage of experiences that polio has made possible. With the new reality of Post-Polio Syndrome, I have met many other polio survivors and this unexpected experience has and continues to be a mysterious blessing.

Those of you of the Christian faith are familiar with the Christmas story as described in Matthew and Luke. There are actually two stories revealed in Luke chapters 1 and 2. Mary and her kinswoman Elizabeth become pregnant within months of each other. Elizabeth is married to an old priest named Zechariah. When the angel Gabriel informs Zechariah that Elizabeth will bear a son, he does not believe that this can happen and he loses his speech once he leaves the temple. At the expected time Elizabeth gives birth to a son. On the day of

the newborn son's circumcision his mother announced that his name would be John. Her neighbors and relatives admonished her and stated that no relative was named John and that the new baby boy should be named Zechariah after his father. Zechariah who had remained mute gestured and asked for something to write on. He wrote that his son's name would be John. Immediately Zechariah's speech returned and he began praising God. Then Zechariah expressed his prophecy. The latter verses of that prophecy read:

"You, my child, will be called a prophet of the Most High God. You will go ahead of the Lord to prepare his road for him, to tell his people that they will be saved by having their sins forgiven.

Our God is merciful and tender. He will cause the bright dawn of salvation to rise on us and to shine from heaven on all those who live in the dark shadow of death, to guide our steps into the path of peace."

This child named John became better known as John the Baptist who preached the forgiveness of sins and offered baptism. He also announced that a greater one would follow him. History bears witness to the apparent fulfillment of John's prophecy.

Perhaps many of us recall the dark days of acute polio and the challenges that resulted. We also know about the dark days of developing PPS and the challenges that have resulted from this unexpected later life adversity. Hopefully we can find strength in the faith that some greater blessing is promised. This is one of the hopes of the Christmas message. This is one of the hopes expressed by Zechariah about his son John. That someone greater than John would follow.

HAPPY HOLIDAYS TO ALL OUR MEMBERS
AND THEIR FAMILIES

Information on Senior Discount Drug Programs

(G) GlaxoSmithKline's The Orange Card (888) 672-6436

- Covers all GSK's drugs. Must have an annual income below \$30,000 per individual or \$40,000 per couple
- 30% average at participating pharmacies

(L) Eli Lilly's LillyAnswers Card (877) 795-4559

- Covers all Lilly's drugs except controlled substances. Must have an annual income below \$18,000 per individual or \$24,000 per couple.
- \$12 Co-pay per prescription for 30-day supply.

(N) Novartis' CareCard call (866) 974-2273

- Covers select Novartis drugs.
- Tier 1 must have an annual income below \$18,000 per individual or \$24,000 per couple. \$12 Co-pay per prescription for 30-day supply.
- Tier 2 must have an annual income below \$26,000 per individual or \$35,000 per couple. Receive a 25% or more discount.

(P) Pfizer's The Share Card call (800) 717-6005

- Covers all Pfizer's drugs. Must have an annual income below \$18,000 per individual or \$24,000 per couple.
- \$15 Co-pay per prescription for 30-day supply.

(T) Together Rx Card (800) 865-7211

- Over 150 select drugs from a group of manufacturers. Must have an annual income below \$28,000 per individual or \$38,000 per couple. (Higher in AK and HI).
- Savings of approximately 20-40% off the amount you usually pay for prescriptions and, in many cases, substantially more.

Make a Place for Your Illness and Put It in Its Place *by Pauline Salvucci*

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Pauline Salvucci is a Professional Life Coach. She is the author of numerous articles on self-care and personal development, including the popular "Self-Care Now!" booklets. Her web site is <http://www.selfcareconnection.com>.

"A place for everything, and everything in its place." That may be a fine idea if you're eyeing the clutter on the living room floor, or a pile or two of old magazines and catalogues collecting dust in a corner. But what has it got to do with coping with illness? Plenty.

Illness is never a welcomed guest in anyone's life. However, when it becomes a visitor in yours, in many cases, it's there to stay. How you cope with it will determine, in great part, how well you love your life. Of the three primary factors which measure your ability to cope: your attitude, the social context of your life, and the quality of the resources available to you, your attitude becomes the foundation upon which the others build.

Making a place in your life for illness may sound like a strange thing to do, but it's a crucial step in learning how to cope with your disease and putting it in its place. Here are some suggestions and tips to help you do this:

Acceptance and Denial are Normal Responses

When you begin to accept having an illness, you open yourself up to interacting with it. This will help you to make a place for it in your life. Feeling both acceptance and denial are normal responses to any major change, let alone a chronic illness. Some forms of illness can certainly limit you and contribute to your feeling different from other people. The thing that makes you different from others is what disease does to your body and how it can affect your emotions. Adjusting to this can be tough enough, don't make it tougher by losing your sense of self, your integrity, and, most of all, your sense of humor. Accepting yourself as a person living with an illness is a process. It doesn't happen all at once. Don't be harsh on yourself when you fluctuate between accepting your disease and denying it. Acceptance isn't something you do once and for all. It's a process. Little by little as you accept your illness, you will make room for it in your life.

