



Polio Outreach of Washington

Established June 1996

July 2012

Volume 26-Issue 1

August 19th
Annual Picnic at
Lake Meridian
Park
\$10/person. See
Page 5!

Mission

Statement:

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

A special thank you to everyone who recently donated to POOW! Your generosity is making it possible for POOW to continue to provide meaningful supports to our members, in the forms of our Website, Information packets, Newsletter and our 800 number.

The POOW
Newsletter is
published November, March
and July. Contact Lois
Barber, POOW Office
Manager, 1 (800) 609-
5538, to give your email

Optimum Recovery

At our meeting today in Renton, we started talking about Traveling Without a Spare (A Survivor's Guide to Navigating the Post-Polio Journey) by Wenzel A. Leff, MD. Although we assigned only a few pages of the first chapter for discussion some people launched right into it and read much more of the book because it is informative and easy to read. We discussed when we reached optimum recovery. It was a different length of time for each of us. Some people had visible handicaps that involved difficulty walking from the beginning but some were able to pass for normal and compete well in sports.

Optimum recovery is not so easy to pinpoint until later when you look back at life. My polio came when I was 7 years old and I was helped at first by an iron lung which took over my breathing. Once I was weaned off the iron lung I went to a rehab hospital where physical therapy exercises helped me gradually regain strength in my paralyzed arm and neck until eventually I was able to go home. I missed a year of regular school.

Throughout my school years I was continuing to regain strength but I had pneumonia annually and then every other year until I finished high school so I believe my optimum recovery was when I finished school and went on to college.

When I was young I felt like I was the polio kid. People all seemed to know because of my family and when I became an adult I made new friends who did not know I had had polio. It felt liberating when I left home and my dear mother would not have 'the chat' with a new boyfriend to tell them I needed to be home by midnight, etc. because I had had polio and needed to take extra care. My mother was wonderful but I hated when she did this because we just all wanted to appear normal—right?

I knew I was not good at sports and could only run in short bursts, but I could pass for normal. I was careful because I did not want to get pneumonia, but I stopped thinking about polio and was happily living life to the fullest. Dr. Leff states, "The Recovery Stage came to an end when the body and mind had done all that was possible to maximize improvement and optimize quality of life following the polio infection." I think that this was my personal optimal recovery. Several of our members in the Renton group experienced this at different ages, but most of us never really thought about the time when our recovery ended.

The post polio can hit 30 or 40 years later. Sometimes we don't notice it because we are losing muscle very gradually over time as we age, but sometimes it is triggered by a physical or emotional trauma. For example: People may be in a car wreck, have a nasty fall, or need surgery, or they may go through a difficult divorce. Of course we can't control all these things but we should take care to avoid doing something stupid.

In our group, people often report that they had a nasty fall. People with normal muscle strength can move without concern whereas people with weakness need to think how they are going to move. On stairs the strong leg goes first when climbing but the weak leg goes first when descending the stairs. If both legs are weak you may need a cane or a crutch.

Another thing that was brought out at our meeting was that doctors need to understand post polio weakness. They focus on the immediate issue without taking all factors into consideration. For example, one of our members was prescribed a medication that was a breathing suppressant; he happens to be on oxygen, 24/7, because only one of his lungs is working! We all agreed that we have to be our own advocate.

Recently my primary care doctor's office called to schedule me for an annual chronic condition follow-up appointment. I thought it was a mistake because I've had PPS for about 20 years and this is the first time they have invited me in for a check-up. Apparently it is a Medicare requirement so I took the opportunity to tell my primary care doctor about my polio history from beginning to current day. Although I have seen him many times I don't feel he really knows my complete history because I go to specialists for all my specific problems and only see him for minor non-polio stuff.

Before my HMO went paperless, when you saw the doctor they would pull the patient file. Mine was about an inch thick. Now all the records are in the computer where any of the HMO doctors can view it but it doesn't hurt to remind them of pertinent things because they probably cannot be expected to review everything, especially if you have a vast amount of data on file.

I think he appreciated my summary and I finished by giving him a copy of [Traveling Without a Spare](#). He thanked me and said it would be a useful resource. I hope he reads it!

Janet Whitworth, Renton

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Revisiting the past...

The other day I came across this article that was published in our January/February 1994 newsletter. Hope you agree that it is still current today, as it was then. Lois Barber

WHY HAVE POOW SUPPORT GROUPS?

- **Chronic disabilities can be overwhelming – we have learned and practiced “I must do it myself,” but now we can’t do so.**
- **We can become isolated; especially if energy and mobility are limited, or we feel family and others don’t understand.**
- **Frustration at the failure of “the system” (medical and social services, employers, etc.).**
- **Family members may feel frustrated, too. Reassurances and emotional support are needed for them as well.**

BENEFITS OF POOW SUPPORT GROUPS

- **We find empathy – “You are not alone.”**
- **Acceptance – group is non-judgmental, so we don’t need to pretend and hide.**
- **Offer relief from fear of the future.**
- **Education – learn more about disability and how it is treated; gain practical skills; become better health-care consumers.**
- **Catharsis – relief of emotions.**
- **Hope – problems CAN be dealt with and made tolerable.**
- **Humor – keeps things in perspective.**
- **Empowerment – take control of the situation; self-help; not a “victim”.**
- **Gain motivation and inspiration.**
- **Increase public awareness – sharing of information, input to businesses, advocate for rights, “organized clout”.**
- **Learn of community resources.**
- **Promote and assist research.**
- **Form new friendships.**

WHY DON'T SOME PEOPLE ATTEND POOW SUPPORT GROUPS?

- **Some people aren’t ready to confront their problems with Post-Polio Syndrome.**
- **“It’s depressing”; “It can’t be cured, so what’s the use?”; “I don’t want to dwell on it.”** These people may be using avoidance and denial to reduce anxiety. In other words, it’s a coping mechanism, not just denial.
- **Information overload may be stressful.**
- **“Too much talk about feelings makes me uncomfortable”; “I don’t like to discuss my feelings in public.”** Also, a person may have such strong feelings, they’re afraid they will go out of control.
- **May be getting sufficient support elsewhere (medical provider, family, friends, religion).**
- **Feel too disabled (or not disabled enough) to fit into group.**

HAVE YOU HEARD ABOUT . . . www.polioplace.org

This site is a service of Post-Polio Health International, made possible by a grant from a small fund by the Roosevelt family. Explore the past, the present and help build a promising future, for the World's Polio Survivors. You are invited to learn by searching the major sections and sub-sections, and to even add your personal knowledge, by submitting an artifact or contacting them.

There are sections and articles devoted to the history of Polio, resources (including books, websites and multimedia), medical articles and a section titled "Living with Polio". This website is truly devoted to Polio survivors and their families. Please go and explore!!

Ah, yes...I'm continuing to adapt to my increasing needs.... Janet Bliss, Renton

I wear a full length leg brace, but began to experience some weakness in my "good" leg. This has necessitated my using both arms when getting out of chairs, couches and, of course, the toilet. I purchased the item below, because my bathroom wouldn't accommodate installing permanent handrails on either side of the toilet. I needed a stand-alone set of safety rails, preferably some that I could use in other locations.

I found other similar models on Amazon, but they were entirely too expensive! This model was less than fifty dollars! With my trusty set of pliers and Phillips screwdriver, and looking closely at the picture, I assembled it in less than thirty minutes. Works like a charm, so light that I can move it with one hand, and I've even been able to transport it on trips in the trunk of my car. It can be used in front of my couch, chairs, and of course, in front of my toilet.

Having to adapt to my increasing physical needs has been a trial, but I do have to admit that when I find something that makes my life easier, I'm quick to share my experiences. I am only recommending this product on a personal level, not as an endorsement from POOW!



CELEBRATING 16 YEARS WITH POLIO SURVIVORS & SUPPORTERS

Polio Outreach of Washington will be celebrating our 16th year. Come and help us celebrate. All polio survivors and their families and friends are invited to join us. The Picnic will be hosted by POOW board members. The meal will be catered and served at 12:00 noon. A large covered area with lots of tables, benches and outlets is available for our use. You may bring a card table and lawn chairs if you prefer. **There is limited parking, please try to carpool.** Restrooms are close to all of the activities. Please bring a light jacket or wind breaker, the park is right on the lake. Please feel free to a lawn chair. In addition to our meal, there will be lots of time for chatting, games and maybe a balloon toss. We will be having live music. We anticipate door prizes and maybe a few raffle items. We look forward to seeing you and welcoming new friends.

When - Sunday 19 August 2012

Where - Lake Meridian Park in Kent - 14800 SE 272nd Street

Time - 10:00 am to 5:00 pm

Lunch Served at 12:00 pm

Make your reservations by returning the registration form no later than 4 August 2012.

LAKE MERIDIAN PARK

14800 SE 272nd Street, Kent, WA

From I-5 take the Kent/Des Moines exit and drive east down Kent/Des Moines Road to Meeker Street. Turn left (east), onto Meeker Street. Drive east on Meeker Street to Smith Street. Drive on Smith Street east up the hill. Stay on the right after crossing Benson Road (104th Ave SE) intersection. The road becomes Kent-Kangely Road. Follow Kent-Kangely east toward Covington. Lake Meridian Park entrance is on the left (North) side of the road.

Polio Outreach of Washington Picnic Reservations

Name _____ Phone _____

Lunch is \$10.00 per person. Total number attending: _____ Total amount enclosed _____

Please make checks payable to POOW

Please return this form to: Lois Barber, POOW Office manager

POOW; P.O. Box 1876; Kingston, WA 98346

If you have any questions, please call 1 800 609-5538

Polio Outreach of Washington Post-Polio Support Groups by Rhonda Whitehead

Asotin County: Tri-State Polio Pals: Established in 1998 by Jim Hueston. The group meets the first Saturday in April and October, from 1:00 PM to 3:00 PM at Tri-State Hospital. Contact: Jim Hueston, 509-758-2187, rockinnj@cablone.net

Benton County: The group now meets on the second Wednesday of every month at 1:00pm. at the Kadlec Neurological Resource Center, 500 Gage Blvd., Ste.106, Richland, WA. Contact Norma Peters 509-946-5485, norevepet@gmail.com

Clallam County: Contact Paul Tucker 360-452-6487, paulaver@olympus.net for information.

Clark County: Please contact either Susie Koeser 360-574-4523 vipsusie@msn.com or Stan Nelson, (360) 892-5314, stanor@juno.com for time and place of meetings.

Douglas, Chelan, Okanogan Counties: North Central Washington: The group meets on the third Monday 5:00 - 7:00 pm, at Prospector Pies, Wenatchee. Contacts Sandee and Jim Thornton 509-884-8856, smt1107@charter.net

Kitsap County: The group meets on the third Saturday of every odd month, from 1—3pm, at Central Kitsap Fire and Rescue Station 56, Bremerton. Contact: Bob Miller 360-692-1381 rmiller@wavecable.com

Pierce County: The location of meetings are held at TACID 6315 South 19th St., Tacoma (98466). Meetings are held on the 1st Monday, 1:00- 3:00pm, for the months of Feb. March, 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

Snohomish County & North King County: Meetings are held the 2nd Saturday of each month 1:00 - 3:00 pm, at the Everett Providence Hospital-Pacific Campus. Contact Rhonda Whitehead at 425-488-0219, lauriswh@comcast.net

The meetings continue to focus on support, education, and friendship! February marked our 21st anniversary.

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

South King County: Meetings are held the third Saturday of each month, noon-2:00pm. First Evangelical Presbyterian Church 19800 108th Ave. SE, Renton, Contact Mimi Sangler at 206-725-8937, fuzzface7@juno.com

Whatcom County: Please contact Patrick Ewing for information (360) 966-4253,

Polio Outreach of Washington

Please use this form when you are submitting any information. Include your name, address, phone number and e-mail address. When you go on vacation or move, please submit an address change to us and also another address change when you return! Thank you.

As an independent, 501(c) (3) non-profit organization we rely on our readers and membership for support. Your donations are appreciated. **The date next to your name on the label is one year from the date of your last donation.**

ALL DONATIONS ARE TAX-DEDUCTIBLE (Please save your cancelled check as it is your receipt for tax purposes)

Please make checks payable to: Polio Outreach of Washington.

Mail your check and completed form to POOW, PO Box 1876, Kingston, WA 98346

First contact with Polio
Outreach of Washington

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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.



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