



Polio Outreach of Washington

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Fall 2011

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Mission Statement:

To help minimize the impact of Post-Polio Syndrome by providing education and support to polio survivors, their families, and healthcare providers.

Calendar:

Fall Board Meeting

October 22, 2011

9:00AM-3:00PM

www.hotel1000seattle.com

Donations are always accepted, appreciated and needed.

Please mail to:

**POOW, PO Box 1876,
Kingston, WA 98346**

Ask a Post-Polio Specialist #3 with Vance C. Eberly, M.D.

Rancho Los Amigos National Rehabilitation Center
Downey, California. Reported by Mary Clarke Atwood
Editorial assistance by Richard Daggett and Vance Eberly, M.D.
Rancho Los Amigos Post-Polio Support Group Newsletter, June 2011

At our December 11, 2010 meeting with Vance Eberly M.D. orthopedist in the Rancho Los Amigos Post-Polio Clinic, he answered questions that were submitted in advance and also from the audience. The questions and answers included in this report are:

- What are the most frequently asked questions at the polio clinic?
 - Do I have post-polio syndrome?
 - Can you give me the medication to get rid of this problem?
- What are your thoughts on stem cell therapy for PPS?
- What are your thoughts about blood pressure and post-polio?
- How are muscles graded?
- Can I exercise?
- What are the general guidelines for hip replacement surgery?
- How can the pain of an arthritic hip be treated?
- In scoliosis, would wearing a corset prevent further curvature?
- What are your thoughts on cholesterol lowering drugs and PPS?

What are the most frequently asked questions at the polio clinic?

Those questions are about diagnosing PPS and medications.

➢ **Do I have post-polio syndrome?**

Post-polio syndrome (PPS) is a clinical diagnosis based upon a person's history and functional decline over time; it is a diagnosis of exclusion. There is no blood test to confirm it. The bottom line is that you had polio (probably in your early years) and had some weakness, even sub-clinical weakness, and you recovered from it. You lived your life for 10 or more years at a certain level of function and then noticed your level of function was declining a little.

You may have noticed some of these possible changes, which are similar to a reversal of the compensatory mechanisms from acute polio.

- Fatigue
- Muscle weakness, Muscle pain, muscle cramps, muscle atrophy
- Joint pain
- Cold intolerance
- Problems swallowing

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- Maybe you have to sit up to catch your breath
- Speaking in shorter sentences and similar things
- When all other conditions are ruled out as the cause, there is a clinical diagnosis of PPS.

The original polio affected the anterior horn cells in the spinal cord which go to your muscles. Those are the nerves that go out from your spinal cord to make the muscles work. Polio killed some of those cells and damaged others.

A muscle without a nerve is useless, it just sits there. That is like a motor in your car without the electrical system making it do what it normally does. If you take away that car's electrical system the motor doesn't work. Over time that motor will just rust. That is what the muscles affected by polio basically do also.

With our body being a biological system, we try to compensate for that. Some of the nerve cells were killed, so the remaining nerves try to branch out and go to other muscles fibers to help compensate and get them to do what they normally do. Then the neuron (nerve) is going to more muscle fibers than it normally does, it is doing more than it usually does over a lifetime, and it wears it out sooner. It will not necessarily last as long. When you have a neuron that has been damaged by polio and it tries to do more than it should be doing, those are the ones that are dropping off over time and you develop PPS.

➤ **Can you give me the medication to get rid of this problem?**

Unfortunately there is no medication to treat PPS. In reviewing the literature you can read about trials for neurotransmitters, neurotransmitter uptake blocking agents, growth factors, growth hormones, anti-inflammatories, anabolics to try build muscles—but none of those work.

If you really look at the cause of polio, then it will make sense that none of these drugs will really work. Polio affected the motor neuron cells; it killed a certain number of them and it weakened others. So you have these damaged or lifeless nerve cells. Taking any of these medications is not going to change weakened or lifeless nerves. There will never be a pill to solve the problem.

What are your thoughts on stem cell therapy for PPS?