Adapting Takes Time and Patience

Like an onion, you peel off one layer of change at a time. The changes you are faced with challenge your ability to adapt. You may have to let go of, or even say goodbye to some activities in your life, either for a time, or perhaps permanently. Grieve this loss. Create a ritual to say goodbye to what is no longer possible for you to do, but don't deny those parts of your life which you enjoyed

and which were important to you. They are a real part of your history and deserve your respect. Some of your life may be different than it was before, but don't treat your past and the things you enjoyed as if they never existed. As you make the changes that your illness requires, you can become more flexible and creative in adapting to change. Keep a journal of the changes you've already made and how you made them. This can serve as a reminder and as a guide for making others as well. As you develop a greater degree of flexibility in adapting to change, the easier change becomes. Above all, don't lose heart!

Befriend Illness as Part of Your Life

You already know how illness affects your body. Now get to know your relationship with it. If you consider your disease an enemy to be crushed, or an unwelcome guest which you refuse to tolerate, how will you allow your illness to be what it is, a part of your life which you can learn to befriend? Do you remember what Lincoln said about a house divided against itself unable to stand? If you're divided against yourself by refusing to get to know this illness, or by waging war against it, how will you come to befriend it? Consider giving your illness a name and talk with it, or write it a letter. Speak from your heart and your passion. Include in your letter everything you think and feel about your uninvited guest. Don't keep your thoughts running around in your mind creating havoc. Then, listen to what your illness says to you in return. If you find this difficult to do, don't be discouraged. It is difficult, but there are rewards. An uneasy alliance is better than none at all.

Feel Like You're Losing Yourself?

Do you feel as if your blue moods are turning into dark depression? Is inertia increasingly becoming more a part of your life? Do you do less for yourself on the days when you could be doing more? Do you isolate yourself from your loved ones and friends? If over a period of time, you are regularly experiencing these feelings and can't shake them, don't hesitate to find professional help. Ask your doctor to refer you to a therapist whose specialty is working with people with chronic illness. These therapists can help you to make your way through difficult times. Yes, it's important to talk with your friends and family, but talking with a professional can be very freeing. They are available to help you sort out your experiences and the many feelings and thoughts you have about yourself and your illness. This isn't the time to "tough it out", or attempt to dismiss your feelings with a mind over matter mentality. Allow yourself to get whatever help you need. It can make a real difference in your life.

Too Much Illness Talk?

Do you feel that talking about illness is taking more of your time and energy than you would like it to? Is it wearing on your family and friends? That can happen, especially when you're first learning about your illness. If it becomes a habit and you feel as if you're losing perspective, here's a way to regain your

balance. Create "talk space". Choose a comfortable place in a room in your home and make time to talk about your disease with your partner and family. Let them know what you're experiencing and thinking. This is a time for honest sharing, for you and for your loved ones. Allow this "talk space" to be the place and time where you discuss your illness. Keep the rest of your home an "illness free talk zone". This will allow you and your family to enjoy one another's company and conversation without reverting to the topic of illness.

Seeing With New Eyes Doesn't Mean Looking Through Rose Colored Glasses

When it comes to putting illness in its place, you might try seeing with new eyes. When it takes you more time to do just about everything, when simple tasks frustrate you because they're not so simple to do anymore, when the familiar becomes foreign, when you can not do the many things you once loved doing, maybe seeing with new eyes can help. If you were an artist and can no longer paint, you can still go to museums or art galleries. If you can't do that, you can enjoy art on the Internet and in books. If you worked with your hands and can no longer use tools to do a job or hobby, teach someone else to do what you know how to do so well. Share your knowledge and lend your expertise. If you loved nature and the outdoors, but can no longer hike, drive along some of the scenic roadways and enjoy the beauty and majesty of nature. Find a way to keep what you have been passionate about in your life. It takes time, work, patience, spirit and heart to make a place for illness in your life. Seeing with new eyes is a tribute to courage and the ability to put this illness in its place.

Reprinted from Colorado Post-Polio Connections, Summer, 2003

Social Support: A Buffer Against Life's Ills

This article first appeared in the Mayo Clinic "Housecall", a free e-mail newsletter for the health consumer found at: <http://www.mayoclinic.com>. It reports that social activities can offer a psychological buffer against stress, anxiety and depression. Social support, including family, friends and regular social activities can also help protect us against developing an illness and can help us cope better with medical problems. It may even increase our life span.

