

# Polio Outreach Of Washington

Established June 1996

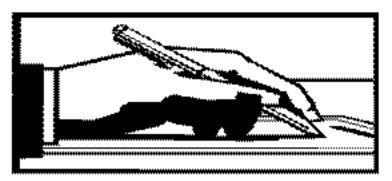
Fall 2010

Volume 24 - Issue 4



**Thanksgiving**.... A time to reflect on the many reasons we have to be grateful. As polio survivors, we appreciate being alive and those abilities that we have after the polio virus made its visit to our bodies. To have the support and assistance of people who care about us and contribute to our daily needs and comfort, cannot be adequately expressed here. It is also such a wonderful gift to have a way to gather together and communicate with other polio survivors for encouragement, education and friendship. We can be truly thankful!

**Thanks for giving**....October is set aside as Polio Outreach of Washington's fund raising awareness month. Polio Outreach is currently the only organization in the State of Washington that exclusively provides education and resources to polio survivors, their support givers and medical professionals. That is accomplished through local support groups, information packets, a quarterly newsletter, and a website. All personnel are volunteers - we do not even pay for office space - so administrative costs are kept to a minimum. The bulk of your donation goes directly to programs for polio survivors. Contributions can be made through United Way, designating POOW as your choice of charity, making a gift to POOW as a memorial to a loved one, or by mailing a check to: Polio Outreach of Washington, PO Box 1876, Kingston WA 98346 Please accept our gratitude for your generosity.



#### Mission Statement:

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

#### Polio Outreach of Washington

Lois Barber, Office Manager poliooutreach.wa@gmail.com

Mailing address: PO Box 1876 Kingston WA 98346

1-800-609-5538

www.poliooutreach.com

A quarterly publication

All POOW personnel are polio survivors or supporters and are non-paid volunteers.

### **Board of Directors**

PRESIDENT - Sue Warren 509-896-5333 q3suz@embarqmail.com

VICE PRESIDENT - Jim Fry 425-398-6994 frydaze3@comcast.net

SECRETARY - Scott Stahr 425-883-7951 RSSTAHR@gmail.com

TREASURER - Vacant

# **Board Members at Large**

Lois Barber, Linda Fry, Bob Miller, Jim Limric, Suzanne Limric, Jan Stahr, Bill Vetters, Lauris Whitehead, Rhonda Whitehead

# Standing Committees 2009-2010

Financial: Sue Warren, Chair; Bob Miller

**Administration**: Jim Fry, Chair; Lois Barber – Office Manager

Outreach: Rhonda Whitehead, Chair and Support Group Assistance, Bill Vetters – Website, Suzanne Limric – Medical Referral List, Linda Fry – Newsletter

**Events**: Vacant

#### SUE SAYS...

Sue Warren, President



Hi!

It was so nice to see so many people at the picnic! With us being so spread out over the state, it's really wonderful to get a chance to visit. But, of course, the picnic also means that our summer has pretty much gone, and it seemed extra short this year to begin with!

October 19th, a Tuesday, we will be meeting at the Holiday Inn off I-5 in Everett, WA, for our Fall Business Meeting. This is the meeting where we hold elections for Board members, who then chose the officers. I'm hoping to see many of you again at this meeting! ;-)

My term as President will be ending in October, and I will not be running for the Board again. I will continue to 'advise' for one year as stated in our By-Laws. As a Board member and as an officer, I have served a bit more than 5 years with Polio Outreach. I have thoroughly enjoyed my service. While I wasn't able to accomplish everything I had on my agenda;-), I hope that I have been a benefit to Outreach.

I want to encourage all of you to continue being involved with Polio Outreach. Share stories, and tips, don't forget to share your jokes and your positive outlooks! Be willing to volunteer with your Board and your support groups - many hands make light work ;-)

Fall is usually the time in which we make our appeal to our members to remember Polio Outreach

**Polio Outreach of Washington Disclaimer:** It is the intention of Polio Outreach Of Washington to make all the information we collect available regardless of our views as to its content. We do not accept liability for any damage resulting directly or otherwise from any error introduced in the transcription, or for any damage resulting directly or otherwise from the information available herein. The opinions expressed in this newsletter are those of the individual writer and the inclusion of a document in this newsletter should not therefore in any way be interpreted as an endorsement or approval.

Articles and portions thereof request permission to reprint from Polio Outreach Of Washington Newsletter Editor, Linda Fry, or President, Sue Warren.

with their financial support. Polio Outreach is a registered 501 (c) (3) charitable non-profit organization, making any donations tax deductible to the full extent of the law on your tax returns. Please keep copies of your donation checks for your receipts. Your donations also are critical to the continuance of our outreach through the newsletter, website, support groups, the picnic.... so I thank you in advance for your support and caring.

