

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

June – July 2007

Carol T. Ranelli, Editor

ANNUAL JUNE LUNCHEON

At Steak & Ale Restaurant, 6900 W. Broad St., at the corner of Glenside and Broad St.

Take the Glenside- North exit off Rt. 64

From NOON until 3:30

We will have a private room and have a choice from a selected menu including beef, seafood and chicken at several different price ranges.

Please respond no later than May 29th to make your reservation:

Call Barbara Bancroft at 204-1688 or Carol Kennedy at 740-6833

Please join us for our annual social get together in June!

Dr. Jenny Aveson with CVS Pharmacy will join us at lunch to introduce herself and answer any of your questions concerning prescription or over-the-counter drugs.

We have no meeting in July

Future Meeting: August 4th

We will have Amy H. Wenzel with Richmond Cardiology Associates, who will speak about cardiac health and diet.

EIGHTH Annual Fall Retreat !!!

It's time to reserve a room for our Eighth 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 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 rooms 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 rooms have microwaves and refrigerators, TV, coffee makers and hair dryers. Those who attended last year gave rave reviews to the facility.

We will offer this for \$130.00 per person based on double occupancy for the entire weekend, including all meals. This is a slight increase from last year, but 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.

We are excited that Dr. Lori Michener will be our Saturday morning speaker.

Dr. Lori Michener an Associate Professor at Virginia Commonwealth University in the Department of Physical Therapy with a joint appointment in the Department of Neurobiology.

Dr. Michener completed her undergraduate degree in General Studies at Lock Haven University in Lock Haven, Pennsylvania; and also a second undergraduate degree from SUNY at Buffalo in Physical Therapy. In 2001, she completed her Doctorate in Physical Therapy at MCP Hahnemann University in Philadelphia, PA. At VCU, she teaches the evaluation and treatment of orthopedic injuries. Additionally she maintains a clinical practice at Virginia Commonwealth University Health System, providing evaluation and treatment to patients with musculoskeletal disorders. Dr. Michener has made numerous scientific presentations at state, national, and international meetings. She maintains an active clinical research agenda in areas related to evaluation and treatment of patients with shoulder and spine disorders. She has received numerous research grants for her research and has published 18 peer-reviewed manuscripts.

She is currently a member of several national organizations, including the American Physical Therapy Association (APTA), the National Athletic Trainers' Association (NATA), and the American Society of Shoulder and Elbow Therapists (ASSET).

Our afternoon speaker will be John R. Hamant, who will give an interactive portrayal of Franklin D. Roosevelt.

John R. Hamant is a native of Baltimore. He received his BFA and MA in theatre from the University of Arizona. John has worked for the Colonial Williamsburg Foundation for 30 years, and though semi-retired, he is still heavily involved in Colonial Williamsburg programming at all levels. During his time at Colonial Williamsburg he has been an archaeologist, character interpreter, director of special events and protocol, and director of evening and special programs. He began portraying FDR, his personal hero, at Colonial Williamsburg about twelve years ago. He has appeared as the president at the White House Visitor Center, the 2006 Washington DC Memorial Day Parade, and countless schools, veteran's groups, and educational programs across the country. John resides in Williamsburg with his wife, Brenda.

We have again arranged to have two massage therapists join us: one has agreed to be available Friday afternoon and evening and both will be available 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 Van Aken will again conduct a "Partners Session" on Saturday afternoon for those interested.

We had our biggest attendance ever last year with members coming from six states. Everyone always enjoys the sharing and fellowship of the weekend. We made new friends last year and look forward to meeting new PPSers this year.

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 1st!!!
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.

FYI: For all members who live in Henrico and Chesterfield County: If you have adaptive equipment on your vehicle (hand controls, scooter hoist, power chair ramp, etc.) you are eligible for a reduced personal property tax rate. Contact your county Commissioner of the Revenue or Tax Office to register and find out what is necessary to qualify. This can amount to a considerable saving and is well worth the time.

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) \$130 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.

Mid-Month Lunch

We will have no mid-month lunch in June.

Wednesday, July 18th we will have lunch at

Michelle's at Historic Hanover Tavern

Located 15 miles north of Richmond on Rt. 301 in the
historic Hanover Courthouse area.

Lunch will be at 11:30. Please call Bev Lordi at 746-3864 by July 15th with your
reservation.

Screening Recommended for Male Polio Survivors

The annual meeting of American Academy for Physical Medicine and Rehabilitation last October in Philadelphia recommended the screening of male polio survivors for bone mineral density (BMD) to prescribe appropriate treatment and to decrease fracture risks.

