

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

June – July 2004

Carol T. Ranelli, Editor

June 5th Meeting

Children's Hospital, 2924 Brook Road, Richmond

Annual June Luncheon

Arrive at 12:30 – Lunch served at 1:00

Old Fashion Summer Cook-out

**The menu will be: Grilled hamburgers and hotdogs
with buns and all the fixin's**

**Southern potato salad, Cole Slaw,
Cucumber-Tomato-Onion Salad with vinagrette dressing
Strawberry Shortcake
Lemonade, Limed Iced Tea or Water**

**Cost is \$13.00 per person payable that day by check or cash.
Make checks payable to "Missy Mauck"**

**Call Frances Thomas at 550-7590 by May 31st
to make your reservation.**

Plan to join us for good food and a chance to visit with friends.

We will have NO meeting in July.

**Don't forget the Sixth Annual PPS Support Group Retreat
will be September 17th – 19th !!!!**

Complete information and registration form inside this issue!

**Rooms are available on a first come - first serve basis.
Deposits are due no later than July 1st.**

SIXTH Annual Fall Retreat!!!

It's time to reserve a room for our SIXTH Annual Fall Retreat at Camp Easter Seal-East from 3 pm, Sept. 17th until noon, Sunday, Sept. 19th.

The camp is situated in Caroline County, VA, about an hour drive from central Richmond.

Our speaker will be **Dr. Lauro Halstead**, noted author and Director of the PPS Clinic at National Rehabilitation Hospital in Washington, DC.

We were honored to have Dr. Halstead speak at one of our PPS Conferences and look forward to hearing him speak on the latest post-polio issues and answer our questions. Dr. Halstead and his wife, Jessica Scheer, will be our guests for the weekend.

We **MUST** have 50 people attending this year as Easter Seals Virginia is strictly imposing their requirement of a 50 person minimum due to increased operational costs. If we do not meet this quota, our support group will have to make up the difference from our treasury. We have subsidized the individual cost in past years to keep member's costs down.

As in previous years, we will be housed in the Federation Lodge, which has meeting rooms, lounge, dining room and bedrooms all in one building. Camp Easter Seal-East is totally handicapped accessible. Each bedroom has an accessible bathroom. This is a totally NON-smoking facility. Linens are provided. We recommend that you bring an egg-crate mattress pad for your bed.

The camp is refurbishing the bedrooms and rearranging the bed set-ups, but we will make every effort to accommodate any special needs. **The bedrooms will be on a first come – first serve basis.** We can also use the dormitory building which is a very nice facility and adjacent to the Lodge and good for all the "single" members who attend.

We have again arranged to have two massage therapists join us on Saturday from 9 until 4. They will charge \$20 for a 20-minute session. You may schedule a double session if you desire. Sign up for the massage schedule will be during registration on Friday afternoon...or upon arrival on Saturday if time slots are still available. We need to know ahead of time how many people will be interested in this service. Please respond on your registration form.

The indoor accessible pool will be available on Saturday afternoon.

We are including an application form in this newsletter for those who already know they will be attending. We are also requesting a \$30 per person deposit by July 1st. This will give us a better idea of what this year's attendance will be.

Final reservations and complete payment MUST be received by Linda VanAken by Sept. 1st. For those who sent in an early deposit – the remainder is due by Sept. 1st.

The cost of the entire weekend is \$125 per person, which includes 2 nights and 5 meals. If you are only able to come for the day on Saturday, the cost will be \$40 per person for the use of the facility, lunch and dinner.

Registration Form for September Retreat

Friday, September 17th until Sunday, September 19th

Please mail to: Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831

WITH check made out to: **“Camp Easter Seals”**

Final payment has to be received by **Sept. 1st**.

Name: _____

Address: _____

Phone: _____ Number of Persons attending: _____

Type of Room accommodation: _____ (single or double)
If you have special needs for bedroom or bathing facilities, let us know.

