

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

December 2006 – January 2007

Carol T. Ranelli, Editor

December 2nd Meeting

Annual Christmas Lunch

**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 November 29th to make your reservation:

Call Bev Lordi at 746-3864 or Barbara Bancroft at 204-1688

Remember to bring a gift suitable for a man or woman, costing between \$10 and \$15. We will conduct our traditional Chinese Auction again this year. Please plan on joining us for this annual holiday social.

January 6th Meeting

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

General Discussion

If you have concerns or questions about post-polio, please attend. Our group is a wealth of information on who, what, when and why.

Note: During the winter months, if there are questionable weather or road conditions, feel free to call an officer to check on meeting cancellation.

**HAPPY HOLIDAYS TO OUR
MEMBERS
AND THEIR FAMILIES**

Get on with Living

By Linda VanAken

When we were young, we all had thoughts and ideas of what our lives would be like. Some might have thought that polio limited their possibilities for the future. I personally think polio simply changed our options, shaped our lives and expanded our horizons. I had physical limitations that steered me away from certain active roles. Being a fireman and running up stairwells or being an athlete wasn't on my radar screen. Neither was I going to pursue a career as a music teacher since I am tone deaf and that had nothing to do with polio. As a child and young adult, I had to evaluate my assets & God-given talents to decide which paths I wished to pursue in life. Polio and the residual affects didn't determine my path; instead it was simply a *factor* in the direction I took towards my life's goals. Life molds us and experiences change us. This forges the person we become. Being a polio survivor is a factor in who I am and how I function. I will not let it be a negative force, nor is it an all consuming definition of who I was, who I am or who I will be in the future.

We acknowledged that polio was a factor in our lives, but strove to overcome and not let it be the driving force in our lives. Its interference with our physical well being did impact many of the choices that we made; however, that challenge can also be a very positive thing. I often marvel at what a dynamic and accomplished group of people I am associated with due to my Post Polio Syndrome. Recently I had the pleasure of sharing a long weekend with my polio peers and their spouses. It was even pointed out that the spouses of polio survivors share a special quality as well. Our partners do not think of us as having a disability, they simply share in the challenges we face. Polio impacts our lives, but it does not always define our lives in a negative manner.

POST POLIO has become a factor in my life. It is a little more difficult to say PPS is *just* a factor and not think of it as an overwhelming roadblock to living my life. PPS is another challenge that will alter our choices, but not deter us along life's path. PPS doesn't have to stop us from living. We must change our attitude about how we "live". PPS requires management of your symptoms, but so do your finances, so do your everyday tasks. PPS is just another factor that must be considered in the plans your make for the rest of your life.

I can almost hear people scoffing at my simplistic views of the challenges of PPS. I don't mean to minimize the true challenges every person who survived polio faces. However, I do wish to encourage you to rethink the importance of PPS in your life. Yes, it is a factor, but it is NOT what you do to *live* your life. You "live" your life through the joys and sorrows, the successes and failures of everyday life. Joyful times help us to appreciate the good part of being alive. That is where we minimize PPS as a factor in life. We change our focus and make being happy a priority in life. Every single day when we wake we should celebrate and think "ok, I made it another day, so I am going to smile more often today". Every single day we need to look for one thing or event that is joyful for us.

It is difficult to fight off the sadness or depression that comes along with a physical disability. It is much easier to give into those feelings when unrelenting pain or overwhelming fatigue is a daily companion. I feel we *DESERVE* to be happy and peaceful. I readily admit that it takes hard work to be in a good mood when you feel like crap. Is it worth it? Absolutely. I have but one life and I'll be darned if I waste half of it being depressed and miserable if there is a chance that I can find ways to enjoy life and be happy.

Polio is something we "overcame". We won't be as lucky with PPS as this isn't something we can simply ignore. Instead we must cope with the ravages of our situation every single day. PPS is scary, but then so was polio. We found ways to live our lives to the fullest even though polio had changed us. We donned braces, had surgeries, used crutches, then we put polio into perspective and got on with the fine art of living. Hopefully we can face life with PPS the same way while trying out scooters and powerchairs. We may not be fortunate enough to have a true recovery period, but with good management and wise practices, we can relegate PPS to a consideration of what choices we make, rather than it being our sole focus in life.

It can be very hard to find the energy and comfort levels needed to rediscover pleasure and find joy in life. There are ways if we are creative and willing to appreciate even the simple things. Gratitude for each simple pleasure or kindness goes a long way in helping us to be more content with our circumstances. There are a lot of things I would still like to "Do" yet in life. Time, finances, and yes PPS will determine whether or not I meet my goals. No matter the journey, no matter the struggles, I hope to find ways to get on with the fine art of living and put that darn old PPS factor where it belongs... in the background, not the forefront of my life.

