

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

June – July 2005

Carol T. Ranelli, Editor

ANNUAL JUNE LUNCHEON

Please join us to celebrate the 20th anniversary of our support group!!!

June 3rd at Children's Hospital, 2924 Brook Road, Richmond

Please arrive by 12:30 as serving will begin at 1:00.

We will have lunch catered by Buz and Ned's Real Barbeque.

The menu will be: Pork barbeque with sauce, pulled barbeque chicken, cole slaw, sour cream redskin potato salad, herbed green beans, rolls, iced tea, lemonade, soda or bottled water.

The cost will be \$13 per person.

Your reservation needs to be in by May 26th. Please call Bev Lordi at 746-3864.

We would love to have many of our long time members attend to celebrate this milestone for our group. We have accomplished many good things for PPSers over the past 20 years. Please come join us for this special day.

After the lunch, we will have a **Brown Bag Auction** to benefit the social committee and help offset costs of our upcoming Annual Retreat in September.

Please bring an item (white elephant, gag-gift or otherwise) in a brown bag with a short clue about the contents attached. Our favorite auctioneer, Dave VanAken, will preside. This is always a lot of fun for those attending!

There will be no meeting in July.

SEVENTH Annual Fall Retreat !!!

It's time to reserve a room for our Seventh Annual Fall Retreat from Friday, Sept. 21st at 3:00 until noon, Sunday, Sept. 23rd.

The Retreat will be held at the Holiday Inn Express Hotel & Suites in Ashland, VA (www.hiexpress.com/ashlandva). This is located right off Rt. 95, just north of Richmond and will be convenient for everyone. We have tentatively reserved 15 guest room/suites and all six handicapped accessible rooms.

The bedrooms will be on a first come – first serve basis.

The hotel serves a multi-course breakfast and we have arranged to have two dinners and a lunch catered by a local caterer. We will have the use of the conference rooms, heated indoor swimming pool, hot tub and exercise facility.

The suites have microwaves and refrigerators, TV, coffee makers and hair dryers. There is a sitting area separate from the bedroom. This facility opened a year ago and is beautifully decorated and maintained.

We are thrilled to offer all of this for \$110.00 per person based on double occupancy for the entire weekend, including all meals. (This is less than the last Retreat at Camp Easter Seals and we have a much nicer facility.)

If you want to come just for the day on Saturday, the 21st, the cost will be \$50 person which includes lunch and dinner.

We are excited that Linda Wheeler Donahue has agreed to be our weekend guest and our Saturday morning speaker. We have used several of her fine articles in our past newsletters. Linda writes and speaks about flourishing with a disability and making good choices to create a positive lifestyle.

She will speak on "My Polio Path: How I Went From Survivor to Thriver."

Linda is President of the Polio Outreach of Connecticut. She is a polio survivor, a disability activist, writer, speaker, and professor emeritus of humanities. She has published over a hundred articles worldwide on subjects of positive living, disability dignity, and increasing happiness through conscious choices. A long-time advocate of disability rights, Linda was invited by President Bush, Sr. to attend the signing of the Americans with Disabilities Act in 1990. She is a frequent presenter at conferences, focusing on the social/emotional complexities of disability. Her avocation is tending to her gardens, with a collection of over 50 rose bushes.

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.

Dave VanAken will again conduct a "Partners Session" on Saturday afternoon for those interested. We are arranging to have several local medical equipment companies there on Saturday showing their products and answering questions.

Final reservations and complete payment should be received by Linda VanAken by August 31st. For those who send in an early deposit – the remainder is due by August 31st.

Registration Form for September Retreat

Friday, September 21st until Sunday, September 23rd

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

WITH check made out to: "**CVPPSG**"

Final payment has to be received by **August 31st**.

Name: _____

Address: _____

Phone: _____ Number of Persons attending: _____

Type of Room accommodation: _____ (single or double) Handicap accessible? _____

If you are single and sharing a room, who will be your roommate? _____

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) \$110 per person based on double occupancy

Price for Saturday only (includes lunch and dinner) \$50 per person

Amount of check sent: _____

Remember, all rooms, including the handicap accessible rooms, are on a first come-first serve basis.
Your registration form, with a \$30 deposit, guarantees your room.
If you know you will be attending, please send your registration in early.

Thank you.

