

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

August - September 2005

Carol T. Ranelli, Editor

visit our website at www.cvppsg.org

August 6th Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond
General Discussion of questions, concerns, new information and products.

September 10th Meeting

PLEASE NOTE: This is the second Saturday, due to Labor Day

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

Two of our members, Frances Thomas and Judy Williams, will discuss their trip in June to the St. Louis Post Polio Conference, "Strategies for Living Well." They will present what they learned from the speakers and optional sessions which they attended.

2005 Central Virginia Post-Polio Conference

On October 1st, we will be presenting an all day post polio conference. Our morning speaker will be **Dr. Mary Ann Keenan** from Philadelphia who will speak on

Protecting Our Joints: Shoulders, Elbows, Knees, Hips

Dr. Keenan is an orthopedic surgeon who is well-versed in PPS problems and solutions.

Our afternoon speaker will be **physical therapist, Sue Briggs, MSPT**

Many of us know Sue from the Richmond PPS Clinic. She will add her insight into dealing with overly used joints.

We will have **pharmacist, Dr. Courtney Goodman** for a short question and answer period at the end of the day.

Lunch will be provided. See registration form and complete schedule inside.

Congratulations to our dear friend, Dr. Courtney Goodman for winning the CVS Pharmacy Paragon Award in June. Dr. Goodman competed against 1,300 other pharmacists in the Virginia-Maryland-Delaware region. The Paragon Award is presented to the person who best exemplifies the qualities and standards which CVS sets for a “neighborhood” pharmacist. Dr. Goodman will be one of our speakers at the October conference.

Mid Month Lunch!!

On Wednesday, August 17th, we will meet for lunch at Crab Louie's Tavern in Sycamore Square, Midlothian at 11:30.

Call Carol Ranelli at 794-7359 by August 15th with your reservation.

On Tuesday, September 13th, we will be meeting at Hathaway Towers, Mary Ann Haske's home, to assemble materials for the October Conference. Anyone who wishes to help is welcome to join us, and then we will have lunch afterwards at a nearby location.

2005 Central Virginia Post Polio Conference
at Children's Hospital, 2924 Brook Rd, Richmond

- 9:00-10 am Registration
10:00-11:30 Dr. Mary Ann Keenan will speak on "Protecting Our Joints: Shoulders, Elbows, Knees and Hips".
11:30-noon Break
Noon-1 pm Lunch
1:00-2:00 Sue Briggs, physical therapist, will speak on dealing with overly used PPS joints.
2:00-2:30 Dr. Courtney Goodman, pharmacist, will answer questions concerning prescription medications, supplements and drug interactions.
2:30-3:30 Question and Answer session with speakers

There will be a \$15 per person registration fee which will include a box lunch. Registration deadline will be September 16th. Registration form and check made out to Linda VanAken should be mailed to:
Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831

We are offering two lunch options: Spring Mix Salad Plate with Grilled Chicken Breast with fat-free Italian dressing; served with fresh fruit cup and oatmeal cookie.

Or:

Beverage will be provided.

There are several totally accessible restrooms close to the conference room.

Registration for 2005 PPS Conference

Name of those attending: _____

Contact Phone Number: _____

Choice of Lunches: _____

Do What I Do – Not What I Say (Pride Goes Before a Fall)

by Marian Schoeller, Florida Newsletter

I find post-polio people for the most part to be highly intelligent, creative, open-minded, successful, nonjudgmental and resilient. There are too many times when we post-polios (myself included) do not practice the advice we tell other post-polios (especially new members of the group) to follow.

I was amazed to hear the conversations around the table at the most recent PPS meeting I attended. One lady was lamenting about having to put up Christmas decorations. It sounded as if her loving husband was even encouraging her to continue to decorate until the job was finished – while she was standing up and as long as she was there, she may as well.

Another lady who has been a post-polio survivor for many years and has obvious problems ambulating, recently had a bad fall. She continues to try to walk outside her home in situations where she could easily but accidentally be pushed down, slip on wet floors or just stumble, trip and fall. I recall when I was still only using crutches, how terrified I was of slipping and falling especially after it rained and I had to go to the store or an office. The fear of falling began for me after, while walking with a can, I fell and fractured my tibia and fibula (both bones of my weaker lower left leg.)