Ask A Therapist: A column focusing on PPS questions and concerns By Maria Cole, OTR/L

Is it possible for post-polio people to become overly dependent on assistive aids?

Polio survivors are often very concerned about "overusing" assistive aids. From early in their lives, polio survivors were taught to keep exercising and rid themselves of any assistive devices. Therefore it can be very disheartening when a therapist now recommends an assistive aid.

When muscles are not supported or are in a very weakened state, body mechanics are changed thus increasing energy expenditure and possibly producing more pain. A device is prescribed when it is determined that stability, mobility and functionality will be enhanced. Appropriately prescribed walking aids decrease the load and pressure on weakened muscles. Providing stability can dramatically decrease the risk of falls and provide much needed relief to those overworked muscles. Assistive devices include but are not limited to walkers, canes, crutches,

wheelchairs, orthotics (braces of one type or another) voice activated software for computers and activities of daily living equipment.

Recently Jane, a 48-year old polio survivor, was seen in our clinic. She is a nurse in one of the busiest hospitals in Boston. When she first arrived, she was struggling with decreased energy and back pain. She was not using any device while ambulating. The physical therapist prescribed Lofstrand crutches and the patient reported less stress on her body with walking and decreased fatigue. Although, initially quite reluctant to use a device, she experienced less pain and increased endurance when walking with the forearm crutches.

It is important that polio survivors feel comfortable with what is being prescribed and the rationale behind the piece of equipment. I often state to the polio survivor that electricity and technology are their friends. If the polio person is "shrinking their world" due to difficulty with walking or standing for more than a few minutes, then assistive aids can really make a difference. Although you may feel dependent on this new piece of equipment, it will provide you with stability and potentially decrease energy expenditure to allow you to enjoy the activities that are important to you.

What are the advantages and disadvantages of a power wheelchair vs. a three-wheel scooter?

This is a common question we receive in our clinic. Most of our clients are much more willing to consider use of a scooter than a wheelchair. However, a three-wheel scooter may not always be the best for you. A power wheelchair is ideal for use in the home as it has a small turning radius. If a person has trunk, neck or arm problems, there are many modifications available. Power wheelchairs also offer more stability for the arms especially if one is diagnosed with carpal tunnel syndrome or ulnar neuropathy. The hand control placement can be changed if there is upper body weakness. There are also more seating options when purchasing a power chair. It is easier to access a table or desk when using a power chair. Power wheelchairs are also used in the community, on both level and unlevel surfaces. The main disadvantages with a power chair are that they are heavier than a scooter and a scooter is more compact and foldable.

A scooter comes in a variety of sizes and often feels less "medicinal" and offers more of a sporty look. A scooter is easily foldable allowing for easy storage. A three-wheel scooter will offer more agility and smaller turning radius than a four wheel scooter, but not as small as a power chair. A scooter works well in the community but not as well in the home due to the larger turning radius and the need to make a K turn. If the goal is for outside occasional use and you are not experiencing any problems with your neck, trunk or arms, then a scooter may be for you.

It is important that you meet with a therapist and a vendor that specializes in power mobility. Many rehabilitation hospitals have wheelchair clinics where you can try various models. Avoid

just meeting with a vendor. The therapist and vendor work in conjunction to make sure the equipment prescribed is ideal for your needs.

Maria Cole, OTR/L, is a senior occupational therapist at the International Rehabilitation Center for Polio at Spaulding Rehabilitation Outpatient in Framingham, Massachusetts.

Reprinted from "Second Time Around", May 2006, Newsletter of the Boca Area Post Polio Group, Boca Raton, Florida

FOR SALE: Electric Mobility Scooter, full size in good condition,
Richmond area
\$800 Call Marilyn at 804-559-0243

Note from the newsletter editor: After mailing every newsletter, we get several back due to change of address or being "undeliverable". Because of the cost of re-mailing with first class postage, we don't resend that edition, but make the change and try again with the next edition. If you are moving, it would be appreciated if you could let us know your new address since it takes time and energy to deal with all these returns and changes.

Thanks!

Pain Management: Watch That Tylenol

We commonly prescribe combinations of Tylenol (acetaminophen) and opiates for control of acute pain. The combination is complementary and can control pain better than either drug alone. However, problems arise if patients/healthcare professionals do not remain aware of the acetaminophen content in the preparation. Failure to do so can result in exceeding the recommended daily maximum of acetaminophen and put the patient at risk for toxicity.