Social support in broad terms includes "talking with a friend over a cup of coffee, visiting a relative or going on an outing with a church or club". These activities are good for our overall health. Social interaction can also increase our sense of belonging, purpose and self-worth, thus promoting positive mental health. It can also help us get through a divorce, a job loss or the death of a loved one. Just knowing someone is available to talk with can reduce negative emotional and behavioral responses to stressful events or other problems.

Social isolation is the opposite and is detrimental to our health. It can contribute to depression and undermine our self-esteem and sense of purpose. Social isolation can also lead to feelings of helplessness and hopelessness. This article warns against abusing these social relationships with excessive complaints about our health and to avoid those relationships that place heavy demands on our time and resources.

The Social Support article gives several ideas for fostering or maintaining relationships. It says that healthy social ties involve give and take. Sometimes we are the one giving support and other times we are on the receiving end. It suggests some areas that might help cultivate healthful relationships:

Get out with our pets. Seek out a dog park or make conversation with those who stop to talk.

Do lunch. Or breakfast or dinner, at least once a month and invite an acquaintance to join you.

Join a hobby group. Find a nearby group with similar interests in such things as music, books, crafts (or post-polio).

Volunteer. Hospitals, churches, museums, community centers, school mentoring programs and other organizations often need volunteers. We can form strong connections when we work with people toward a mutual goal.

Suggested guidelines while we are nurturing our social support system:

Go easy. Don't overwhelm friends and family with phone calls or e-mails. Communication can be brief – five minutes on the phone or several sentences for e-mail.

Don't compete with others. This might turn potential friends into potential rivals.

Adopt a healthy, realistic self-image. Both vanity and avoid relentless complaining. Nonstop complaining is tiresome and can be draining on support systems.

Adopt a positive outlook. Try to find the humor in things.

Listen. Make a point to remember what's going on in the lives of others. Then relate any interests or experiences you have in common. Sharing details about our life can also help to establish rapport.

Social connections provide a sense of belonging, security and a welcoming forum in which to share our concerns and needs. Plus, we may get as much or even more out of friendships and social networks when we are the source of comfort and companionship.

Reprinted from the "Rancho Los Amigos Post-Polio Support Group Newsletter, June, 2003.

Here's an Anti-Aging Strategy: GO SHOPPING

Isn't that an intriguing title? This article concerning our mental outlook appeared in the newsletter "Brain in the News", published by the Dana Foundation. It first appeared in the Baltimore Sun.

The article postulates that one reason women usually outlive men is that women do more shopping. The authors explain that shopping provides three essential ingredients for a healthy life: physical activity, mental activity and gratification.

When we go shopping it requires that we leave the house (internet shopping doesn't count) and move about throughout the store. This increases our physical activity level. Shopping also requires that we use our mind. We must decide if one item is a better buy than another or if a color will clash with the other colors in our wardrobe. And, finally, we get a sense of gratification or enhanced self-image. All three are essential for well-balanced living.

In contrast, the author portrays many men as couch potatoes. As their wives are active, mentally alert and have enhanced their self-image, the husbands are sitting at home, watching TV and living life vicariously through their favorite sports teams

While PPS might have limited our ability to do strenuous activity, it is still important to be as active as possible. We are not limited in the ways we can use our brain, or what we can do to maintain a positive outlook.

Maybe we should conduct a PPS study to verify that this theory is true. Any volunteers???

Travels with Bob *by Gordon Kerby*

Bob, my patient wife and I went off on another trip. This time, at the gentle urging of the Polio Déjà View editor, we visited **Stony Point Fashion Park (Fashion Park)**, to give you our observations about the accessibility of the place.

First, however, I need to briefly explain something. If you missed the last issue, you would not know that Bob is the name of my trusty three-wheeled scooter that enables me to take these jaunts. So, now lets go to the Fashion Park.

Opened in September of this year, Stony Point Fashion Park has 3200 parking spaces. Of these, 46 are designated as handicapped. They are evenly spaced around the Fashion Park in clusters varying from 2 to 6 spaces each. It is an open mall with an interior common area. I'll refer to it as the courtyard. You can get directly into the courtyard via five easily accessible walkways. A sidewalk circles the Fashion Park, so look for the curb cuts carefully, especially when you're leaving the mall. I nearly missed a curb cut and almost took a sudden, unexpected drop off of the curb. The two most popular entrances are on the northern side where P.K. Chang's and the Brio Tuscan Grille are located and on the eastern end where the Champs Restaurant and the Rio Grande Cafe are located. There are six handicapped parking spaces at each of these entrances.

