

# POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

August - September 2008

*Carol T. Ranelli, Editor*

visit our website at [www.cvppsg.org](http://www.cvppsg.org)

## **Saturday, August 2<sup>nd</sup> Meeting**

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

Our speaker will be Corrine Gutierrez L.Ac.,MSOM, a licensed acupuncturist. Corrine will be joined by two of her associates;

One is a dietician who studied at Bastyr--she is also a nurse and very holistically trained; the other does detox therapy.

## **Saturday, September 6<sup>th</sup> Meeting**

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

Our speaker will be Jane McAllister , MS,OT  
Guild Certified Feldenkrais Practitioner

She will discuss "Moving More Easily and the Myth of 'No pain, no gain'"

She will briefly discuss why many therapists today have repudiated the "no pain, no gain" approach to movement and exercise. She will then do a Feldenkrais lesson in sitting so we can experience improvement without straining or hurting.

**\*\*\*\*\* 2008 Annual Retreat!! \*\*\*\*\***

**Please make your reservations by August 31<sup>st</sup> for our annual Retreat.**

**All information about the weekend is in this issue, along with registration information. Join us for an informative and fun weekend!**

## Mid-Month Lunch

**Thursday, August 14<sup>th</sup>, we will meet at Bookbinder's Grill** at 11:30  
1244 Alverser Drive, across from Chesterfield Towne Centre off Huguenot Rd.  
We have been there several times, so most know how to get there.  
Call Bev Lordi at 569-4232 by August 11<sup>th</sup> with your reservation.

**Thursday, September 18<sup>th</sup>, we will meet at Manakin Grill** at 11:30  
12912 Plaza Drive off Broad St; take I-64 West towards Charlottesville, take Exit  
173 Rockville/Manakin – take a left at end of off-ramp at stoplight onto Rt. 623  
Ashland Rd. Go about ¾ mile, take right onto Plaza Dr.  
This has been a highly rated eatery and we look forward to trying it!

Their website is: [manakingrill.com](http://manakingrill.com) to see their menu and directions  
Call Bev Lordi at 569-4232 by Sept. 15<sup>th</sup> with your reservation.

*From your editor...*

After 12 years as editor of the "Polio Deja View", I have given the board...and now the membership, notice that this will be my last year publishing the newsletter. It has been a rewarding job for me and I am proud when I get such positive feedback from members in Virginia and beyond.

There are PPSers whose only source of information or connection with other polio survivors is through the newsletter; who have no internet support or can't get to a support group meeting. It's good to know you aren't alone with your challenges, fears and concerns. To have had a small hand in that has been quite a gift.

I have made friends and heard from PPSers I would have never met because of this job, but I have reached a point in my life where my family and my health need my utmost attention.

Therefore, I need to "turn the keyboard over to someone else". It isn't as monumental a job as some might think. Other than occasional help prepping the newsletter for mailing, I have handled it all on my own; but it can certainly be "done by committee".

The next editor (or editors) can make it their own, create their own format, put their own spin on it. I will be happy to show any volunteers what I know and how I go about "putting an issue to bed". (Got to love that EDITOR talk!)

I sincerely hope that someone will step forward to manage this part of our group's effort to keep the membership informed. If you have any questions about the job and what it entails, please call me.

..... *Carol Ranelli*

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*I participated in this study last year and just received Dr. Harrison's findings. I thought I would share the results... C. Ranelli*

**Results from University of Texas, Austin on Women with PPS and Aging**  
Conducted by Tracie Harrison, PhD, RN, FNP, Assistant Professor in School of Nursing

When we looked at the collected data taken from our survey, we felt it demonstrated the complexity of women's lives as they age with polio. We found that the degrees of functional limitation did not significantly predict how satisfied women were with how they were treated as women. Valuing both the giving and receiving of help to and from others and welcoming information from others about changes in their health did predict satisfaction with how they were treated as women. This indicates that women's satisfaction with the way they were treated has less to do with their perceived level of function and more to do with the way they process the way they are treated in their interpersonal relationships.

This data also supported the assertion that the frequency of pushing to endure pain and fatigue to remain active predicted the number of other illness reported besides polio. Pushing to endure pain and fatigue also predicted more ability to fulfill important social roles. This indicated that women with polio may push themselves past comfort levels in order to do more things in their lives that are important to them but by doing this they may increase the likelihood that they develop further problems beyond the initial reason for their functional impairment, which was polio. The most common illnesses reported were wear and tear and stress related illness such as osteoarthritis, back pain and high blood pressure. Further research is needed to be able to test these findings over time.