PPS and the Central Virginia Post-Polio Support Group

The Central Virginia Post Polio Support Group is celebrating its twentieth anniversary this summer. Maybe “celebration” is a misnomer for this event. I am sure that most of us wish we had never heard of PPS and never experienced it as a reality. PPS has caused most of us to change our life styles and our thinking about how to deal with disability.

One of the early supporters of our PPSG is Susanne Hirt. Sue is now elderly and requires the help of others for her daily needs. Several years ago I wrote an article about Sue’s life and her contribution to our group. That article is on our website at:

<http://cvppsg.org/henrysdesk/>

Sue was a physical therapist at the Medical College of Virginia (MCV) Hospital during the worst of the polio years. She was an advocate of the Sister Kenny treatment for acute polio. Before coming to MCV, Sue had met Sister Kenny and studied Kenny’s theories while she was at the University of Wisconsin. During my years in medical school at MCV (1962-1966), Sue was the director of the school of physical therapy. Because of Sue’s current failing health many of her papers were distributed and I was fortunate enough to receive her files/papers on polio and PPS.

Among her papers are what seem to be lectures that Sue presented to physical therapy students. The papers are typed with some underlining and words added in the margins. One of these lectures is titled “The Treatment of Poliomyelitis” and the lecture is dated September 25, 1945. Her lecture emphasized the importance of an early assessment of the extent of paralysis and the recommended treatment. The presence of muscle spasm and weakness were important to detect and measure. Her treatment recommendations were almost identical to Sister Kenny’s methods. The best treatment for muscle spasm was the application of hot packs. One portion of her lecture that I found to be of interest was Sue’s detailed instruction regarding what came to be known as the Kenny hot packs. A demonstration of the application of hot packs was performed as Sue lectured. Here are Sue’s words:

“The packs are best made of a soft material that contains 60-100% wool. They are cut to the size of the patient, covered with a water repelling material, f.i. oil silk and an outer woolen layer as protection. They are boiled and applied as hot as possible, which is safe only if most of the moisture has been removed. They are applied firmly and evenly preventing carefully any sensation of pressure or restriction, particularly to swallowing and respiration. Joints are left free to avoid the sensation of immobilization, only hip and shoulder joints are excepted due to the large muscle groups crossing these joints which frequently are in spasm. The packs cool off to body temperature in 15 to 20 minutes, but will not chill the patient if secured safely. The frequency of application varies with the acuteness and painfulness of the spasm, an average is 5-6 applications during 8 hours. Intensive packing may be used for severe cases, i.e. renewal of packs every 15 minutes or even more often if spasm produces respiratory distress. Packing is discontinued as soon as normal pain free joint movements can be obtained.”

For many of you this description of the “hot packs” may result in some painful memories. Among Sue’s papers was a lecture she presented on September 13, 1943 to the University Club at the University of Wisconsin. The topic of her lecture was “The Kenny Method of the Treatment of Poliomyelitis.” This would indicate that Sue was on the cutting edge of the advances made in the physical therapy treatment of polio.

Her papers would also indicate that she was well aware of PPS before many of us learned of this condition. She had saved an issue (Volume 2, Number 1) of the Polio Information Center News. This newsletter was published by the Polio Information Center located on Roosevelt Island, NY, and this issue was dated Fall 1984. The article reported the results of a questionnaire that had been mailed to many polio survivors several years previous. This effort resulted in 700 completed questionnaires. The findings validated the physical changes which were affecting a great number of people who had polio 25 to 30 years ago. The detailed results of this study would require a separate essay. However, it is evident that the problems with weakness, fatigue and pain were gaining momentum twenty-two years ago. The greatest number of complaints at that time was shortness of breath (85%), dizziness (65%) and depression (44%). I suspect that these complaints were high because most polio survivors did not know what was happening to them and they were continuing to overdo and push through pain.

When other survivors and a few health care providers became aware of these physical changes, the diagnosis of PPS became more accepted. Thus, in July 1986 the first meeting of the Central Virginia Post-Polio Support Group was held. Sue Hirt was there. The history of our group is printed elsewhere in this newsletter. It is now twenty years later. We are all twenty years older, but we are more knowledgeable and wiser. We are an upbeat support group, but have come together in times of loss when one among us has died. On a personal level I look forward to our meetings because we have esprit de corps, which is defined as “the common spirit existing in the members of a group and inspiring enthusiasm, devotion, and strong regard for the honor of the group.”