The "pill" that everyone is looking toward today is stem cell therapy. Dr. Evely believes that stem cell therapy will have limited usefulness for people with the late effects of polio.

If you were a child going through your growth years and got polio, and it affected the muscles and you have muscle weakness, then all the other tissues don't experience the normal stresses they would. Frequently there will be leg length discrepancies, hypertrophic development of the joints and of the bones. Over time there will be joint contractures.

The muscles that those nerves once innervated have been nonfunctional for many years and become fibrotic. They are replaced with scar tissue and fat. Over time, a muscle that has not been worked for many years, regardless of the cause, is not going to work anymore once you try to fire it back up.

So, if stem cells are placed in the spinal cord, and for example the nerve axon finds its way all the way down to the calf muscle, that calf muscle is not going to be working, even if it is innervated. It is a worthless muscle at this point in time. Then the joints are still going to be contracted and you are still going to have all of the problems associated with long term denervation of the muscle.

With that said, stem cell therapy will not be completely useless for the late effects of polio. Dr. Eberly thinks that polio survivors, who have bulbar symptoms, where polio affected the brain stem, might have these symptoms:

- Breathing difficulties
- Swallowing problems
- Central fatigue where they are chronically tired
- Decreased concentration

In the future, people with these symptoms might benefit from stem cell therapy. Dr. Eberly does not know of any ongoing stem cell research for PPS right now. The important thing is that stem cell research is happening. Once it is optimized, stem cell therapy will probably be applied to every disease state. Researchers don't necessarily have to be looking at PPS currently, because in the future they will be able to apply what is learned to other diseases.

What are your thoughts about blood pressure and post-polio?

Blood vessels are smooth muscles and not affected by polio or PPS. Many primary care physicians do not have much background in polio and treating PPS. Generally speaking, exercise is good for helping control hypertension. If you are in a wheelchair most of the day, your muscle strength is such that activities of daily living are probably sufficient exercise for that person.

How are muscles graded?

Muscles are graded from five to zero. A grade five muscle is normal strength. The grading then goes down 4, 3, 2, 1, and 0. A muscle graded zero is flaccid paralysis. However, this is not a linear scale. When you go down from grade 5 muscles to grade 4 muscles, you do not lose 20% of the strength—the loss of strength is actually about 50% to 60%. When you go from a grade 4 muscle strength down to grade 3 it is similar—another 50% to 60% loss. At grade 3 you are basically down to about 20% to 25% of normal strength, which is what is needed for activities of daily living.

Can I Exercise?

People who had polio and whose muscle strength is globally about 25%, then activities of daily living are exercise for those people. If they go out and try to exercise, then they run the risk of developing PPS because they are making those nerves work much harder than they should. Remember, you have damaged nerves doing more than they should. If you really push them you are going to wear them out sooner and it is going to make you weaker by doing exercise rather than making you stronger. That weakness is permanent—it is not recoverable because you killed off those nerves by overworking them.

If a person is thinking about starting an exercise program, Dr. Eberly recommends that you first have a manual muscle test (MMT) done by a good physical therapist. Then look at the MMT results. If most of those muscles are grade 3 or less you should not be doing an exercise program. However, you should also avoid doing nothing, because a weak muscle group can be made weaker by disuse. So there is a fine line for those with existing muscle weakness.

People who have PPS usually know their bodies and understand what they can and cannot do. Exercise is based upon your muscle strength. Sometimes a small amount of exercise is good. It all depends upon the individual, and everyone is different.

What are the general guidelines for hip replacement surgery?

Hip replacement surgery is for someone who has hip arthritis. The hip hurts a lot and the medications don't work. The important aspect for someone who had polio is that you need to have adequate strength around the hip to hold that ball in the socket. If you don't have that muscle strength, and you have the replacement, the hip will dislocate. A chronically dislocating hip is much more painful than an arthritic hip. The muscle group on the side of the hip that lifts the leg out should be about grade 3 or 3+ or better. The patient should be able to hold his leg out against gravity for about a count of 10. If you cannot hold that leg out that long, then you should not have a hip replacement because you really run the risk of having an unstable hip. That is more problematic than the hip arthritis itself.