Julie K. Silver, MD and Dorothy D Aiello, PT, Harvard Medical School/Spaulding Rehabilitation Hospital, Boston, tested the hypothesis that male polio survivors are at risk for low bone mineral density. The authors compared polio men who ranged in age from 38-81 to age-matched normative data. The polio men were 12 years old or older when they had polio (85%); currently are ambulatory in the home (75% of the time with or without assistive devices); and currently use some assistive device (82.5%). Some had both hips tested; some just one.

All the hip scores bilaterally for the polio men had a lower BMD than the age matched data. The lumbar BMD data was within normal limits in the same comparison.

While further research is needed, the authors recommend screening polio men for osteopenia/osteoporosis, because they are at high risks for falls with subsequent fractures.

Reprinted from "Post-Polio Health", Winter, 2006; Vol. 22, No. 1

Physical Therapy

By Susan I. Fish, MAPT

During recent years, I have had the opportunity to meet and work with patients experiencing the late effects of polio. Many times I have detected some frustration and anger regarding my professional's lack of experience in treating Post-Polio patients. I write this brief article now for two reasons:

- ◀ To explain and help you understand this lack of knowledge on the part of many of my colleagues.
- ◀ To provide some guidelines regarding Do's and Don'ts when seeking physical therapy.

Most Physical Therapists (PT's) working today weren't even alive during the major polio epidemics. Their formal education regarding poliomyelitis was more historical than factual, with little more than definitions of pathology and no clinical experience. Post-Polio Syndrome is only recently being recognized and its existence is still questioned in some medical circles. Both acute polio and post polio syndrome present clinical pictures which are unlike any other neuromuscular condition. Without the experience of working with acute polio patient and with little documented information regarding the treatment of Post-Polio Syndrome, it is not surprising to find professionals lacking in knowledge.

Although, there may be reasons for a lack of knowledge, a responsible professional should NOT treat any condition that he or she is not confident and knowledgeable in treating. You may be able to direct a PT to appropriate resources. Please see the resources at the end of this article and I would be happy to help also.

Reasons for seeking physical therapy will vary. You may be referred to a PT to help you with your Post-Polio Syndrome. You may be referred for rehabilitation following corrective surgery for a polio related condition. You may also be referred for a condition not necessarily related to polio at all, such as arthritis, bursitis, tendonitis, fractures, osteoporosis, low back pain, stiff neck, etc, etc. Your physical therapist is well trained to treat these other conditions. However, your post-polio status should be taken into consideration when designing a program. Here is some advice.

Do's and Don'ts to keep in mind when going for physical therapy:-

- ◀ Do trust yourself and the knowledge you have gained over the years about your body.
- ◀ Do be willing to alter your lifestyle.
- ◀ Do avoid fatigue.
- ◀ Do get enough rest.
- ◀ Do pace your activities rather than discontinuing them.
- ◀ Do conserve energy. It may make more sense to spread your activities out, allowing for rest periods, rather than eliminating interests and activities.

- ◀ Do recognize that your body is aging and some physical changes will occur which are not related to post-polio. There **IS** a normal aging process even though post-polio may be a part of it.
- ◀ Do respect your feelings. This may be a difficult adjustment time for you; seeking emotional as well as physical guidance may be a wise thing to consider.
- ◀ Don't follow advice regarding physical exercise if you become fatigued while doing it.
- ◀ Don't become short of breath with exercise.
- ◀ Don't do more than your body feels comfortable doing.
- ◀ Don't cause pain with activity or exercise.
- ◀ Don't gain weight.
- ◀ Don't reject using aids and assisting devices without giving them serious thought. (They are meant to conserve energy and preserve anatomical structures, i.e., joints, muscles, tendons, cartilage and ligaments.) Most are delighted and surprised by the increased endurance and energy they have with the use of canes, wheelchairs, motorized scooters or the many other easily found assisting devices.

Reprinted from Triad Post Polio Support Group, The Seagull, February 2007

With the return of warm weather and increased physical activity, I think we need to remind ourselves about.....

MANAGING EXERCISE

By Lauro S. Halstead, MD

It is well known from muscle physiology that exercise of various types improves both muscle strength and endurance. Following episodes of acute paralytic polio in the past, individuals often went through long periods of exercise training and muscle re-education to regain the strength and muscle mass they had lost. In fact, exercise was frequently viewed as the "cure" for paralytic polio. The belief of many persons was that they could overcome or "beat" polio if they did enough exercises.