People often underestimate acetaminophen's ability to damage the liver. In fact, acetaminophen is the most common cause of drug induced liver failure. Taken acutely, just 10 grams can cause life-long liver problems and 20 grams can be fatal. Although many acute overdoses represent "suicide attempts", chronic use of greater than the maximum recommended dose of 4000mg/day has resulted in accidental toxicity in many patients, particularly those taking multiple medications that contain acetaminophen. In pain management, this may also occur when patients increase intake of combination opiate-

acetaminophen preparations to control their pain, without considering the acetaminophen content.

How does acetaminophen cause damage? Most acetaminophen is conjugated in the liver to form inactive metabolites. A small portion is metabolized by the cyto-chrome P-450 system to form N-acetyl-p benzoquinone-imine (NAPQI). NAPQI is very toxic, but it is quickly detoxified by glutathione and converted into nontoxic compounds. Large doses, however, saturate the main route of metabolism causing more acetaminophen to be converted to NAPQI. Liver injury occurs once glutathione becomes depleted and NAPQI is allowed to build up. Certain patients have an increased risk of developing liver toxicity from acetaminophen, including those who fast or have inadequate protein intake and those who use alcohol. Both alcohol and starvation deplete glutathione stores, and alcohol induces cyto-chrome P-450 enzymes, increasing the formation of NAPQI. In long-term alcohol users, as little as four grams in 24 hours can cause liver toxicity. Liver toxicity can also occur in moderate or "social" drinkers. Patients who consume more than two alcoholic drinks a day should avoid regular or excessive acetaminophen use. The use of drugs that induce cytochrome P-450 enzymes also increases the risk of toxicity. These drugs include barbiturates, Phenobarbital, hydantoins (Dilantin, etc.), carbamazepine (Thgretol), rifampin (Rifadin), isoniazid and sufipryazone.

The acetaminophen content of several commonly used pain relievers at Ocala Regional Medical Center are shown below, along with the number of tablets that may be given in a 24-hour period before 4000mg of acetaminophen is exceeded.

Remember, addition of cold product combinations, acetaminophen PM for fever, etc, also add to the total daily count – these numbers would need to be reduced further if other preparations containing acetaminophen are given.

Medication – 24 hour limit	
Darvocet N-100 (6).....	650 mg
Vicodin (8).....	500 mg
Lortab 7.5 (8)	500 mg
Lorcet 10 (6)	650 mg
Tylenol #2, #3, or #4 (13)	300 mg
Percocet 5 mg (12)	325 mg
Talacen (6)	650 mg

WATER

- 75% of Americans are chronically dehydrated. (Likely applies to half the world population.)

- In 37% of Americans, the thirst mechanism is so weak that it is mistaken for hunger.
- Even MILD dehydration will slow down one's metabolism as much as 3%.
- One glass of water will shut down midnight hunger pangs for almost 100% of the dieters studied in the University of Washington study.
- Lack of water is the #1 trigger of daytime fatigue.
- Preliminary research indicated that 8 to 10 glasses of water a day could significantly ease back and joint pain for up to 80% of sufferers.
- A mere 2% drop in body water can trigger fuzzy short-term memory, trouble with basic math and difficulty focusing on the computer screen or on a printer page.
- Drinking five glasses of water daily decreases the risk of colon cancer by 45%, plus it can slash the risk of breast cancer by 79% and you are 50% less likely to develop bladder cancer.

Recent Experience Using Immunoglobulin to Treat Post-Polio Syndrome

Lauro Halstead, MD, Post-Polio Program, National Rehabilitation Hospital, Washington, DC, and Julie K. Silver, MD, International Rehabilitation Center for Polio, Framingham, Massachusetts

Over the past 20 years there has been a growing body of evidence that suggests an inflammatory process may be causing most, if not all, of the symptoms of post-polio syndrome (PPS). In 2002, Henrik Gonzalez and colleagues, working in Stockholm, Sweden, reported finding an elevated level of cytokines—a marker of inflammation—in the cerebral spinal fluid (CSF) of a group of polio survivors with PPS. Elevated levels of proinflammatory cytokines (as opposed to anti-inflammatory cytokines) are found in a number of neurological disorders with an inflammatory component such as multiple sclerosis. Other researchers have also found elevated proinflammatory cytokines in individuals with PPS but normal levels in polio survivors without PPS.