How can the pain of an arthritic hip be treated?

Treatment for pain in an arthritic hip is limited. First you try the different anti-inflammatory drugs. Keep in mind that anti-inflammatories are the only class of drugs that work for some people and not for others. So you try one and if that doesn't work, then you try the next one.

A hip injection can be done periodically for arthritic pain relief. That has to be done under fluoroscopy because the hip joint is so

deep and so well covered by bone that you have to demonstrate that the needle is actually inside the joint before you inject steroids in it. That procedure might be done three or possibly four times a year. When you have polio you do not have nerve pain, but you may have muscle pain and/or joint pain.

In scoliosis, would wearing a corset prevent the continuation of the curve?

It depends upon where the curve is and how big the curve is. For a severe curve the corset itself will not help. You would need to have a TLSO (Thoracolumbosacral orthosis) clamshell type thing, which is very uncomfortable to wear.

What are your thoughts on cholesterol lowering drugs and PPS?

If you have elevated cholesterol and a cholesterol lowering drug is recommended by your physician, take it. If you develop a side effect where it affects your muscles then you should stop taking it. This is the same as with the general population.

These answers help us better understand some of the challenges facing polio survivors as they grow older. Our thanks to Dr. Eberly for so willingly providing answers to these questions. We appreciate his time, effort, and humor.

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This report can also be viewed and printed at: http://www.ranchoppsg.com/2011-6_newsletter.pdf

LETTERS FROM OUR MEMBERS:

Donald Perry, of Benton County, writes,

I am a polio survivor, 64 years old and in the past ten years I have had major deterioration in my right ankle. The pain was becoming too great to walk any more. My options were; wheelchair, bone fusion and very little other options. My first option seemed at best, to be fusion. However circulatory problems prevented that from being a reasonable choice. Through research I found an option which was never mentioned in any of my many conversations with doctors that I have seen in the past ten years. It seemed, maybe, too simple to work.

Even so, I thought "why not" so I asked my Orthopedic Dr. for an RX to have an orthotic brace. The process was simple: make a mold from the knee down, for a brace that fits in the shoe. Some minor tweaking and WOW! I can walk on my own two feet. Before the brace my mobility was between fifteen and twenty minutes a day. After adjusting to the brace, my walk time is now thirty to forty minutes in one session. In the past year my mobility has been increased ten times what it was before I added the brace.

Resting and managing exercise through the day, my energy has increased dramatically; my weight has dropped about thirty pounds. It is still a work in progress, and it's not perfect, but it is so much better than my other choices.

This may or may not help other post polio victims, but I feel everyone should be aware of all that is available. For more than a year now I have found a new lease on life and I am going to enjoy it with my family and friends for as long as it lasts.

Donald G Perry, Richland

Polio survivor from 1948 outbreak

We're going green... The primary means for sharing useful information about PPS and how to deal with it, is performed by the support groups, and enhanced with the newsletter, and the website: www.poliooutreach.com You may also contact Lois Barber, Office Director, mapabarber@centurytel.net or call: 1 (800) 609-5538 to give your email address for on-line newsletters, instead of printed copies.

What Your Voice is Saying About You: Vocal Changes and the Late Effects of Polio Mary Spremulli, MA, CCC-SLP, Punta Gorda, Florida

Why does my voice sound this way?

Over the last few years, a number of individuals with a history of polio 40 or 50 years ago have been referred to my speech pathology practice complaining of changes in their vocal function. They were often young children at the onset of their polio, so some of them are unsure if their original diagnosis was bulbar or spinal.

Now, many of them in their 60's and 70's report voice problems or changes, such as: –my voice is weaker; –my voice is scratchy and hoarse. Not infrequently, these changes in voice are accompanied by changes in swallowing function with associated complaints of increased –choking when eating or drinking.

Is this related to having had polio?