When people started getting new weakness many decades later, that same belief was still in tact. As a result, many individuals resumed exercising on their own, often with a vengeance, frequently producing additional weak-ness. Based on these anecdotes and the initial theory that PPS was caused by overburdened motor neurons, it is understandable that most clinicians were cautious about prescribing any form of exercise. Now, more than a decade later, there is considerable evidence that almost everyone can benefit from some form of exercise. For man individuals, this level of exercise may be nothing more strenuous than gentle stretching or various types of yoga. For others, it may be considerably more vigorous and even include aerobic training. With this range of options, it is impossible to prescribe a set of exercises suitable for everyone. Instead, a list follows of general principles and guidelines that can be used by most people with PPS to develop a safe and effective exercise program:

- Individualized and supervised program. Exercise programs should be supervised initially by a physician or physical therapist experienced in neuromuscular diseases, if not polio. All

programs should be customized to each person's needs, residual strengths, and symptom patterns. Given these constraints, research studies have shown that some polio survivors (but not all) can improve muscle strength (caused by new muscle hypertrophy and the growth of additional terminal axon sprouts) and enhance cardiovascular endurance with a closely monitored training program. In fact, some studies have reported an increase in strength in muscles both *with and without new weakness*.

- Type of exercise. There are numerous kinds of exercise. Finding the one that is right for each person and each limb often takes trial and error. Usually, it is a good idea to find two or more exercises that can be varied, exercising specific muscles every other day. For example, walking or exercising the lower extremities one day and alternating with an exercise for upper extremities the next day. This program provides a period of rest for each muscle group and variation that keeps the overall exercise program challenging and enjoyable. As a general rule, muscles that have a grade of 3 or less (using the muscle examination scale: 0 = no contraction up to 5 = normal strength) should be protected and not exercised; grade 3+ muscles can be exercised with caution; grade 4 and 4+ muscles can be exercised moderately; and grade 5 muscles can be exercised more vigorously.

- Expect improvement. Exercise should make one feel better physically and psychologically or both. If the activity is not strenuous enough to improve an individual's strength, much less the cardiovascular system (e.g. stretching or yoga exercises), it still should give a psychological lift just to be doing a special activity for oneself on a regular basis.

- Listen to your body. Avoid pain, fatigue, and weakness. These symptoms are signals that your muscles have overworked. A brief period of fatigue and minor muscle pain for 15 minutes to 30 minutes after exercise is usually normal. Symptoms that last longer than 30 minutes to 60 minutes reflect muscle overwork and possible injury. If this occurs, the exercise should be reduced or stopped. *Any exercise that causes additional weakness should be discontinued immediately.*

- Pacing. Pacing has been shown to be safe and effective in increasing strength in some individuals. The intervals of exercising can be as short as two minutes to five minutes alternating with equal intervals of rest. The evidence also shows that secondary symptoms, such as generalized fatigue, can be reduced as individuals become conditioned and are able to perform more work with less expenditure of effort.

- Use your best muscles. Polio is often a focal, asymmetric disease with variable amounts of weakness in different limbs. Exercise the limbs least affected or those completely unaffected by polio, while avoiding the more affected extremities. For instance, if only the legs were affected, then the arms can be used in a fairly strenuous program that includes swimming or using an upper extremity arm bicycle; meanwhile, the legs will usually get adequate exercise in the course of doing daily activities.

Hydrotherapy. Water therapy was the exercise of choice for many persons during their recovery from the original polio. It is still excellent therapy. Because of the buoyancy of water, it allows people to do things they can't perform on land. For especially weak limbs, inflatable cuffs can be used to float an extremity. For other limbs, water resistance provides a workout that can be fine-tuned to each person's strength. The principal disadvantages of hydrotherapy are that the temperature may not suit one's body and it may be difficult to find pools that have lifts (if needed). Also, the surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.

· Warm-up and cool-down. As with other exercise programs, a warm-up followed by gentle stretching should be done to improve flexibility and reduce the possibility of injury. After exercising, a cool-down period should take place. Finally, the type of activity should be one that the participant enjoys to minimize the potential for dropping out because of lack of interest.

Halstead, M.D., Lauro S., editor. Managing Post-Polio, A Guide to Living Well with Post-Polio Syndrome. Washington, D, C.: NRH Press, 1998. pp. 30-33.