I believe that, “a word to the wise” should be sufficient. But unfortunately that doesn’t always get through. It never fails to surprise me how stubborn we can be. *Is it our ego which prevents us from using mobility aids?*

I know that I tend to push myself and overdo activities when I feel especially rested. I also know I have a huge sweet tooth and really enjoy desserts and will have an alcoholic drink or two. I don’t believe in completely depriving myself of those things I enjoy, but MODERATION is a keyword.

We need to use our intelligence and think what the long-term consequences of how we may be putting our health and safety in jeopardy by our unwillingness to put into practice what we’ve learned.

Reprinted from the “Polio Outreach of Washington” newsletter, second quarter, 2005.

Rest, Pacing and Timing

By Grace R. Young, MA, OTR

Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.

REST

Try to rest at least one hour during the day. If you work and resting at lunchtime is not possible, take a one-hour rest immediately after work. This will make your evening activities more productive and enjoyable.

Lie down to rest so your back doesn't have to support your body weight. Sitting takes 1/3 more energy than reclining. If you want to read, use an overhead book holder so your hand and arm muscles won't stay tense. You can listen to music, practice visualization or meditate; the point is to allow all the muscles in your body to relax.

PACING

Have you had days when you felt so good that you took on an ambitious project and kept pushing yourself so you wouldn't lose momentum? Were you incapacitated for a few days after that? It is tempting to overdo on your good days. However, you'll be more productive over all if you plan your activities for a balanced lifestyle.

Prolonged activities such as cleaning house or gardening can leave you exhausted for the rest of the day unless you break them into short segments with rest breaks in between. Before starting an extended activity, decide how long you will work at it and allow a 15 minute rest break every 30 minutes. Use a kitchen timer to let you know when to stop working and when to start up again.

Alternate light and heavy tasks throughout the week. Split your ambitious projects into daily segments throughout the week and stick to your plan no matter how good you feel on any particular day. Plan fewer activities for the days when evening activities are on the agenda.

TIMING

You may have different levels of pain and fatigue at various times of the day. Activities which are simple to perform in the morning may be difficult later in the day or vice versa. For example, if cooking supper in the late afternoon is too stressful, prepare most of it in the morning, to be reheated later.

HOW CAN YOU JUDGE IF AN ACTIVITY IS TOO STRESSFUL?

The easiest sign is a feeling of fatigue while you are in the midst of the activity. This seems obvious but many of us do not pay attention to our body. If the level of fatigue is out of proportion to the level of activity, the activity may be too stressful even if your mind says it

shouldn't be.

If there is a change in the quality of movement. For example, you develop a tremor or "jerkiness" in your motions while performing the activity.

If there is a change in the quantity of movement; that is, decreased range of motion. For example, you can usually lift your arm to a certain height but that height lessens as you continue the activity.

If you start to use compensatory movements. For example, you "hunch" your shoulder in order to raise your arm or you swing your leg out to the side instead of flexing at the hip.

Wytheville Again

A year ago I wrote about the Wytheville, Virginia, polio epidemic of 1950. Wythe County had 16% of all the polio cases reported in Virginia in 1950, which was the year of the worst polio epidemic in the history of the Commonwealth of Virginia. I also wrote about the efforts being made by the Wytheville Museum to collect memorabilia concerning this epidemic of polio that hit the town. Last year I wrote the following:

"Over the last fifty-four years the lasting effect on the families of this community has become part of Wytheville's shared cultural heritage. The town did not become a ghost town in 1950. The citizens did not panic. They dealt with this unexpected epidemic in very appropriate and supportive ways. In fact the citizens of Wytheville do not want to forget this sad, but historic time. The town's Department of Museums has done research and have begun a two year project about the Wytheville Polio Epidemic of 1950. This project will include three components. The first one occurred on June 30, 2004, and there is more on this event in this text. The second planned component is the publishing of an oral history book in January 2005. The third component is the opening of the permanent polio exhibit in the town museum. The exhibit will include an iron lung, a pediatric iron lung, old prescription records from 1950 and a reproduction of the highway sign warning travelers of a "polio outbreak" in Wytheville."

This writer attended and participated in the first component of the Wytheville polio project on June 30, 2004. The Wytheville Department of Museums has recently completed the second component of their stated goals.

"A Summer Without Children" is the recently published book, which is an oral history of the Wythe County 1950 Polio Epidemic. The book is loaded with photos from the time of the epidemic and many quotations by survivors, family members, health care professionals and town officials of fifty-five years ago. After reading the book I wrote Linda Logan of the Wytheville Museum and stated the following:

"All I can say is that it is the best book out there regarding the personal experience of

polio from everyone's perspective; meaning the polio victims and survivors, the families of polio victims, the doctors and health care professionals as well as civic leaders who dealt with this great invisible threat in a small town. The photos are amazing in making the whole experience visible and real. I commend everyone involved in this project for an outstanding accomplishment."

If you are interested in reading a well documented oral history of a small town polio epidemic, this book would be of interest to you. If you would like more information about purchasing this book, you may E-mail Linda Logan at lindal@wytheville.org or call the Wytheville Museum gift shop at (276) 228-5498 or go to the following website to order the book.

<http://museums.wytheville.org/publicationsresearch.htm>

Since I am writing about a new polio book I would like to mention five new books that may be of interest to some of you.

1. *Polio and Its Aftermath* by Marc Shell. Dr. Shell is a Professor of Comparative Literature and English at Harvard University. He is also a polio survivor. His book is an excellent examination of the personal and cultural impact of the polio epidemics of the twentieth century. It covers not only the scientific, but the revelation of polio in the family, the schools, the books and movies of the time and every detail of life. I highly recommend it. List price \$35

2. *Living with Polio* by Daniel J Wilson. Wilson is a professor of history at Muhlenberg College and is also a polio survivor. This book is historical but includes the testimonials of over one hundred polio victims. It is a gripping book and tells the reader about the physical and psychological experiences of actual survivors. I would also recommend this book for those interested in the history of the personal experience. List price \$29

3. *Splendid Solution* by Jeffrey Kluger. Kluger is a senior writer for Time and has written previously about Apollo 13. This book is about the quest for a polio vaccine, especially the Salk vaccine. The book not only involves science, but personal egos, competition among researchers and politics. If you would like to learn more about Jonas Salk and the development of the Salk vaccine, read this book. List price \$25.95

4. *Polio, An American Story* by David M Oshinsky. Oshinsky is a professor of history at the University of Texas at Austin. This book is a detailed overview of the terror of polio in the 1950s, the competitive effort to find a vaccine, the unique development of the March of Dimes as a successful fund raising organization and the success of the largest public health drug

trial in medical history. If you like history, this book is for you. List price \$30

5. *Breath, Life in the Rhythm of an Iron Lung* by Martha Mason. This book is an outstanding memoir of the life of Martha Mason. Mason contracted a severe case of polio in 1948 in Lattimore, North Carolina, on the very day that her older brother's funeral was held. Her brother had died of acute polio. Mason has lived in an iron lung ever since in Lattimore, NC. In 1960 she graduated from Wake Forest University as valedictorian of her class. She has a way with words and her story is compelling to read. I highly recommend it. List price \$24.95

This year of 2005 marks the fiftieth anniversary of the successful development of the Salk vaccine. Beginning in 1955 and over the next few years the number of polio cases sharply declined in the USA. With the addition of the Sabin vaccine the number of polio cases around the world greatly diminished. The number of polio cases from wild virus polio in the USA has been zero for twenty-five years. The number of polio cases around the world is a number that is getting smaller. The good news is that many of us have found each other because of Post-Polio Syndrome. Post-Polio Syndrome is not good news, but finding each other is. Fortunately many books are being written to document for future generations what we all went through. Hopefully, our shared experience will never be forgotten.

Work Smart, Not Harder

By Grace Young, MA,OTR

It is hard to overstate the importance of good body mechanics. Good body mechanics is your own ability to use your body with maximum efficiency – to work smarter, not harder in doing the things you do.

Using your body efficiently reduces muscle weakness and pain, fatigue, backaches, neck pain and even a predisposition to developing nerve compression problems such as carpal tunnel syndrome.

Since each person has an individual pattern of muscle weakness, standard rules may not apply to everyone. But there are some common principles that apply to most of us:

* **Be willing to sit down.** Prolonged standing is stressful: some polio survivors say it is harder for them to stand in one place than it is to walk. Sitting lessens the demand on the cardiovascular system and relieves the weight bearing joints of the legs and the back. It takes 25% more energy to perform an activity standing than sitting. You can sit while working on hobbies, while dressing, shaving or styling your hair. No polio survivor should stand in the shower. It is energy wasteful and dangerous.