In many of these instances, the change in voice can represent further weakening of the respiratory and phonatory (voice production) system. In particular, if individuals had initial bulbar polio symptoms, they have likely already spent a lifetime using some compensatory respiratory and oral-pharyngeal muscle function. This muscle function may now be further weakened due to further muscle degeneration, age-related changes, muscle disease atrophy or vocal misuse. Separating out the causes and contributors to current voice problems can be challenging for the voice therapist or otolaryngologist.

Why should I see an Ear, Nose and Throat Doctor (ENT)?

Any sudden changes in voice function, or any change, such as hoarseness, that persists for more than a few weeks warrants an examination by an ENT. The ENT will conduct a direct visualization of your vocal folds and larynx (voice box) by passing a small scope with a camera through your nose and making sure there are no growths, such as nodules (calluses that form from misuse) or polyps (a usually benign, fluid filled outgrowth of tissue that also may be from misuse) or tissue changes suggesting a more serious diagnosis.

A direct visualization can also confirm the contribution of acid reflux, in particular stomach acid that escapes from the top muscle of the esophagus (food pipe). This type of reflux, is also referred to as laryngopharyngeal reflux or ‘silent reflux’ and it is often a factor causing hoarseness or other voice changes.

Patients are often surprised when the ENT prescribes anti-acid medication for their voice changes, not realizing that our anatomic design places the opening of the esophagus and the opening to the windpipe dangerously close, and the vocal folds often receive the insult of acid which may escape from the top muscle of the esophagus.

What is a voice evaluation?

Following an ENT examination, patients are typically referred to a speech language pathologist (voice therapist), who may conduct further instrumental examination using videostroboscopy. In videostroboscopy, a rigid scope with a camera attachment is placed through the mouth to visualize the larynx and evaluate the dynamic movement of the vocal folds.

The voice therapist will also perform a clinical evaluation of vocal function. This exam involves

Taking a thorough history that includes questions about how you use your voice throughout the day, medication use that may be affecting your voice - particularly inhalers and steroids - as well as any surgery you may have had on your throat or any tubes placed down your throat during surgery in an emergency to maintain ventilation. Measurement of pitch, vocal intensity and voice duration are obtained, as well as observations of your respiratory patterns.

In addition to this history and perceptual data, the voice therapist will observe how you use your breath support and voice during conversational speech. Behaviors that can harm the vocal folds, such as frequent throat cleaning, or coughing, will also be noted, as these common habits, over time, can injure the vocal folds. You will likely also be asked about hearing, since a decline in hearing may cause difficulty in your ability to accurately judge vocal intensity in your own voice or others.

Although not directly related to voice production, the vocal folds position at the opening of the windpipe also makes them gate keepers against foreign bodies entering into the upper airway. Therefore, you will be asked about any problems you may be having with choking or coughing when eating or drinking. These symptoms may also be an indication that the sensation of the larynx or function of the vocal folds have declined in some

way, permitting food or liquid to now enter your upper airway. A separate swallowing evaluation maybe recommended.

Can voice therapy help?

Once an accurate diagnosis of your voice problem is made, treatment will likely be a combination of medical and therapeutic management. Problems requiring further medical treatment will be handled by the ENT. These may include medications to treat acid reflux, thick/thick mucus/secretions or to reduce post-nasal drainage. More serious problems, such as polyps, may require surgery.

The voice therapist will focus on vocal hygiene, which includes modification of environmental factors that may be serving as irritants to the larynx and vocal folds, instruction in the methods to eliminate throat clearing and other abusive habits, and encouraging improved hydration through water intake and/or steam.

Then, much like a music teacher, the remainder of voice treatment will focus on improving functional use of your voice instrument. In the case of someone with poor diaphragmatic breathing and respiratory muscle use due to polio and post-polio symptoms, a modified respiratory muscle training program may be recommended.

Relaxation techniques and methods to reduce muscle straining in the neck muscles and larynx may be demonstrated. Use of optimal pitch and posture and techniques for improving loudness without straining will all be emphasized. Voice treatment may be offered for six to eight visits, with development of a home exercise program to encourage strengthening of the system, preservation of muscle function and maintenance of any improvement achieved. For individuals with voice changes from PPS, conservation techniques, including use of personal voice amplification devices may also be beneficial.