These findings strongly suggested that anti-inflammatory medications might be an effective way of treating PPS symptoms. One of the most potent anti-inflammatory medications is immunoglobulin. Immunoglobulin is a group of protein molecules that is part of the body's immune system. These molecules play an important role in defending the body from bacteria and viruses and are used to reduce inflammation in a variety of neurological disorders. When immunoglobulin is given intravenously it is called IVIG.

With this in mind, researchers began administering IVIG to polio survivors with PPS and discovered they were able to reduce proinflammatory cytokines to normal levels and improve some of the symptoms of PPS. As these were small preliminary investigations, they lacked the rigor of larger, more definitive studies using a randomized, placebo-controlled design.

In the most recent study, published by Gonzalez and co-workers in *Lancet Neurology* (Vol. 5, Issue 6, pp. 493-500) in June 2006, the researchers studied 142 polio survivors at four university clinics who were randomly assigned to either an infusion group or a placebo group. This was a double-blind study, so neither the polio survivors nor the investigators knew whether they were getting the study drug or not.

All subjects were carefully screened to ensure a diagnosis of PPS; exclusion criteria included obesity, unstable chronic diseases or the presence of musculoskeletal disorders with symptoms that mimicked PPS symptoms. The researchers evaluated a number of outcomes including a selected study muscle with 25–75% of expected strength for age and gender, a quality of life measurement, an assessment of vitality, overall muscle strength, level of physical activity, fatigue and pain.

The results showed that the study muscle strength improved, on average, 8.6% in participants who received the immunoglobulin compared with those who received the placebo.

Although 8.6% difference was statistically significant and seems impressive, it reflects a mean improvement of 2.3% in the treatment group combined with an average decline of 6.3% in the placebo group. (This is in contrast to the average decline in muscle strength reported in the literature of 1–2.5% per year.) The authors discuss several explanations for the marked decline in strength in the placebo group but the reasons for this finding and the discrepancy with other reports are not clear. Other significant findings in the study group included an improvement in vitality, an increase in physical activity and a reduction in pain (in one subgroup). Overall, the study drug was well tolerated.

Is this good research?

The research design and implementation are excellent. However, future studies done in different geographic locations by independent researchers are needed to verify the results.

Which polio survivors will benefit?

It is not entirely clear at this time who will benefit the most from this medication. Because the diagnosis of PPS is still imprecise, perhaps the only way to be certain if you would be a good candidate or not for IVIG treatment, is to have your cytokine levels checked. This involves having a spinal tap to obtain a sample of CSF and access to a lab that performs these tests on a regular basis. It is important to keep in mind that an average muscle strength increase of 2.3% in the IVIG group may translate into more significant gains in one's ability to function.

What are the side effects?

IVIG is given intravenously, therefore usually in a hospital setting or in a physician's office. A typical course would be an infusion once a day for 3–5 days. The rate of the infusion can affect the side effects which may include fever, headache, nausea, vomiting, fatigue, backache, leg cramps, itching, flushing and elevated blood pressure. (This is not a complete list.) Polio survivors should also be aware that more serious side effects, including renal failure, have occurred rarely over the years.

What does IVIG treatment cost and will my insurance cover it?

Cost may vary depending on the pharmaceutical company. Even the cheapest might cost as much as \$10,000 per course of therapy. Because insurance companies vary in what they cover, check with your individual carrier or Medicare. Unfortunately, there are only two randomized, placebo-controlled, double-blind studies in the literature describing the use of IVIG in individuals with PPS. One, published by researchers in Norway in a Norwegian language medical journal, involved 20 subjects but did demonstrate positive benefits for the treatment group. The other study by the Swedish group was published in June 2006 and discussed briefly above.

Is this enough data to justify coverage by an insurance company in the US? We doubt it, especially as there have been no similar studies published in the US. Despite this, the authors know of two individuals in this country who have been treated with IVIG and obtained reimbursement from their insurance companies.

The use of IVIG in people with PPS shows some promise but further research is required to prove its value and determine who will likely have the greatest benefit.

Sidebar:

Is it Ivlg or IVlg
or IVIG or ??

All of these abbreviations are in use today. The National Institutes of Health (NIH) uses IVIG. The brand name used in the Gonzalez study mentioned in this article was Xepol, manufactured by Instituto Grifols, Spain.

About the Authors

Lauro Halstead, MD, is the Director of the Post-Polio Program at the National Rehabilitation Hospital (www.nrhhealthtown.com/healthtown/network/network.aspx) and Professor of Rehabilitation Medicine, Georgetown University Medical Center, Washington, DC. He is the editor of the forthcoming second edition of *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome*.