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### The Big Four Polio Painful Body Parts

**Polio Shoulder** Because polio survivors usually have more leg than arm muscle weakness, they use their relatively stronger uppers to compensate for weaker lowers. So, when getting up out of a chair, climbing out of the bath or walking using crutches, the arms take the freight. The joint that complains most is usually the shoulder, the pain typically caused by bursitis or tendonitis. Sometimes, shoulder pain and an inability to lift your arm directly upward in front of you may be signs of a rotator cuff tear that could require physical therapy or, possibly surgery.

**Polio Neck** Polio shoulder can also be a part of polio neck, when the muscles that move the head and those that "shrug" the shoulders upward, go into spasm due to overuse, weakness and poor posture. Polio neck is also the number one cause of headaches in polio survivors.

**Polio Wrist** Polio wrist is usually caused by carpal tunnel syndrome, the squishing of the nerves that pass across the wrist. Polio survivors have much more carpal tunnel syndrome than the general population because pain in the wrists develops in the same way as polio shoulder – from overuse of joints – and in the case of wrists, with repeated hyper-extension(bending backward) as

you push yourself upward from sitting to standing or walk using crutches.

**Polio Hip** Pain in the hips also is often the result of bursitis or tendonitis caused by weak hip muscles trying to keep you from wobbling back and forth. Polio survivors, and many doctors, immediately assume that all hip pain is due to arthritis. Polio survivors can have arthritis, but hip pain is almost never caused by arthritis. Again, it is irritated tendons and ligaments that are making you hurt. What's more, what you call hip pain may actually be caused by low back or butt muscles going into spasm as they try to compensate for weak leg muscles.

**What to do about the big four?** Since pain is triggered by overuse, you need to take the load off of angry joints, their weakened muscles and nerves and their abused ligaments and tendons. Raising the height of chairs, using a toilet booster seat with handles grips or a frame to help you stand and using a wide tub bench instead of standing in the shower or hauling yourself in and out of the tub will take the load off your upper body.

Once you are up, using light-weight Loftstrand (cuff) crutches is better than using nothing or even a cane. If you have "polio wrists", crutches that have foam-covered handles or hand grips shaped to evenly distribute weight across your palms could be a big help. (see [www.walkeasy.com](http://www.walkeasy.com)). Crutches are also helpful for polio hip since they balance you from front to back and side to side, taking the load off of strained tendons and ligaments and weak hip, back and butt muscles. Of course, rolling in a power wheelchair or scooter is better than walking to ease all post-polio pain.

If taking the load off isn't helping enough, bursitis, tendonitis and muscle spasm can be treated by a physical or occupational therapist with ultrasound, heat, ice, deep muscle massage, biofeedback or training for proper posture or gait. Your doctor may want to try a non-steroidal anti-inflammatory drug like ibuprofen or Celebrex. However, oral steroids should almost never be used to treat bursitis and tendonitis since their side effects are very unhelpful for most polio survivors. However, a few injections of cortisone and a local anesthetic into a joint or a muscle, followed by the above therapies can knock down inflammation and prevent spasm. Local injections of cortisone in the wrist can also help rescue inflammation and swelling in those with carpal tunnel syndrome.

**\*\*Remember that the best remedy is to NOT OVERUSE in the first place. If you start feeling pain or joint discomfort, that is the time to stop!! Rest is the best and easiest remedy for the BIG FOUR.**

Reprinted from *New Mobility Magazine*, June, 2006 and "*Second Time Around*" newsletter from the Boca Raton, FL PPSG, July, 2008

### **If the Shoe Doesn't Fit.....**

Oddshoefinder.com is a free site that connects "people with odd shoes with people who need odd shoes," according to their website. Many people with feet of different sizes buy one pair of shoes for each shoe size and use only one shoe from each pair, leaving a closet full of unused shoes. Once oddshoefinder.com has enough users, they believe that most people

should find a wide range of pairs of shoes available in both of their sizes, making it a simple matter to order a pair of shoes of many brands, styles and colors.