With the changes that are coming we have already changed Outreach's mailing address. All correspondence, invoices and donations should be mailed to:

Polio Outreach of Washington PO Box 1876 Kingston, WA 98346

Our 800# will stay the same as always 800-609-5538. Lois Barber, our wonderful Office Manager will still be available for questions and information. ;-)

As with so many of us, I have to make some changes in my life. I've been having significant increasing weakness in my legs, so my children and I have agreed I need to move a tad closer to civilization! ;-D So as soon as I return from the meeting, I will finish packing my belongings and move about 60 miles closer to my doctors, family (and grocery stores!) For a short time I will be 'disconnected' from phones and internet, but as soon as I'm back on the grid I will let people know.... I'm going to miss the quiet, and the great people of Bickleton, but not the long drive to the grocery store! I will still plan on coming to the annual picnic, and of course to meetings when I can.

Have a GREAT day, week, Fall, life!! ;-D

Sue Warren



This is the time of year in Polio Outreach of Washington when the Board of Directors are elected to serve as managers of the affairs of the corporation. According to the by-laws there shall be a minimum of four and a maximum of twelve directors, elected from the individual membership. The term of the directors shall be two years with one half of the directors elected each year. Many times a director will volunteer to remain on the Board for additional terms. The Board of Directors appoints the officers from its members. No director shall serve in the same capacity for more than two consecutive terms *unless directed by the board of directors*.

It is with heartfelt appreciation that recognition is due for the commitment and unselfish service that our current Board of Directors and outgoing officers have displayed this past year.

# Polio Outreach of Washington Post-Polio Support Groups

Please contact the group leaders for further information.

#### **Asotin County: Tri-State Polio Pals**

4th Saturday, 1:00 PM to 3:00 PM Tri-State Hospital. Jim Hueston, 509-758-2187, rockinnj@cableone.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: Polio Outreach of North Central Washington**

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

#### **Kitsap County**

3rd Saturday of every odd month 1:00 - 3:00 pm Bob and LouAnn Miller,360-692-1381 rmiller@wavecable.com

#### **Pierce County**

1st Monday 1:00-3:00 pm TACID Bldg-Tacoma No meeting January or July. Apr.,Aug.,Dec. potlucks 11:00 am Marlys Tron, 253-863-9556 Sandra Morley 253-752-6176

#### **Snohomish County & North King County**

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

#### South King County: website:renton-postpolio.info

3rd Saturday of each month noon to 2:00 pm - potluck Mimi Sangder 206-725-8937, fuzzface7@juno.com

#### **Spokane County**

1st Tuesday of every third month at 6:30 pm. Shriners Hospital in the 5th floor auditorium, Sharman Collins 509-448-8517 or sharmanrcollins@msn.com

#### **Whatcom County**

Patrick Ewing 360-966-4253 pre47airstream@aol. com

Note to support group leaders: Please notify the newsletter editor of any contact information or meeting changes for you. Thanks!



**Pierce County: Tacoma Group** welcomes visitors and new member to meetings this Fall...

October 4- guest speakers from TACID and Pierce County Human Services

November 1 - Bake Sale / Book Exchange

December 6 - Holiday event with music, potluck and raffle.

**www.renton-postpolio.info** The place to learn about what the Renton post-polio support group has been up to and is planning. Links to other websites.

www.poliooutreach.com The place to find medical information, resources, support groups and more...



# Happy Birthday to Jeanne Jordan

October 9 is the day to greet Jeanne Jordan with special wishes! She is exhilarated to be celebrating her 90<sup>th</sup> birthday. It is said about Jeanne that she enjoys life, is not a critical person, does not complain, and takes no medication. She is a true inspiration to fellow polio survivors who have been told that their life span may be decreased because of having had polio. Jeanne is *living* proof that this may not apply to everyone! She is a member of the Pierce County group and has attended the past two annual picnics. Jeanne resides at Harborview Manor in Tacoma. Congratulations, Jeanne!



## **PLEASE TAKE NOTE:**

#### **Breathing & Sleep A Free Symposium**

#### Sunday November 21, 2010 9:00 am to 2:30 p.m.

Defining neuromuscular breathing basics and empowering people with PPS, ALS, and muscular dystrophy to better participate in their own care.