Our larynx is a rather amazing organ. Our ability to use its shared functions of breathing, digestion and voice production make it clearly one of our uniquely human gifts. Throughout our lives, our voice mirrors physical growth and other body changes. It conveys our physical and emotional health, and at times, it inspires poetry.

Mary Spremulli is a speech-language pathologist in private practice, a clinical consultant with Passy-Muir, Inc, and a national seminar leader on medical topics. Mary sent a copy of her Voice Aerobics DVD, with her recommendations for usage, for POOW member's use. For more information contact POOW Secretary, Janet Bliss, and/or go online to: voiceaerobicsdvd.com.

Laughter is the Best Medicine

Sitting on the side of the highway waiting to catch speeding drivers, a State Police Officer sees a car pattering along at 22 MPH. He thinks to himself, this driver is just as dangerous as a speeder!" So he turns on his lights and pulls the driver over. Approaching the car, he notices that there are five old ladies -- two in the front seat and three in the back -- wide eyed and white as ghosts.

The driver, obviously confused, says to him, "Officer, I don't understand, I was doing exactly the speed limit! What seems to be the problem?" "Ma'am," the officer replies, you weren't speeding, but you should know that driving slower than the speed limit can also be a danger to other drivers." "Slower than the speed limit? No sir, I was doing the speed limit exactly... Twenty-two miles an hour!" the old woman says a bit proudly.

The State Police officer, trying to contain a chuckle explains to her that "22" was the route number, not the speed limit. A bit embarrassed, the woman grinned and thanked the officer for pointing out her error. "But before I let you go, Ma'am, I have to ask... Is everyone in this car OK? These women seem awfully shaken and they haven't muttered a single peep this whole time." "Oh, they'll be all right in a minute officer. We just got off Route 119."

ajokeaday.com

Polio Outreach of Washington Post-Polio Support

Groups by Rhonda Whitehead

Please contact the group leaders for further information.

ASOTIN COUNTY: TRI-STATE POLIO PALS Established in 1998 by Jim Hueston
4th Saturday, 1:00 PM to 3:00 PM
Tri-State Hospital.
Jim Hueston, 509-758-2187, rockinnj@cablone.net

BENTON COUNTY

3rd Saturday 1:00pm Kadlac Neurological Resource Center, 712 Swift Blvd, Richland,
Norma Peters 509-946-5485, norevepet@gmail.com

CLALLAM COUNTY

4th Friday of every odd number month, Sequim
Library 630 N Sequim Ave, 10:30 to 12:30,
Paul Tucker 360-452-6487, paulaver@olympus.net

CLARK COUNTY

Susie Koeser 360-574-4523 vipsusie@msn.com
or Stan Nelson 360-892-5314 stanor@juno.com

Douglas, Chelan, Okanogan Counties: North Central Washington

3rd Monday 5:00 - 7:00 pm, Prospector Pies, Wenatchee,
Sande and Jim Thornton 509-884-8856, smt1107@charter.net

Kitsap County

3rd Saturday of every odd month 1:00 - 3:00 pm
Bob Miller 360-692-1381 rmiller@wavecable.com
It is with sadness we announce the March passing of Lou Ann Miller, co-leader of the Kitsap
County Support Group. Lou Ann and her husband Bob started the group in 2004. Bob will
continue to act as Group Leader.

Pierce County

Meeting location: TACID 6315 South 19th St., Tacoma (98466)
Meeting dates and times:
1st Monday, 1:00-3:00pm, for the months of Feb. Mar., May, June, Oct., and Nov. (September is
the only month where the meeting is held on the 2nd Monday.)
Potlucks are held at noon, for the months of April and Aug., and our holiday potluck event for
December begins at 11:00am.
No meetings for the months of January or July.
Contact either Marlys Tron, 253-863-9556 or Sandra Morley 253-752-6176