Because of PPS our group was formed and because of our group we have educated, advocated and supported each other. We will continue to exist for these purposes for years to come.

History of the Central Virginia Post-Polio Support Group

The Central Virginia Post-Polio Support Group was created because a polio survivor was having baffling symptoms and wondered if others like herself were experiencing similar problems. Thus began Margo Gathright-Dietrich’s search for others who wanted information about these new problems.

Margo founded our support group with four others in July of 1986. They met at Dumbarton Library in Henrico County. In addition to the polio individuals, Sue Hirt, a retired physical therapist and

Professor Emeritus of the Medical College of Virginia, was present at that first meeting. Sue had treated polio victims in the late 1940's and early '50's. She continued to be an invaluable source of information for those of us who were too young to remember the original bout with the polio virus.

From that first meeting, our support group grew quickly and met at various locations, including the Adult Day Care Center and the Center for Independent Living. The group met at Sheltering Arms Hospital for many years on the third Thursday evening of the month from 7:00 til 9.

On August 11, 1988, the group had its first election of officers: Margo Dietrich as president, Bill Pannell as vice pres., Pat Skiba as treasurer, Pat Poole as recording secy., Dorothy Cole as corresponding secy. Jack Wilson and Jean Watson were the Program Committee.

Our group made a decision to affiliate itself with Easter Seals Virginia from the beginning and continued to do so until we became a non-profit organization in Sept. of 2005. Lila Weisberg was the first director of Easter Seals to work with the support group. She retired in Sept. of 1988 and Jewel Cooke took over as Easter Seals Regional Director and became a member of our board.

Another board member we hold in high esteem was Charley Brower who was our representative with The March of Dimes and promoted our causes to them. Charley first attended our meetings in April of 1988.

The following is a time-line of events which creates the history of our support group.

March 21, 1989 – Approved the first set of By-Laws.

Saturday, May 19, 1990 – 1st annual Spring Social Dinner at the Richmond Marriott

Dr. Monmahon Khokhar, at the time with Sheltering Arms Hospital, was the first doctor to work with the group in regard to PPS. In July, 1990, he attended the Washington Rehabilitation Hospital PPS Clinic and reported back to the group. He began working on creating a PPS Clinic at Sheltering Arms.

Saturday, September 22, 1990 – Pat Poole hosted a covered dish picnic at her home for the group. This was repeated the following year.

December 2nd, 1990, Sunday afternoon – Held the 1st Annual Christmas Party from 2:30 -4:30

February 25, 1991 – First article about the support group was featured in the Richmond Times-Dispatch newspaper.

June, 1991 – Member of the group met with the Director of Sheltering Arms to discuss the possibilities of creating a post-polio clinic.

November – December 1991 – First issue of our newsletter was mailed. Sandra White was editor and there were 200 on the mailing list. We asked for suggestions for a name and by the next issue, Polio Deja View was suggested by Charles Hamilton of Richmond.

September, 1991 – Dr. Henry Holland attends his first meeting and presented his first program, “The Emotional Effects of Dealing with PPS” in March, 1992.

November, 1991 – Dr. Henry Stonnington, Medical Director and John Allred, Director of Sheltering Arms met with the group to explain their plan for the Post-Polio Clinic.

January 13, 1992 – Board members met with the Post-Polio Clinic team to discuss the final touches and express our concerns and wishes.

January, 1992 – Monthly meetings of the support group moved to Saturday afternoon from 2 til 4 in the afternoon.

March 26, 1992 – Opening of Sheltering Arms PPS Clinic. Approx. cost for an evaluation was \$900, including EMG. They saw 37 people the first year, then increased the days a week which the clinic was held to meet the demand.

April 11, 1992 – Covered dish lunch meeting from 1-3 at Jack and Karen Wilson's home in Darlington Heights, VA.

April 25, 1992 – Richmond Times-Dispatch runs an article on the opening of the PPS Clinic.

October, 1992 – Dr. Jane Wootton heads up the PPS Clinic.

January, 1993 – We temporarily move our Saturday meetings to The Rehabilitation Hospital of Virginia on Fitzhugh Ave. while remodeling is done at Sheltering Arms.

May, 1993 – First time that Dr. Lauro Halstead from National Rehab Hospital in DC spoke to our group. It was a monthly meeting and 76 attended.