Before we go into the courtyard to visit the stores, we found that you have the option of going into the three anchor stores, Dillards, Saks and Galyans, directly from the parking lots. These three stores are all handicapped accessible. Dillards has doors that open automatically and both Saks and Galyans have convenient press pads that allow you entry. The aisles inside these three stores are also scooter friendly. But if you're not in a hurry, you can visit all of the stores by scooting in the courtyard. The courtyard is easy to negotiate and in nice weather, it is a pleasant place to scooter and window shop. If you need directions or information to a store, you can scooter up to the convenient customer service building located in the middle of the courtyard. Customer service also has four complimentary wheelchairs that are available on a first come-first serve basis. And being an out door mall, you can also rent an umbrella there if you're caught in the rain, since not all of the stores have awnings or overhangs to shelter you from inclement weather.

The Fashion Park has approximately ninety stores, all on one level. As I mentioned before, the three anchor stores are quite accessible. In scooting around the courtyard, I found only one other store that had a device to automatically open the door, and that was Hollisters, a 20s something clothing store. I'm a little past the age for that style of clothing, so I didn't go in. Anyway, what I found while scooting around the courtyard, was typically what you find at such a mall. None of the smaller stores (with that one exception) have built-in easy access into the stores. However, if its nice day, a lot of the businesses do keep their doors open which makes entry very easy. And based on my experiences there, if the clerks inside see you at the door outside, they'll gladly help you get in. But if not, you may need a companion to help you open the doors of the store that you would like to visit.

But before we would try to go in a store, we could generally tell by window shopping there, whether it was scooter accessible or not. Our observations from doing it that way, was that the accessibility of these stores, ranged from excellent (nice scooter wide aisles) to impossible (very narrow aisles). We didn't visit all ninety stores of course, though my wife

would have liked to have tried (just kidding). On our visits there, we had wanted to visit several specific stores and along the way, we stopped in several restaurants. So here's a sentence or two on some of the places we visited as well as an interesting feature that we found in a number of the stores. They all have manually opening doors, including the restaurants.

Dillards, Saks and Galyans – I've already mentioned them, so you know about their accessibility.

Smith & Hawkin – We found generally scooter friendly wide aisles and a public handicapped accessible restroom. More on that subject later.

Restoration Hardware – Bob and I had trouble negotiating beyond the front of the store. So we found that this store was not very scooter friendly. They also have a public handicapped accessible restroom, though it looked difficult to get to.

Sur La Table – The aisles were scooter friendly, but there were some tight spots inside the store.

Storehouse – We found generally scooter friendly aisles and so we were able to maneuver through most of the store. They also have a public handicapped restroom

Public handicapped accessible restrooms— Many of the stores have this kind of restroom, even if it looks from the outside of the store that it is not scooter accessible. Just look for the decal down low on the storefront glass. I only visited two of these facilities and found that they appear to be designed for wheelchair access, not scooters, with oversize doors that you may find difficult to open. In my situation, I parked Bob beside the restroom and walked inside. If you're unable to do this, it may be a problem. On the plus side, it's a nice convenience to have these facilities located throughout the Fashion Park and so, not have to go to the general public restrooms located at one end of the courtyard.

Now on to restaurants-

Starbucks – Has a handicapped marked table just inside the door, where you can park your scooter, but you'll have to walk to the counter to place your order.

Brio Tuscan Grille – Has a location just inside the door, where you can park your scooter and walk to the table if you're able.

P.F. Chang's China Bistro – They don't have a designated spot for parking the scooter, but they said that they could find a place to park a scooter if necessary.

Rio Grande Café – They let you park your scooter at an out of the way corner with the baby strollers.

You probably read and heard that this is a dog-friendly mall. On our visits there, we saw very few dogs and those we saw were generally well behaved. So we didn't have any trouble with dogs barking at Bob or trying to bite his tires.

Anyway, this is again a quick accessibility review of a large regional mall and I'm still learning how to do such writing. Next time, when I look at restaurants, I'll be more observant about overall scooter access to the dining tables.

I hope you will find this information helpful when you visit there.

Dr. Jane Wootton retires from Sheltering Arms

On October 29th, several members of our PPS Support Group gathered for dinner at Skilligallee Restaurant to show appreciation to Dr. Jane Wootton, former head of the Post Polio Clinic at Sheltering Arms Hospital and to wish her "Happy Retirement".

Dr. Wootton was presented with a plaque from the support group as a thank you for her years of dedication and service to the clinic.

Dr. Albert Jones will be heading the PPS Clinic in the future. Many of us are familiar with Dr. Jones from the past and we appreciate his taking over the task of continuing the PPS Clinic.