Are you interested in scheduling a massage therapy session? _____

Will you be attending just for the day on Saturday? _____

Number attending: _____

Do you have any special dietary requirements? _____
(We cannot change the pre-set menu unless there are specific needs)

Price for the weekend (2 nights and 5 meals) \$125 per person

Price for Saturday only (includes lunch and dinner) \$40 per person

Amount of check sent: _____

Personal View Point: Housing Options by Carol Ranelli

At some point, all we PPSers have to consider what are the best housing options for us as we age and develop increasing mobility problems. We may reach retirement and decide to move to a warmer climate or closer to children and grandchildren. We may find we have money to invest and the best venture now is real estate. All of these are great reasons to seek out one level living or whatever the housing options are in the area where you decide to live. Unfortunately, none of these reasons applied to me.

I spent the first few months of this year "soul-searching" where I wanted to live for the next several years. Having lived in the same house since I moved to Richmond 27 years ago, this was home to me. I've had the same next door neighbors and the majority of my friends lived in this neighborhood. I was comfortable in this area of Richmond, which has grown increasingly convenient over the years. Everything I need is at my fingertips. But there was one problem... I was a single woman who had an acre of property and a two-story house, along with increased fatigue and muscle weakness. What was I going to do?? How could I manage this??

OK... I was going to approach this as realistically and methodically as possible. Many others in my PPS support group had dealt with this problem. They had found new housing that suited their needs; given up two-story houses or townhouses for one level homes, patio or cluster homes, condos or smaller homes with minimal yard. If they could do this, so could I. But there was one problem, this turned out to be a very emotional issue for me.

I turned to my most "logical" and practical friends. I talked with friends in the support group who had gone through this housing dilemma. Help me brainstorm this issue. Help me figure out the pros and cons. Walk with me through the options. I need someone who can distance themselves from the emotional parts.

The first thing I decided was that I didn't want to leave this area of the city. I was not giving up my social base. I was comfortable here. I had friends I could call on for help if needed. To me, this was of utmost importance since I don't have family in town. Next, I talked with realtors, visited new construction sites of empty-nester communities, saw what was available for resale and considered my finances. I had to consider the physical, emotional, financial and stressful aspects of an actual move!

After looking outside my property for options, I then looked at what I had. Because I always had some limited mobility... used crutches outside the house and wore a brace, I had bought a house that had only one step from the garage into the house. I had to be able to get groceries in the house! Several years ago, my father had built me a sectional portable ramp which could be set up in the garage to get a wheelchair in and out easily. OK, this getting in and out of the house was a piece of cake. I had already put raised toilet seats in the powder room and master bath, plus there was room to increase door width in both rooms if necessary. I already had the bathing situation taken care of... transferable bath benches that I had used for a number of years. I had accumulated more medical equipment over the years than Westbury Pharmacy!

Now, for the yard. I had been fortunate that over the past several years, I had found wonderful people to cut my grass, do my leaves, mulch, plus any other heavy yard chores that came up and they were reasonably priced and dependable. I compared that annual cost to the costs of "maintenance fees" in maintenance-free communities and I came out ahead! I also had two beloved dogs that loved their wooded, fenced-in yard. I wasn't ready to send them into retirement too!

Now, for the stairs. This seemed to be the biggest drawback to staying in this house. Several years ago, I had started my research on stair lifts, so I started looking into it again. There are several places in town that carry and install different brands. I had three companies come to the house to give prices and discuss options. They were all within a few hundred dollars of each other in price. I went to each showroom to "test drive" their stair lifts and see what they looked like in person. I eventually went with Virginia Elevator Co. who took a special interest in the polio community and I felt went beyond the normal sales situation. It is now installed and I love riding up and down the stairs instead of wasting that precious energy or dealing with the possibility of a fall.

I have heard many members of our group talk about moving or making changes in their present homes. It's something that most of us, able-bodied or not, will have to face eventually and it isn't an easy decision. So many factors come into play that make it a very individual decision for each person or couple.

What this mental (and emotional) exercise answered was essentially: Where will I be happiest? I am happiest in a home I have taken great pride in, which has "Carol" written all over it (I am a designer for goodness sake!), in a neighborhood where I feel safe and comfortable, where my friends live and where I can make the house work for me. I feel most of the major problems have been solved. Is it ideal? Probably not. But for the time being, it works for me and contentment is a wonderful feeling.

From Henry's Desk *by Henry Holland*
The Grief of Post-Polio Syndrome

I went to another funeral this month. Another long time member of our Post-Polio Support Group died. His name was Mel Bleiweiss. Like many of us Mel was courageous, persevering, gentle, generous and a man of integrity. Each month I read a lot of Post-Polio Support Group newsletters from around the country. The mention of the deaths of polio survivors is becoming more frequent. The vast majority of our number originated from thousands of people who had polio in the twenty-year span from 1935 to 1955. Thus, most of us are over fifty years old and many of us are over sixty years old. Most polio surveys indicate that the average age of polio survivors with Post-Polio Syndrome (PPS) is around sixty-two to sixty-four years. Thus, we are entering an age group where death becomes an increasingly higher risk.

I looked at the obituaries in today's Richmond Times Dispatch (May 9, 2004) and found twenty-five deaths in which the age of death was mentioned. Of the fourteen women who died, ten were over the age of eighty. Of the eleven men listed, six were over the age of seventy. These numbers are somewhat indicative of national averages. The average death age for women in the USA is approaching 80 (around 78). The average death age for men is around 74 to 75. Are polio survivors at a greater risk to succumb before reaching an average life span? The answer to that question is not clear, but gives one reason to think.

So much of what happens as the result of PPS may increase the risk of some life threatening event. Because of increased stress on the total body system, reduced activity, weight gain, systolic and/or diastolic hypertension, accidents/falls, infections, emotional factors and aging before our time, PPSers very well may be at a higher risk to die at an earlier age than our relatively able bodied peers. I wrote an article on "Is PPS Fatal" two years ago and came to the conclusion that PPS is not likely to be fatal. The reader can read that article on our web page at <http://www.cvppsg.org/index2.html>. Look at the link for "From Henry's Desk" and the article is listed.

I recently went to a medical conference on stroke. The five risk factors given for increasing one's likelihood of having a stroke or a cardiovascular event were cited as:

1. Elevated glucose (blood sugar) even at moderate levels
2. Elevated systolic or diastolic blood pressure. The optimal blood pressure is 130/80 or below.
3. Elevated cholesterol or blood lipids. The statin drugs are effective in lowering cholesterol, especially the bad cholesterol or LDL
4. A history of tobacco or illegal drug use
5. Lack of exercise.

With all of these medical warnings I believe that we still have to deal with the grief of PPS, which alone can be a burden. Grief is often caused by the loss of a loved one or the loss of a significant part of one's identity. The vast majority of polio survivors had an identity apart from polio. This identity may have been associated with marriage, parenting, occupation or career, community involvement or by religion. With PPS, all of the previously mentioned components of our identities may have been affected and lost

in part. We are confronted with “Why is this happening to me now?” We are having to make life style changes that we did not expect and the necessities of these changes does not seem fair after so many successful adjustments earlier in life.

As a result of PPS our independence may be lost or at least threatened. Many of us have to depend more on our spouse, family members and friends. Some of us have to pay for necessary help. Some of us are no longer able to work and have to live on fixed incomes with rising medical costs. Some of us are not able to drive a motor vehicle as safely as in the past. Some of us have been forced prematurely to bring a successful career to a close. Some of us can no longer safely lift our grandchildren. Physical barriers can often be overcome or marginalized. Every older person eventually faces a reduction of activity and energy, but PPSers often face these reductions long before becoming truly elderly.

All of these realities for many polio survivors produce a feeling of grief which may never be fully resolved. I think many of us have worked through this grief. Hopefully we will not withdraw or isolate ourselves from family members, friends and other polio survivors. Expressing and talking about what we feel is usually helpful and therapeutic. Often the inner resources of one's faith can certainly be both helpful and inspiring in facing the grief of PPS. I have also found that some of the poetry that I read and studied in my youth can be uplifting and even more meaningful as I grow older. One example is the poetry of English poet William Blake (1757 - 1827). The excerpt below, written in 1808, reminds us “not to cease from mental fight.” Most PPSers can understand this approach to the grief of PPS.

And did those feet in ancient time
Walk upon England's mountains green?
And was the holy Lamb of God
On England's pleasant pastures seen?

And did the Countenance Divine
Shine forth upon our clouded hills?
And was Jerusalem builded here
Among these dark Satanic mills?

Bring me my bow of burning gold:
Bring me my arrows of desire:
Bring me my spear: O clouds unfold!
Bring me my chariot of fire.

I will not cease from mental fight,
Nor shall my sword sleep in my hand
Till we have built Jerusalem
In England's green and pleasant land.