



# Polio Outreach of Washington

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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.

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 address for on-line newsletters, instead of printed copies.

How many of us have experienced excruciating pain, and when we try to call the doctor, instead of help we encounter an unresponsive medical staff? Recently, one of our POOW members contacted me, in desperation, seeking help; any kind of help, just HELP!

I Googled the doctor's name, found his website, and contacted him using email. I copied most of what our member had written to me, and then added that I was writing as a concerned polio survivor and as a member of Polio Outreach of Washington state. The thrust of my written concern was his unresponsive staff.

Guess what? I received an immediate response and our member was contacted that same day. Additional meds were prescribed and the MRI that had been recommended for two weeks after the surgery was changed to within a few days. By the way, the unresponsive staff person called our member no less than 6 times to make sure that she was comfortable with all of the decisions and appointment times! This illustrates part of what I used to teach as part of my Special Education curriculum: assertiveness training.

## **What can we do, as individuals, to obtain the quality medical care that is so vital to us?**

Too often we are intimidated by people who are considered to be specialists in their field. This is understandable, but it is important to remember that we are ultimately in control.

Without our knowledge as to how we are feeling, both physically and emotionally, physicians can only rely on lab tests. A lab test cannot tell the doctor that we're experiencing pain where there shouldn't be pain. An x-ray or MRI can only show where there might be a problem, but the patient is the only one who can tell the doctor whether or not it is manageable as is.

To be assertive is not to be rude it is simply stating a fact. It may not necessarily be what someone else wants to hear, but you have the

right to express yourself and how you view your needs. In order to accomplish this, I have a few simple suggestions.

- **Take a notebook with you to your appointment** and have a list of your current medications and their dosages. Put the date of your appointment on one page and have your questions written down before you meet your doctor. How are you feeling? What are your problems? Keep it simple. Try to use simple word descriptors: dizziness, tired, pain in shoulder, arm, back, leg, etc. Sleep patterns are also important to note.
- **Know what you want to have happen.** It can't hurt to write this sentence on one line of your notebook, and then rehearse! You may feel a little silly at first, but by the time you say your "sentence" 3-5 times, it won't seem so strange when you tell your doctor what you need. "I want to know why I am suddenly experiencing ...." "I fell last week and now I have pain in my ...." "What can I do about ...." "My vision is suddenly blurry, is this a side effect of my new medicine?"
- **What are your options?** Add a new medication, reduce, or increase the current dosage, Physical Therapy, exercise, lose or gain weight, surgery. Do you understand these options, and if not, then it is your responsibility to ask questions.
- **Do you understand what is being recommended, and why?** Ask the doctor to explain. Have him/her show the results of the x-ray and/or MRI. **What are your options?** If you're not satisfied with the explanations, then ask for a second opinion. Your records, including lab tests, x-rays, and MRI, will be available upon request.
- Finally, you may want to ask a trusted friend or a family member to accompany you to your appointment. All of us "freeze" when presented with hard choices and too much information. Having a second set of ears can help, when you later try to process what was recommended.

Having surgery to correct one issue and then compounding the problem because of an inadequate understanding of the post-polio condition was a nightmare for our POOW member. Having a step-by-step procedure or a back-up plan for remedying medical problems has allowed her to have more control. Expecting respect, a timely response to a concern, or question, or even making the decision to request a second opinion will allow all of us to stay-the-course. We are our best advocates. Be assertive by being prepared. We're not called, "Polio Survivors" for nothing!

***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](http://www.poliooutreach.com) You may also contact Lois Barber, Office Director, [mapabarber@centurytel.net](mailto:mapabarber@centurytel.net) or call: 1 (800) 609-5538 to give your email address for on-line newsletters, instead of printed copies.***

## Annual POOW Picnic

On August 19<sup>th</sup> over 70 members attended the annual POOW picnic! The BBQ lunch was provided by Longhorn Catering of Auburn, and we had wonderful music for the entertainment performed by the employees from Woodsmen of the World. POOW also received a generous donation of \$300.00 from their organization!

After those extremely hot days we were kind of cold sitting under the cabana shelter. The sun did not break through the clouds until most people had already left which was a shame. But we had two celebrities present: Peg Kheret, the author who has published many books for young people and who also authored a book about her personal experience with polio and Dr. Wenzel Leff, a medical doctor and a polio survivor, who recently wrote Traveling Without a Spare.

Special thanks to everyone who planned and implemented the plans to make this picnic a success! Lauris Whitehead manned the parking lot, Bill Simpson and Kory Lemon delivered our food, Mimi Sangder and Rhonda Whitehead coordinated the location, Jan and Jay Reed manned the reception table, Lois and Stan Barber handled the set-up and reservations, and Rhonda and Lois worked hard to coordinate the door prizes and raffles! Rhonda Whitehead was instrumental in organizing the picnic for the POOW board!! Whew!! This picnic definitely took a village to be successful! Way to go, everyone!

### Central Washington Fires

The effects on Polio Survivors living in the Wenatchee Valley area has been significant. As many of you know the fires in the Wenatchee area have long over-stayed their welcome. At this writing, we are into our fourth week of continued smoke and it has been a concern to everyone's health. The last two days have shown promise and given us a much needed break. The wind has returned and blown the smoke out of our valley. We are all rejoicing in this break. The smoke does come back but each day is closer to rain and snow! In looking around at the hills of Wenatchee not one home was lost, but the fire line was right at the back door of many home owners.

Free N95 masks were given, and could also be purchased at some of our local stores. The carbon monoxide level has been very high and dangerous here. This is also true in surrounding areas. You just never realize how much things mean, until they are taken from you.

#### Comments from some of the post-polio members in the Wenatchee Valley:

Chris: Smoke made her eyes burn and she felt like she was on a pack a day of cigarettes. It took more of her energy to get from the house to the car and to the shops and back.

Marilyn: When she mowed the lawn she felt extra tired. She drank water and then would mow again. She went into labored breathing as her mower isn't self-propelled. She was panting after she was done which she says is most unusual for her. She has had trouble with a runny nose.

Jim & Sandee: They experienced extra coughing and weeping eyes.

Don & Carol: They tried staying inside. They experienced the runny nose and light headaches.

Dianna: She comes to our group from Omak. As they were getting closer to Wenatchee to attend our September meeting her breathing became too difficult and headaches started which forced them to turn around and go home. Omak is also having fires so she isn't free from the smoke and sometimes panic attacks set in along with other concerns.

Helen: She spent four days in Renton with family to give herself a rest from the smoke. Otherwise she is here coughing and struggling with itchy eyes.

Dean & Trina: They always wore the masks but even with that they did feel the smoke caused some irritations. They are hoping that there will not be lasting effects.

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

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

Benton County: *The group will now meet on the second Saturday of every month at 1:00pm. at the Richland Public Library, 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. Elaine Stoner, a founding member of the polio education system in Oregon and Washington, moved to Washington, D.C.. She will be greatly missed.

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 3<sup>rd</sup> 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: Meetings are held at TACID 6315 South 19th St., Tacoma (98466), 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. All are welcome to the December holiday event with a potluck, entertainment, and raffle. Come early!

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, pre47airstream.com

## **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**

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