#### Salk Institute for Biological Studies

10010 North Torrey Pines Road La Jolla, CA 92037 | 858.453.4100

#### Presenters include our own:

#### Joshua Benditt, MD, FCCP

Northwest Assisted Breathing Center University of Washington Medical Center Seattle, Washington

#### Louis J. Boitano, MS, RRT, RPFT

Northwest Assisted Breathing Center University of Washington Medical Center Seattle, Washington

For more information go to www.salk.edu/breathingandsleep



#### WE ARE GOING GREEN...



Reading the newsletter on the website, **www.poliooutreach.com**, or having it sent to your e-mail address saves Polio Outreach the cost of printing and mailing it to you. If you would be interested in not receiving the newsletter by mail, simply call the office manager, Lois, at 1-800-609-5538 and let her know!



**Books Available in the POOW office: (cost is \$10.00 each)** 

3 copies of <u>The Survivor Personality</u> by Al Siebert, Ph. D. 6 copies of <u>Post-polio Syndrome</u> by Julie Silver, MD & Anne Gawne, MD



### ANNUAL PICNIC A BIG SUCCESS!

The 14<sup>th</sup> annual Polio Survivors and Supporters picnic, held on August 22<sup>nd</sup> at the Auburn Game Farm, turned out to be one of the best attended events of POOW! We had a crowd of about 90 people present and thoroughly enjoying the day. Not only was Washington State well represented with representatives from most of the organized groups in our state, there were also visitors from Oregon who expressed interest in having their own polio support organization in their state. We even had two special guests from Florida, but more about them later.

The weather this summer has been so unpredictable, and so it was that day. The chosen day, following one that saw high temperatures in the 90's, was on the cool side, and we didn't have to worry about the glare from the sun for most of the day, but we stayed dry. The weather certainly didn't dampen the spirits or the appetites of those enjoying the KFC catered lunch, meeting and greeting friends. The conversation was very lively and fun for all. In addition, there were a good variety of donated items for the raffle and door prizes to be given out to the lucky winners.

We were honored to have three distinguished celebrities with us this year. The three shared the "stage" to give us a wide variety of informative, educational, interesting and really fun discussions and talks. All polio survivors themselves, these speakers were wonderful to have.

Our first speaker, Barb Gratzke, treasurer of the International Post Polio Support Organization, gave us some real insight on what is happening nationally on the Post Polio front. She and her husband travelled to our corner of the world in their fully accessible motor home all the way from Florida. We were indeed fortunate to have these two great polio support workers join in the camaraderie and also be part of the program.

Peg Kehret, internationally known and highly decorated author of more than 50 books, was our second speaker. It was truly an honor to have Peg speak to us. While most of her books are children's books about a large variety of subjects that children understand and love, she has written one terrific book, Small Steps, about her experiences with polio when she was a young girl. This moving story will bring back many memories to polio survivors as she struggles through the physical and emotional trauma so many of us understand. Peg's book has received many honors and has been read by millions. It is a very worthwhile book for all of us to read. Peg is at this time collecting as many polio stories as she can find, compiling them so they can be remembered into the future. It was terrific to have a speaker of this status at our picnic.

Finally, we were entertained with the very funny presentation by Debbie Wooten. Returning to our picnic to tell of her recent adventures in her hilarious style was great fun. Debbie makes sure we all feel a bit more comfortable about ourselves when she tells of some of her adventures with her post polio. Debbie has become a well known comedienne over the years, even being considered for America's Got Talent. We always appreciate having Debbie coming to our picnics.

The entire Pierce County Support Group, under the leadership of Marlys Tron, deserves our applause of gratitude for planning and preparing such a special day for us all. Thank you to all who helped to contribute to the success of the picnic, to all who sponsored the picnic with donations of prizes and cash (Sumner Rotary gave a gift of \$300 to help with the picnic expenses) and to all who attended. A good time was had by all!

Be sure to watch for information on next year's picnic and mark your calendar when the date is set. You surely would not want to miss a single one of these fun events.



Peg Kehret,
author and speaker
with
Maryls Tron
picnic chairperson

"I'm proud to be a polio survivor. I hope all of you are proud, too.

We had - or have- one of the most devastating diseases ever, yet we've coped and overcome and carried on, with humor, grace and plenty of determination. I say, hooray for us! Let's celebrate our accomplishments, cherish our family and friends, and look forward to the day when polio will be eradicated from the earth."

I enjoyed chatting with everyone at the picnic. Thanks again for having me.

Peg



Debbie Wooten, comdienne



#### EXERCISE TIPS ON POST-POLIO

Post-polio is *not* a flare-up of the polio virus. The symptoms are thought to be due to overusing the surviving nerve cells that have been doing double-duty. Post-polio syndrome can include a variety of symptoms including: generalized joint and muscle pain, severe fatigue following moderate activity, muscle weakness and loss of muscle use.

The key word connected with Post-polio is "Overuse". Post-polio sufferers should never overdo their activities. Research indicates that exercising three times a week is best, starting out slowly and using three to six repetitions. