



Polio Outreach of Washington

Established June 1996

March 2014

Mission Statement

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

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Survey Response

By Stan Barber

Thank you for participating in the survey sent along with last summer's picnic announcement. 326 surveys were returned, many with contributions included. The Board of POOW thanks you for your very generous support. We are starting off with the question that got the most responses with 112 people wanting to know more about Treatment & Exercise for PPS.

See SURVEY continued on next page

SAVE THE DATE
July 19th
POOW Annual Picnic
See Page 4



Very Important Newsletter Information

By Lee Sanne Buchanan

*The July 2013 mailing, which included the survey and a plea for donations also had a place to indicate if you wanted to remain on the mailing list. **If you have not made your wishes known, then this could be your last mailed newsletter.** You can call the POOW office at 1-800-609-5538 or e-mail: poliooutreach.wa@gmail.com to update your preferences.*

The reason for reducing the mailing list is financial. This year there have been three Polio Outreach newsletters It requires most of the budget of POOW to make that possible. We want to make sure each newsletter actually reaches a reader who wants it!

The Board of Directors is giving serious consideration to trying out a largely online newsletter. In addition to being extremely inexpensive, we could communicate directly with the IN box of our reader's e-mail more frequently. We realize not all recipients of the newsletter have access to a computer and cannot receive the newsletter on line. Because of that, mailed newsletters will still be available for those that request them. However, we do need to know if you still want to receive the newsletter and in which format. Donations are always welcome but mailed newsletters will still be available free of charge. All work done by POOW is done by volunteers. The hours given by the board, by group leaders, picnic planners and editors is awesome. The one goal shared by all is to facilitate education, and support of polio survivors.

The last part of this process is enlisting a new editor for the POOW Newsletter. Editors come and go and although my stay has been brief, I have enjoyed it immensely. I am happy to help as we (hopefully) transition to more online newsletters. If you enjoy writing and can find your way around a computer please call me at 425-531-7942. You may also get in touch with any of the board members or group leaders listed on the back page.

Survey results continued from front page

Treatment and Exercise for PPS.

The number one survey question which received the most queries was “treatments & exercise for PPS”. Trying to answer the question it turns out, is not so easy. There are many sources of information available and a wide range of opinions on this question. We chose references from six sources, keeping in mind, “one size does not fit all”. **Before you began any physical regimen, It’s always important to consult and coordinate with your medical provider.**

1) **Listen to yourself!** Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms.

Activity is NOT EXERCISE! Some polio survivors believe the more you exercise, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. You need to substitute a “conserve it to preserve it” for the “use it or lose it” philosophy. *Ref: The Ten Commandments of PPS, New Mobility, June 1999. Dr Richard L Bruno. Dr Nancy M. Frick*

2) “I found that I could accomplish much of the non-weight-bearing benefits of swimming by exercising in bed. While laying down, the buoyancy effect of the mattress allowed me to do lots of exercise movements for my legs and back that I could not do while standing or sitting-exercises I could otherwise only do in water. I refer to these as my **swimming-in-bed-exercises**. As you’ll see, swimming in bed is especially easy to adapt to provide slow movements for coordination and stretching for improved flexibility and range of motion”. *Ref: Traveling without a spare. A Survivor’s Guide to Navigating the Post-Polio Journey. By Wenzel A. Leff, MD*

3) **In Occupational Therapy**, the focus of treatment for Post-Polio is **Energy Conservation**. Specific techniques applied to daily living activities increase endurance, maintain strength and muscle power; therefore preventing muscle strain, respiratory and cardiovascular stress.

Analyze: how much energy and endurance you have in one day. How do you want to use that energy?

Pace Yourself: Allow ample time to complete each task. Take your time with tasks and rest before you are really tired.

Establish a Routine: Plan each day to include only what you can realistically accomplish. Write out a schedule.

Arm Work: Activities requiring arm work cause greater changes and stress on cardiovascular and respiratory system than does leg work.

Avoid over exertion and fatigue: For long term goal of maintaining endurance and muscle strength, avoid overexertion and fatigue through mobility options available.

Organize work centers: closer, lower, lighter.

Use wheels to transport: There are electric carts available in many stores.

Sit to work whenever possible: This speaks for itself.

Ref: Ben Berman Outpatient Rehabilitation Center, St. Mary’s Medical Center, Energy Conservation for Post-Polio.

4) **Exercise-Friend or Foe:** Overuse has been found to be a significant if not the main factor underlying many of the problems survivors of polio have. There are three types of exercise forms that are important to a polio survivor: Exercise for suppleness; exercise for strength; exercise for fitness. **The key to a successful fitness program is a thorough medical evaluation, especially cardiovascular and musculoskeletal, and an individual professionally supervised exercise regimen.** *Ref: Dr Brigitta Jann MD, (courtesy,*

Atlanta Post-Polio Association)

5) **Exercise:** Muscle stretching and joint range of motion exercises are important whenever there is muscle weakness. Any exercise program should focus on building endurance, not strength.

Muscle Weakness: Muscles that are weakened by polio in general cannot be strengthened by a vigorous exercise program and this may aggravate or enhance the development of weakness. *Ref: "Excerpt from the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. Eds. Headley, JoanL. And Frederick M. Maynard, MD. Post-Polio Health International (1999).*

6) **What are your options?** Although lifestyle modification is primary treatment for symptoms of post-polio syndrome, as a post-polio patient you should have some kind of exercise program, yoga or mild stretching if aerobic exercise is not possible to keep the body limber, maintain range of motion, and provide a sense of well-being. Because post-polio syndrome is believed to be a disorder resulting from overuse of muscles, **the key to optimal function is controlled or monitored exercise.**

Swimming is ideal exercise because most effects of gravity are countered and the buoyancy facilitates use of your weak or painful joints. In heated water, the total therapeutic benefit can be greater than that expected from heat of exercise. *Ref: "This article was adapted from PATIENT CARE magazine, June 15, 1988 issue"*

I don't know if this information brings clarity to this question, I do hope it shows the wide range of options one can find which may bring some easing from the effects of Post-Polio. Next newsletter, we will try and answer Question #2 of the Survey: "Non-PPS symptoms that Polio Survivors often have".

Stan Barber
President, POOW, 2014

Stan's Corner

Happy New year to you all! Has anyone else noticed how fast this year is passing? Maybe we're just a little busier and need to slow down a bit!

I recall reading a surprising comment from one of the aviation magazines I read, about some of our Army Air Force pilots serving in the Mediterranean during WWII. In 1944 60 American military personnel were diagnosed with polio! And our military personnel were sent back to the states for treatment. I think of today, how much easier air travel is and Seattle as a transportation hub, the greater likelihood someone with the virus can pass through our area. I wish we could each of us, convince just one young mother/father to have their child vaccinated.

*Yours in service
Stan Barber*

P00W Annual Picnic . SATURDAY July 19th

All polio survivors, their families and friends are invited to the annual picnic hosted, this year, by the South King County Post Polio Support Group. This fun-filled event is being held at the Auburn Game Farm Park in Auburn, Washington. We will gather from 11-3.

The meal will be catered by Longhorn Barbecue for \$10/person and will be served at noon. The menu will include BBQ pork spare ribs and chicken, beans, potato salad, cornbread and honey butter, along with plenty of the famous Longhorn Barbecue sauce.

A large covered area with lots of tables, benches and outlets is available for our use. You are welcome to bring a card table and lawn chairs if you prefer. There is plenty of convenient parking and accessible restrooms are close to all activities. We look forward to seeing you and welcoming new friends.


RESERVATIONS MUST BE MADE BY FRIDAY, JULY 11.

Direction to Auburn Game Farm Park
3030 R. Street SE
Auburn, WA 98002



1. From I-5 or Hwy 167 take Hwy 18 exit. Take the Auburn-Enumclaw exit
2. Turn left onto Auburn Way South
3. At the intersection of M Street, be in the right-hand lane to take Howard Road.
(watch for the Walgreens on the left)
4. At the end of Howard Road, turn right onto R Street SE. Continue through the light at 29th SE. Park is immediately on the left.

Picnic shelter is at the end of the road.