### Life in a Post Polio Support Group

Around our country and the world there are numerous post polio support groups. Most of these groups were founded in the decade between 1985 and 1995. Some were founded some time after 1995. I am a member of the Central Virginia Post Polio Support Group (CVPPSG). The CVPPSG, which was founded in 1986, as most support groups has four primary reasons for existing. One is to provide mutual support for the members of the group. Another is to provide education in regard to Post Polio Syndrome. Still another is to provide advocacy in regard to the rights of polio survivors in our society, particularly regarding issues related to the American Disabilities Act, our civil liberties and our medical well being. Lastly we exist for social inaction involving the shared joy of meals, parties and even trips together.

Post polio support groups are subject to the dynamics of any group. Issues that may arise with any group are splitting, petty jealousies, leadership problems and burn out. Theoretically the people experiencing PPS should be about equal between the sexes. The only difference on average is that women have a longer life span than men in the general population of the USA. This writer has observed that many male PPSers do not have the staying power for a support group that many women have. Often men simply want the information that a support group may offer and are not interested in social interaction. Also, men often are less comfortable with sharing their feelings and are more likely to still be in denial regarding what is happening to them. Generally, women are more comfortable in expressing their feelings and talking about what is happening to them and find it therapeutic. Men often prefer to hide in a cave when emotions are involved and simply want to know the way to fix a problem. The male PPSers that become involved in support groups usually become effective members of the group. Spouses, family members and significant others are active in our group. Several times during the year our group holds ©partner meetings# for the benefit of the spouses or partners of the PPS members. This is also therapeutic because many of these people have a common interest. They love and care about someone who has PPS.

Another unique aspect of PPSers is that no two members have exactly the same physical problems with PPS and situations may vary significantly between members. A crisis for any member can occur at any time. Unexpected problems with fractures, infections, cardiovascular conditions and cancer can occur to

PPSer and cause even greater stress. Our group has experienced more deaths among members in recent years than in earlier years. We are all getting older and aging has its own difficulties for anyone with a chronic condition.

Some Post Polio support groups have diminished in size and even stopped meeting. This can result for many reasons. If meetings become more complaining and less supportive in nature, some members simply get tired of this and stop coming. Good leadership is important. A flexible leader who has an active board or a team of leaders who willingly share responsibilities will ensure a healthy support group. Also a newsletter that is written and edited well is essential in communicating valuable information to members who may have great difficulty in attending meetings or simply live too far away to make travel practical. Our group has been fortunate to have a great editor for over a decade. Newsletter articles are often shared with other newsletters around the world. Without a newsletter it is difficult to maintain a support group.

As members can experience fatigue; thus a support group can experience fatigue as part of a group process. Splitting can occur if a clique within a group seems to control all decision making or seems to capture more attention during a meeting. Dominant personalities can affect group dynamics for the whole. The best approach for such situations is for the leaders to try to address the problem on an individual basis or in by inviting those who feel left out to be included in leadership or areas of responsibility on a voluntary basis.

A common psychological defense that polio survivors have utilized for years is denial. It is difficult for us and some groups to cope with surrendering this defense. Another defense that is often used is projection. This simply means that some individuals with problems find it easier to blame someone else for problems than to do some self examination. Often anger is the underlying emotion that provokes the defense of projection. Support groups can listen to complaints, but if complaining becomes a pattern for an individual or a group, some type of therapeutic intervention would often be helpful. For support groups that may be in decline an independent consultant who is trained in group process might be helpful.

Most support groups are doing well and meeting their goals. It is a reality that Post Polio Support Groups will cease to exist at some time in the future. This will occur as our generation of polio survivors passes on and the disease will hopefully be eradicated from the planet earth. The Post Polio support group movement has been remarkable as we have never had a national organization to solicit funds, provide education, invest in research and provide advocacy. Some organizations have been helpful, but we have never had an organization similar to the Multiple Sclerosis Society or the Muscular Dystrophy Society to work for

us. The March of Dimes remembers us, but that is the extent of it. We as individuals have done well to accomplish a lot on our own. Many support groups have done the same thing; that is accomplishing a lot on their own. So often the individual experience parallels the universal.

Did you know?..... **RX** Information from Jenny

### **WHAT YOU SHOULD KNOW ABOUT MEDICAL IDENTITY THEFT**

Medical identity theft is when someone's personal information is used, without permission, to get money, prescription medicines or medical services. Examples: a person uses someone else's name & info to have a surgery, causing that person to be billed for the surgery; a group of criminals uses info stolen from a health clinic to bill the insurances of individuals for services that were not actually provided. This can cost the victim thousands of dollars. Medical identity theft can also involve the addition of false or incorrect info to a person's health records. This is dangerous because it could cause you to be treated incorrectly by a doctor, based on the false info.

Medical identity theft can be hard to detect. The best thing you can do is pay attention to ALL documentation pertaining to your healthcare:

- Review all insurance statements & bills for accuracy
- Request summaries each year of what your insurance(s) paid—if you see something wrong, contact your insurer or healthcare provider immediately.
- Review your credit report regularly—it may contain collection notices for hospitals, medical labs, etc. if you are a victim.
- It may be pricey, but you can request copies of your medical records to review them for accuracy.
- Ask for a list (called an "Accounting of Disclosures") of who your medical info has been given to.
- Always notify your insurance company if you lose your insurance card.

If you suspect that you are a victim of medical identity theft, you may need to deal with both credit problems and incorrect info in your medical records. The following list will help ensure you cover all your bases:

- Check insurance benefits paid to you in the last year.
- Check your credit report. If there are incorrect charges, you will need to contact the billing department of the provider who is billing you to explain that this is a case of identity theft.
- File a police report, and get a copy for yourself.
- Get a copy of your medical records and correct any info that is false.
- Get a list of disclosures of your medical records, so you know who else might have the incorrect info (insurances, providers, etc.)

- Be sure to notify all of your providers of the incorrect info in your medical records.

### **IDENTITY THEFT RESOURCES:**

- \* Identity Theft Resource Center 858-693-7935  
[www.idtheftcenter.org](http://www.idtheftcenter.org)
- \* Department of Health & Human Services 800-368-1019  
[www.hhs.gov/ocr/hipaahowto.pdf](http://www.hhs.gov/ocr/hipaahowto.pdf)  
[www.hhs.gov/ocr/hipaa/consumer\\_summary.pdf](http://www.hhs.gov/ocr/hipaa/consumer_summary.pdf)

### ***Answers to questions from May monthly meeting:***

- 1) The manufacturer of Walmart's Lisinopril is an American manufacturer, not an overseas manufacturer. Also, the pharmacy within Walmart is owned by Walmart, not an outside company or third party.
- 2) The patent for Restasis is not due to expire until August 2009, so next year would be the earliest that a generic may come out for it.

As always, don't hesitate to call if you have any questions.

Jenny Aveson

## **Ninth Annual Fall Retreat !!!**

The Annual Fall Retreat will be Friday, September 19<sup>th</sup> until Sunday, the 21<sup>st</sup> at the Holiday Inn Express Hotel & Suites in Ashland, VA ([www.hiexpress.com/ashlandva](http://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 rooms and all six handicapped accessible rooms. If you need a handicapped room, please let us know what your exact needs are; you may only need a bath bench or raised toilet seat. If you can supply your own, it would benefit those of us organizing the Retreat.

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 rooms have microwaves and refrigerators, TV, coffee makers and hair dryers. Those who attended in previous years gave rave reviews to the facility.

**We will offer this for \$120.00 per person based on double occupancy for the entire weekend, including all meals. This is \$10 less than last year, as the support group is still subsidizing part of the total expense.**

If you want to come just for the day on Saturday, the 22nd, the cost will be \$50 a person which includes lunch and dinner.

Our speaker for Saturday morning will be Dr. Albert Jones, who has been the Director of the Post Polio Clinic at Sheltering Arms for several years. Dr. Jones is also the Medical Director of Sheltering Arms. His main topic will be "Osteoporosis In Post Polio Patients", but he will have a Question and Answer session at the end of his presentation.

In the afternoon, we will have Shawn Majette, an attorney with the Thompson, McMullen Law Firm, who will be presenting a motivational/comedy/ magic show.

We have arranged to have one massage therapist join us on Saturday from 9 until 4. She 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 Van Aken will again conduct a "Partners Session" on Saturday afternoon for those interested.

**It is imperative that you make your reservations as soon as possible!!! We are working with a busy hotel and they need to know the exact number of guests by September 1<sup>st</sup>!!!**

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

We welcome all who have attended in years past and any new members who would like to share their polio stories, ask questions and generally have a rewarding and FUN weekend!

See next page for registration.

# Registration Form for September Retreat

Friday, September 19th until Sunday, September 21st

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 31<sup>st</sup>**.

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) \$120 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.**