Julie K. Silver, MD, is the Director of the International Rehabilitation Center for Polio (www.polioclinic.org) at Spaulding Rehabilitation Hospital in Framingham, Massachusetts, and an Assistant Professor at Harvard Medical School. She is the author of *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families*.

“It is not unreasonable in the meantime for polio survivors to share the information about the current studies with their physicians and begin a dialogue about the possible use of IVIG in the future.”

From Henry's Desk by Henry Holland

Sports, Polio, Lionel Trains and the Church

For the eleven years before I contracted polio I enjoyed and thrilled in participating in all types of sports. I preferred team competition over individual sports. I loved baseball, football and basketball which were the main sports for males in the 1940s. I also enjoyed running which I have written about in the past. In my backyard in the north side of Richmond I had a homemade basketball goal which was nailed to a large oak tree. My paternal grandfather and one of my uncles were excellent carpenters and constructed this goal for my friends and me. In school we often chose up sides and played sandlot baseball until the bell rang to begin school. In the fall when the leaves would be falling we would do the same thing with sandlot

football. I thoroughly enjoyed all of these sports and was fairly good at them. I also was fast and enjoyed racing both sprints and longer races. I am delighted that I have vivid memories of all of these competitive sports activities. To this day I dream of them, only to wake up to reality.

On September 17, 1950 a micro organism named the poliovirus put a permanent end to my running and active participation in sports. After polio for two years I exercised and did everything imaginable in order to regain all of my strength in order to run again. I wanted to do what Wilma Rudolph later did in 1960 in Rome. However, the damage was too great and all I could do was find a way to compensate. I turned to coaching or counseling in sports. For seven summers while in high school, college and even one summer in medical school I was a counselor at a boy's day camp. I mostly coached baseball and basketball, but also running and archery. In college I coached my fraternity's intramural basketball team and I did the same thing for my medical class' intramural basketball team. In high school I was a spotter for the football team at all home games. A student from each school would help the public address announcer identify players from each team on each play. These students were called "spotters" and it was fun to do. In high school and college I covered sports for the school newspapers. The sports that I could still do despite polio were archery, table tennis and golf. I did these as often as I could. Once I got into the later years of medical school I no longer had time for sports participation. My two daughters have coached and my son is currently the swim coach at Randolph-Macon College in Ashland. All six of my grandchildren are active in sports.

At the conclusion of World War II I received my first Lionel electric train on Christmas 1945. One week after being discharged from the Medical College of Virginia Hospital in December 1950 I received my second Lionel electric train on Christmas day. For the next four years I continued to add to my Lionel trains. These marvelous toys became a healthy escape from the reality of my handicapped state. With the help of the same uncle mentioned previously I had a rather elaborate layout of Lionel trains. Two 4 X 8 pieces of ply board were connected at right angles. I learned a lot about electrical energy because of these trains. These trains were set up the better part of the winter during those years. At night time I could dim the lights in the train room and the various lights on the layout would come alive. I could make regular train runs, see the crossing gates go down as the train passed, sound the whistle and even have smoke come out of the smoke stack on the steam engine. This was a time of pure pleasure and fantasy which provided a temporary escape from the realities of the damage of polio.

Most of the time during those adolescent years there was no real escape from the aftermath of polio. I sought a theological explanation to what had befallen me. There are many healings of paralytics recorded in the New Testament of the Bible, but I knew that such miraculous events did not occur in my neighborhood. I did begin attending a local protestant church. I felt welcome there again and the playing field seemed a little more level because there were other people with a broken spirit in my midst. This has been my experience through the years. The famous theologian Reinhold Niebuhr once described the church this way:

"The Church is curiously a mixed body consisting of those who have never been shaken in their self-esteem or self-righteousness and who use the forms of religion for purposes of self-aggrandizement; and of the true Christians who live by a "broken spirit and a contrite heart."*

We will soon be celebrating the holiday season that is religiously inspired. I hope most of you have vivid and joyous memories of your pre polio years. I hope you can be grateful for the inner strength you felt and experienced in living your life beyond polio. I would like to imagine that each of you found healthy paths of temporary escape from the reality of the damage of polio. I am confident that most of you looked beyond yourselves and found comfort in overcoming life's hardships. Post Polio Syndrome has also tested our resolve to find ways to overcome a broken spirit.

**The citation is found in Reinhold Niebuhr: His Religious and Political Thought, edited by Kegley and Bretall and published by MacMillan in 1961.*