 **P00W Picnic Reservation**

Saturday, July 19th, 2014 • 11 am-3 pm • Lunch at noon

Name _____

Phone _____

Longhorn Barbeque lunch/\$10 person

Total Reservations_____

Make check payable to P00W

Call or return form by July 11 to Lois Barber, Office Manager
P.O. Box 1876
Kingston, WA 98346
1-800-609-5538

Good information about anesthesia awareness

The New Jersey Department of Health has printed and distributed 10,000 wallet-sized cards with vital information on anesthesia dangers in polio survivors and on Post-Polio Sequelae, a disabling condition affecting the state's 50,000 polio survivors.

Created by Dr. Richard Bruno, Director of the International Centre for Post-Polio Education and Research at Englewood Hospital and Medical Center, the yellow, double-sided card was suggested by the Ocean County post-polio support group to comply with New Jersey Senator Loretta Weinberg's 2004 "Post-Polio Sequelae Public Awareness" bill.

"Doctors have forgotten about North America's nearly two-million survivors of the polio epidemics of the 1940s and 1950s," said Dr. Bruno, who is also chairperson of the International Post-Polio Task Force. "Because of damage the polio virus did to the stem of the brain, polio survivors are easily sedated and often get too much anesthesia." Bruno has seen polio survivors end up on a ventilator in intensive care after minor surgery or even a colonoscopy.

The New Jersey DOH card features a prominent, red "ANESTHESIA WARNING!" and lists easy sedation and difficulty breathing and swallowing as problems that can be avoided by using lower doses of anesthetics in polio survivors. The card also lists increased sensitivity to cold and pain as post-operative problems in polio survivors.

"The polio virus kills neurons in the brain and spinal cord that produce the body's own morphine," Bruno explained. Bruno's research has found that polio survivors are twice as sensitive to pain as those who didn't have polio. He recommends a general rule of thumb for treating polio survivors—"The Rule of 2": two times the usual amount of pain medication for two times as long, and the usual amount of anesthesia divided by two. "All doses of medication must be adjusted for individual polio survivors," Bruno cautioned. "And, polio survivors should never have same-day surgery because of excessive sedation from even appropriate doses of anesthesia."

The flip side of the DOH card lists the "late-effects of polio," called Post-Polio Sequelae, overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, cold intolerance and breathing and swallowing difficulties that can develop in midlife. "Doctors are also unaware of Post-Polio Sequelae, or say that they 'don't believe' in PPS," said Bruno. "PPS is very real and very treatable if polio survivors can reduce the 'overuse-abuse' of their remaining, overworked poliovirus-damaged neurons."

Groups may request cards by going online to NJ.gov/health/feedback.shtml. More information about anesthesia concerns and Post-Polio Sequelae can be found at PostPolioInfo.co

PRINT and CUT OUTER EDGE
(fold here)

<p>ANESTHESIA WARNING! <i>I am a Polio Survivor...</i></p> <ul style="list-style-type: none">• EASILY SEDATED, difficult to wake;• Difficulty BREATHING and SWALLOWING with anesthesia;• HYPERSENSITIVE to PAIN and COLD. Need heated blanket and increased pain medication post-op. <p>For more information, visit: www.nj.gov/health/cd/postpolio/index.shtml</p> <p>C1510</p>	<p>I am a Polio Survivor with Post-Polio Sequelae (PPS) unexpected midlife symptoms:</p> <ul style="list-style-type: none">• Overwhelming Fatigue• Muscle Weakness• Muscle and Joint Pain• Sleep Disorders and Cold Intolerance• Difficulty Swallowing and Breathing• Heightened Sensitivity to Anesthesia <p>(over)</p>
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“Tell Me more about the State POOW Board??”

Polio Outreach of Washington has been in existence for over 20 years as a 501(c)3 organization. It is an all-volunteer Board and its 11 current members are rotated by yearly elections for two-year terms. In the distant past we received some funding from Easter Seals but now we support ourselves with all income is coming from people interested in our activities. We have modest expenses going to having a functional board (i.e., office supplies, postage etc), but the overwhelming expense is publishing and mailing the newsletter.

The Office Manager, Lois Barber, fields calls from Washington and places across the country from people newly diagnosed with Post Polio, or from those who want more information. In fact information and education about Post Polio might well be considered our single biggest reason for existing. As you see on Page 7 of this newsletter, there are 7 active support groups along with 4 who are less active for the time being. If you ever attend a group and see the sharing, the fellowship and the help members give to one another, you will understand in an instant how important POOW is.