Almost any activity can be performed while sitting if you analyze and plan ahead. However, sometimes sitting down causes your work surface to be too high, which can fatigue your arms. It is not a good trade-off if you rest your legs but overuse your arms. One solution I use for working at the kitchen counter is a drafting chair that has a pneumatic height adjustment, a footrest (very important that your legs don't dangle) and an adjustable backrest. A high bar stool would also work, provided you can get one and off easily.

I also use a kitchen cart on wheels that has a lower surface. The bottom shelf folds up so I can put a cutting board on the top shelf and sit with my legs under it while I prepare food. Then I just roll the cart over to the counter and transfer the food.

* **Use assistive products to help you get up.** Getting up from chairs is often a struggle. To give myself a little "lift", I had a high density foam cushion, four inches thick, fabricated at an upholstery shop. For a small fee they covered the cushion with fabric and added a carrying handle. There is also the "catapult seat," a device with a pneumatic piston that compresses when you sit and expands when you want to stand, thus helping to lift your weight out of the chair. You can also buy chair leg extenders to elevate the whole chair. (Editor's note: I have found extenders in 3", 4", 5" and 6" heights. I have 3" extenders on my "family room" chair and it's made a big difference on my shoulders when I get up.)

* **No power lifting.** Lifting and setting down a load can be hazardous to your health, as improper movements can squander energy and cause back injuries. Take a moment and assess a situation before you start the lift. How much does the object weigh? Must it be carried and how far?

If your legs are strong enough, it is best to squat and lift with your legs, not your back. Always test the weight of the load first by pushing with your foot. Injuries occur because a load is heavier- or lighter- than expected. If the load does not push easily it is certainly too heavy for

you to lift safely, so ask for assistance. (Of course, a good rule of thumb for polio survivors is to ask someone else to lift.) Remember not to hold your breath during strenuous activities, especially lifting. Inhale at the beginning of an activity or when you reach out or upward. Exhale when you are exerting yourself during an activity, such as lifting, pushing, pulling or bending. If leg weakness prevents you from lifting with your legs, you need to take extra precautions to avoid muscle overuse and back injury. Do not stand up while holding a load.

* **Use aids for carrying** Lifting and carrying aren't good for polio survivors. They pull your center of gravity forward, which can strain your back and over use the shoulder, arm and leg muscles. This is one area where a few changes can save a lot of energy. (Remember it is dangerous and not energy efficient to carry anything up and down stairs.) There are four inexpensive carrying aids essential for conserving energy.

1. The kitchen utility cart on casters enables you to transport dishes, glasses and food with just one trip from the counter to the table and back again. Use the cart to carry items in the house.
2. Rolling backpacks – initially marketed for students- are great for books, files, even clothing.
3. A lightweight luggage cart is useful for more than traveling. Take it to the mall to carry your purchases and use it for transporting loads between the car, the house or office and from room to room. Keep the luggage cart in a handy place. Open and ready for use.
4. A collapsible grocery cart carries bulkier loads, like laundry, grocery bags and garden plants. Remember that you can push twice as much weight as you can pull and you'll have less risk of back strain. Pushing forward builds up momentum and gives you something lean on for support.

* **Take it easy in bed.** One load you always need to be careful about moving is you. To save energy when you get into bed, sit on the edge and lower yourself onto one side while supporting yourself on your arms. Bend your knees and bring legs and feet up onto the bed, then roll over on your back. Reverse these movements to sit up or get out of bed. Remember these movements to sit up or get out of bed. Remember to put your feet over the edge before you sit up. It also helps to have a nightstand neat to hold onto when you sit up.

Editor's note: For those of us with limited use of our legs, these movements may not be possible. From personal experience, I have found that getting out of a bed that's too low is a "killer." If you are buying a new bed or mattress keep in mind a height that will make getting up from bed easy. For an existing bed, consider the height extenders we mentioned for chairs. It can make a great deal of difference. Also remember, you don't want a bed that is TOO high, so it can endanger you for falling while getting out of bed.

On another note, for those of us who cannot lift our legs except by using our hands and arms, I find that getting dressed, changing shoes, getting in and out of a car, etc. can be very exhausting during the course of the day. Having to pick up each leg to get it where I want it wrecks havoc on my upper arms and shoulders. I try to plan ahead when laying out clothes, when arranging my bath items, when gathering materials for hobbies or work, etc. Any advanced thought that will save me from having to make unnecessary movements is well worth taking the extra time.
CTR

Reprinted from "The Seagull", Triad Post Polio Support Group of Greensboro, NC; May, 2005