Marlys writes, "The Pierce County Support Group hosted an "Indoor Summer Potluck" on August 1, 2011. I tried to track down the start of our group, but found it to be more difficult than expected. The group appears to be nearing its twentieth birthday. Elsie Allen recalls that the group began meeting at a Chinese restaurant in Lakewood, now part of University Place. Dave Metzler seems to have been the founder. According to Louise Lindeman, her diary first mentions that on June 24, 1992, she and her husband, Wally, attended a meeting held in Lakewood and

the speaker was a Physical Therapist from Michigan. In November of that year, the group began to meet at TACID. During this early time, Margaret Soule was the Chairperson. In 1994, Darlene Brown was the group's leader, followed by Linda McCallum (for the period of 1997 to 2005). Louise has chaired the group from 2005 to the present (she states that she had lots of good help!).

A special event happened in March 2011, when Gretchen Roosevelt, granddaughter of FDR, spoke to our group, shared stories, and pictures, and donated a book signed by Elliott Roosevelt.

Pierce County has 10-12 active members and are delighted when other county members choose to visit their meetings. They would welcome anyone in the area who has had polio to attend." For additional information, contact Marlys Tron at 253-863-9556 or Sandra Morley at 253-752-6176. TACID is located at 6315 South 19th St., in Tacoma (98466).



On August 1, 2011, members of the Pierce County Support Group, and guests, met for their annual potluck indoor picnic. Wonderful food and conversation was shared by all!



Snohomish County & North King County

2nd Saturday of each month 1:00 - 3:00 pm, No meeting in August.
Everett Providence Hospital-Pacific Campus
Rhonda Whitehead 425-488-0219 lauriswh@comcast.net

Spokane County

Meetings have been cancelled until further notice. Sharman Collins 509-448-8517 will remain the contact person. sharmancollins@msn.com

South King County

Third Saturday of each month, noon-2:00pm. First Evangelical Presbyterian Church
19800 108th Ave. SE, Renton, Mimi Sangler 206-725-8937 fuzzface7@juno.com
Members attended a picnic at the Renton Cedar River Trail Park on August 22, 2011.

Whatcom County

The Bellingham Support Group is no longer holding meetings, but Patrick Ewing will be the contact person for anyone in the area wanting information.
Patrick Ewing pre47airstream@aol.com

Medicine and Health

National Consumer League: "Medicine only works when you take it right!"

One in three Americans never fill their prescriptions, and a third of hospital admissions are linked to poor adherence. This is especially true for people with chronic health conditions that can worsen quickly without proper medication use.

In addition, the NCL reports that up to \$290 billion a year in medical costs can be attributed to poor medication adherence. "The least effective and most expensive pill is the one a beneficiary never takes. Following the labeled directions for prescription medications is one of the easiest ways to help protect and improve overall wellness. Read the instructions carefully and contact a doctor or pharmacist with any questions."

National Institute on Aging/Senior Health:

Talking about your health means sharing information about how you feel. Sometimes it can be hard to remember everything that is bothering you during your doctor visit. Making a list of your symptoms before your visit will help you not forget to tell the doctor anything.

Symptoms can be physical, such as pain, fever, a lump or bump, unexplained weight gain or loss, change in energy level, or having a hard time sleeping. Symptoms can also involve your thoughts and your feelings. For example, you would want to tell your doctor if you are often confused, or if you feel sad a lot.

When you list your symptoms, be specific. Your list should include:

- what the symptom is
- when it started
- what time of day it happens and how long it lasts
- how often it happens
- anything that makes it worse or better
- anything it prevents you from doing.

When you are being honest about what is bothering you, it does not mean you are complaining. The doctor needs to know how you feel to help figure out your health problem.

A physical exam and medical tests provide important information, but it is your symptoms that point the doctor in the right direction.

Websites that may be of interest:

Poliooutreach.com

Polioplace.org

AARP.org/health

Post-polio.org/edu/healthcare/PostPolioHealthCareAll.pdf skally.net/ppsc

HealthSupportCenter.org/polio.html

Thejigsawpuzzles.com (play 20-250 pieces-online)

Polio Outreach of Washington

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Medicine & Health

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