February, 1994 – Peer counseling begins at the PPS Clinic.

April, 1994 – Hugh Gallagher, author of “FDR’s Splendid Deception” speaks to our group.

August 25, 1994 – Another article is in the Times-Dispatch about our group.

January-February, 1995 – Ed Gates and Pat Poole co-chair the Newsletter Committee; eventually, Ed takes over as editor.

March, 1995 – After two years, our monthly meetings move back to Sheltering Arms.

April, 1995 – First meeting which focused on caregiver-partner PPS issues. Rev. Rose Young was the moderator.

March 30, 1996 – 1st Annual PPS Conference was held at Sheltering Arms. Dr. Lauro Halstead, Hugh Gallagher and Dr. Jane Wootton were the speakers at an all day conference. 150 attended.

September, 1996 – Carol Ranelli becomes editor of our newsletter.

August, 1997 – Dr. Henry Holland, then president of the group, had us divide into age groups according to when we had polio. Each group discussed their individual experiences. A lively and boisterous period followed; ie: the birth of the “PPS Toddlers”. Later, he even wrote an article for the newsletter entitled “The Toddler Mystique”.

September 25-27, 1998 – 1st Annual PPS Retreat at Camp Easter Seals East in Caroline County, VA. Dr. Jane Wootton was our speaker on Saturday morning with a “Post-Polio Update.” Dr. Rizwan Ali spoke in the afternoon on “Psychological Aspects of PPS.” We also had vendors presenting their products in the gym. Cost was \$50 a person for the weekend and \$15 for Saturday. The treasury subsidized the remaining costs. Thirty people attended for the weekend and three for Saturday only.

November 14, 1998 – 2nd PPS Conference was held at Sheltering Arms. Dr. Richard Bruno was our speaker for an afternoon conference.

December, 1998 – First CVPPSG webpage was designed on the Easter Seals website.

It was during this time that many members of the group would go out to dinner after the Saturday monthly meetings. It was a way to continue talking about PPS issues and just socialize with friends.

April, 1999 – Dave VanAken conducts his first “Caregiver/Partner session” during a monthly meeting.

September 24-26, 1999 – 2nd Annual PPS Retreat at Camp Easter Seals East. Pam McMillan, counselor at Sheltering Arms spoke on “Dealing Psychologically with PPS.” She also conducted a Family Support Discussion with spouses. Cost was \$75 for the weekend, \$15 for Saturday. 20 attended.

January, 2000 – Started requesting \$10 dues to offset the cost of the newsletter, conferences and retreat.

February, 2000 – Marilyn Decker, Social Chairman, organized the first Brown Bag Auction to raise money for social events during the year.

April, 2000 – Reestablished the Peer Counseling group for the PPS Clinic. Eight members of our group participated.

August, 2000 – Our monthly meetings move to Children’s Hospital on Brook Rd, when Sheltering Arms Hospital building is sold.

September 22-24, 2000 – 3rd Annual PPS Retreat at Camp Easter Seals. Sue Briggs, PT was to speak on the “Role of Physical Therapy in PPS” and Jann Hartman spoke on “Nutrition and PPS”. Cost was \$85 for the weekend and \$15 for Saturday. 15 attended.

October 7th, 2000 - Outgoing president, Henry Holland, was presented a plaque from the support group for his outstanding service and leadership during his terms as president.

March 24, 2001 – 3rd PPS Conference held at Children's Hospital from 1 til 5. “2001- A Brace & Pace Odyssey.” Dr. Mary Ann Keenan, an orthopedic surgeon and head of the PPS Clinic at Moss Rehab in Philadelphia was our speaker, as was Dr. Jane Wootton. Cost was \$10. 51 attended.

September 21-23, 2001 - 4th Annual PPS Retreat at Camp Easter Seals. Planned speaker could not attend, so Henry filled in. We also had small group discussions for PPSers and their caregivers. 22 attended.

November 3, 2001 - Charlie Brower was given a plaque for his years of work as liaison for March of Dimes on behalf of our support group.

September 20-22, 2002 – 5th Annual PPS Retreat at Camp Easter Seals. Biggest attendance yet when 41 attended; people from six states attended. Commonwealth Medical Associates gave morning presentation on the latest assistive devices and equipment. We also had a panel discussion of Dr. Bruno's book “The Polio Paradox”. Cost was \$75 for the weekend and \$25 for Saturday.