Reprinted from Colorado Post-Polio Connections, Volume 22, Number 1, Winter 2007

From Henry's Desk:

Class Reunions

Often on the Internet Polio list services, writers will frequently sign their names followed by something like "Class of 1950." This method of identifying the year that one had polio started some years ago. Of course these "classes" of people who had polio extend over many decades. Perhaps this is proper. From the onset of polio to the current time when many of us are living with Post-Polio Syndrome (PPS), all of us have learned a lot and have achieved an education that is not recognized by a formal degree. Probably most of us have earned a doctorate in philosophy in polio or a Ph.P.D.

I had polio in 1950 at the age of eleven. Throughout my adolescent years and young adult years I wore a long leg brace on my right leg and developed some scoliosis as I grew. I had much insecurity during the second decade of my life. I felt I was competing on an uneven playing field. I loved sports but could no longer compete in sports because of my physical handicap. As compensation I covered sports for my high school newspaper and for my college newspaper. I also did some coaching of younger boys and even some peers during these years. In college and medical school I did some intramural coaching of basketball. In many arenas I think I compensated well, especially in my academic studies.

Forty-five years ago I graduated from college. I went to college on a scholarship based on academics and partly on my intention to become a doctor (physician). This goal was directly motivated by my experience with polio. The college I attended for four years was situated on

top of a hill in the Valley of Virginia. Every day I climbed that hill at least twice a day in order to attend classes and labs. The brace on my right leg and the strength of my left leg made those climbs possible. The same challenge occurred in medical school. Again, I was fortunate to attend medical school on a National Foundation Scholarship. The medical school that I attended was also situated on top of a hill. I climbed hills and steps to get to my destination. For the twelve years involving high school, college and medical school I managed to get where I needed to go on foot. In retrospect it was amazing how durable my overall health was during this time. I never missed one class because of illness or injury during those twelve years.

A few days ago I attended my forty-fifth college reunion. The college I attended was all male until twenty years ago when it became coed. Thus, the people at the reunion were many male graduates and their wives. All of my classmates in attendance were walking and only one had any sign of a disability. This classmate was walking with a cane because he had a bad hip. Most of my classmates had gray hair or their hair was obviously colored. Some could stand to lose a few pounds. However I was the only one in a wheelchair and the only one on the entire campus using a ventilator.

These men and their wives were my peers. Looking around the room at one of the receptions the reality of PPS impacted on me. Forty-five years ago I had walked across the campus with them on my graduation day and I "walked with them" with my brace on my right leg. At this reunion I could only roll with them; thanks to modern technology. The change in me compared to forty-five years ago was directly resulting from PPS. My classmates did not have PPS. All of us had aged but what happened to me was more than aging.

There are many medical articles which attempt to explain the causes of PPS. The articles are fine and medical science should continue to seek an explanation for PPS. However, my clinical observation in many settings is that PPS is usually obvious when compared to others of the same age who did not have polio. Most of our peers are walking and not rolling, breathing without assistance, not dealing with various levels of fatigue and are in no obvious pain. When so many people who had polio over a half a century ago are now living with PPS, I do not need the Mayo Clinic or the Center for Disease Control to convince me of the reality of PPS.

I have been a member of the Central Virginia Post-Polio Support Group for almost sixteen years. Every month when I meet with these seasoned polio survivors I feel like I am at a class reunion. We have some events of personal history in common and we are now connected because of PPS. I have learned more from these people about PPS and life than I have learned from any classroom course. The advantages of sharing experiences and seeking solutions are difficult to measure. I hope all readers are able to participate in Post-Polio support groups. The experience is often uplifting.

I have been blessed by many people and have been encouraged at important and critical times in my life. In the past I walked and climbed many hills and now I roll up some of those same hills. I was in the Polio Class of 1950 and what an education a life with polio has

provided. I feel as if I have earned a second doctorate, the one mentioned above, a Ph.P.D. This second doctorate enables me to look back with a philosophic mind. The poet William Wordsworth said it better with these words:

Then, sing ye Birds, sing, sing a joyous song!
And let the young Lambs bound
As to the tabor's sound!
We in thought will join your throng,
Ye that pipe and ye that play,
Ye that through your hearts to day
Feel the gladness of the May!
What though the radiance which was once so bright
Be now for ever taken from my sight,
Though nothing can bring back the hour
Of splendour in the grass, of glory in the flower;
We will grieve not, rather find
Strength in what remains behind,
In the primal sympathy
Which having been must ever be,
In the soothing thoughts that spring
Out of human suffering,
In the faith that looks through death,
In years that bring the philosophic mind.*

*from William Wordsworth's Ode to Intimations of Immortality from Recollections of Early Childhood