There is some Board discussion being given to arranging a spring ‘field trip’ to the Gates Foundation in downtown Seattle to see their large polio display. In past years there have been activities such as this. The annual picnic serves to enhance the support function of POOW.

Please consult the back page of this newsletter for Board members names and contact information. Anyone listed is happy to hear from you and feel free to use the 800 number. Anyone wanting to receive the newsletter online is free to share their e-mail address. Newsletters are always available on our web site below.

Polio Connections Quiz

Many famous people had Polio, and you probably never knew it.

1. What do Alan Alda and Donald Sutherland have in common (other than overcoming Polio)?
*Both played Hawkeye Pierce (Alda on TV/Sutherland in the movie, M*A*S*H)*
2. What is the connection of Elvis to Infantile Paralysis (another name for Polio)?
He had a picture taken of him getting the Salk vaccine to show it was OK.
3. Who wrote, “Save the Last Dance for Me?”
Polio survivor Doc Pomus (Jerome Felder) wrote it for his wife who loved to dance.
4. What famous director had polio? *Francis Ford Coppola*
5. What famous violinist had polio? *Itzhak Perlman*
6. What connection is there to the famous Steiff Teddy Bears?
Margarete Steiff, the German seamstress who made the famous bears, had polio.
7. What polio survivor invented an artificial heart?
Paul Winchell (he was also the voice of Tigger)
8. Who was a Physical Therapist with polio patients before she was an actress? *Olympia Dukakis*
9. Name 2 famous people whose wives had Polio.
*John Nordstrom’s wife.
Dick Francis’ wife Mary (who is believed to have written
or contributed highly to many of his books until her death in 2000)*
10. Who had the earliest recorded case of Polio in the UK in 1773? *Sir Walter Scott*

All groups welcome visitors!

Support Group News

Pierce County

Meetings are held at TACID, 6315 South 19th Street, Tacoma 98466, 1-3 pm on the first Monday in Feb, Mar, May, June, Oct. and Nov. **Potluck at noon in April.**

Contact Marlys Tron 253-863-9556 or Sandra Morley 253-752-6176

Benton County

The Tri-Cities group will meet the first Wednesday of each month at the Richland Public Library, 955 Northgate Drive. Next meetings will be April 2 and May 7. Contact Norma Peters 509-946-5485 norevepet@gmail.com

Kitsap County

The group is **under new leadership** but is still meeting on the 3rd Saturday of every odd month from 1-3 pm, at Central Kitsap Fire and Rescue Station 56, Bremerton.

Contact Lois or Stan Barber. 360-297-2671 mapabarber@centurytel.net

Snohomish County and North King County

Meetings 2nd Saturday of each month, 1-3 pm, at the Everett Providence Hospital-Pacific Campus. The meetings continue to focus on support, education and friendship.

Contact Rhonda Whitehead 425-488-0219 lauriswh@comcast.net

Douglas, Chelan, Okanogan Counties North Central Washington

Meets on the third Monday 5-7 pm at Prospector Pies, Wenatchee.

Contact: Sandee and Jim Thornton 509-884-8856 smt1107@charter.net

South King County

Meetings on the third Saturday of each month, noon-2 pm.

First Evangelical Presbyterian Church, 19800 108th Ave. SE, Kent.

Contact Mimi Sangder at 206-725-8937 fuzzface7@live.com

Clark County

Please contact Susie Koeser 360-574-4523, vipsusie@msn.com or

Stan Nelson 360-892-5314, stanor@juno.com for time and place of meetings.

**The following groups may not meet regularly but are interested in hearing from you.
New interest could re-activate the group.**

Asotin County: Tri-State Polio Pals

The group is **no longer holding regular meetings**

Please contact Jim Huetson 509-758-2187 rockinnj@cablone.net

Clallam County

Contact Paul Tucker
for information 360-452-6487
paulaver@olympus.net

Spokane County

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

Whatcom County

Please contact Patrick Ewing
for information,
360-966-4253
pre47airstream.com

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PolioOutreach.com

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Newsletter Information

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To receive newsletter via
email or by mail contact:

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Polio Outreach of Washington

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