October, 2002 - Several members of our group took Jewel Cooke and her husband out to dinner as a thank you for her years of service to the group as Regional Director of Easter Seals Virginia. She is leaving Easter Seals for work at another non-profit organization.

September 19-21, 2003 - 6th Annual PPS Retreat was cancelled at the last minute due to Hurricane Isabel. Camp Easter sustained power outage and many trees were down.

October, 2003 – Dr. Jane Wootton retires from Sheltering Arms. Dr. Albert Jones will head up the PPS Clinic. Within a year, the PPS clinic is disbanded as an organized entity.

January, 2004 - After several months of work, our CVPPSG website was up and running. Eric Johnson, with University of Richmond, is our web master. He worked with the group to redesign our logo and will continue to maintain and up-date the website.

February 28th, 2004 - We begin to organize our “mid-month lunches”.

September, 2004- 6th Annual PPS Retreat at Camp Easter Seals. Dr. Lauro Halstead was our first speaker, giving a PPS Up-date. Dr. Courtney Goodman, Pharmacist later spoke on PPS and Medications. 29 attended. This was our last retreat at Camp Easter Seals as it was sold within a year.

January, 2005 - The CVS 2004 Volunteer Challenge Grant selected us as an Outstanding Group. The original amount applied for was \$500, but CVS granted us \$1,000.

April, 2005 - President Carol Kennedy applied to the IRS for non-profit status. She had been working toward the final application for several months, both through the State Corporation Commission and the IRS.

September 24th - The application was received as APPROVED. We are now independent of Easter Seals Virginia.

October 1, 2005 - All day Post Polio Conference at Children's Hospital. Fifty attended. Speakers were Dr. Mary Ann Keenan who spoke on "Protecting Our Joints" as well as Sue Briggs, PT and Dr. Courtney Goodman who answered questions on medications.

March, 2006 – We receive authorization for Non-Profit Mailing status. Our first newsletter was mailed using our Non-Profit permit.

June, 2006 – Our Annual June Lunch will be a celebration of our 20th Anniversary!! We've come a long way in the past 20 years! Congratulations to our Support Group for a job well done.

This history was created by Carol Ranelli with the help of past newsletters and minutes from general and board meetings...plus the recollections of members.

Past Presidents

Margo Dietrich – Founder	1988 – 1989
Jean Watson	1989 – 1990
Mary Wilkinson	1990 – Feb. 1994 (resigned)
Carol Ranelli	Feb. 1994 – Sept. 1994
Henry Holland	1994 – 2000
Carol Kennedy	2000 - present

FYI: For Your Information

- Take a look at The Society for Accessible Travel & Hospitality's website at www.sath.org. The society is a "a nonprofit educational organization that has actively represented travelers with disabilities since 1976." You will find helpful information and resources regarding traveling with disabilities. You can also call the group at 212-447-7284.
- The Boca Area Post-Polio Group in Boca Raton, Florida is promoting their 4th trip, a 7-night cruise to the Eastern Caribbean on Royal Caribbean Cruise Line departing Sunday, Nov. 12th. For more info, contact Faye at 1-866-447-0750.
- Mobility limitations can make a trip to the mailbox feel like a trek over the Rockies. There is, however, an easier way to get your mail: hardship delivery provided by the U.S. Postal Service. If you qualify, your mail carrier will deliver your mail to a more convenient location, such as to your front door instead of your mailbox. There is no extra fee, but you must apply and qualify for the service.

According to the USPS, a change in the delivery point will be considered if the "existing delivery point imposes an extreme hardship," such as a mailbox at the end of a long, steep driveway or an apartment lobby several floors down.

The final decision is made by your local post office, which may or may not have the resources to fulfill your request – even if you qualify. But it doesn't hurt to ask. Follow these simple steps to get approval:

Step 1: Obtain a written statement from your doctor that lists both your medical condition(s) and the reason why you require hardship delivery.

Step 2: Submit both your doctor's written statement and a letter from you that also clearly cites why you need this type of delivery. The letters should be submitted together to your local post office.

Step 3: A decision will be made by your local post office if you are eligible for hardship delivery. Decisions are made on a "case-by-case" basis, according to the USPS.

To contact your local post office, call 800-275-8777 or visit www.usps.com and search using your zip code.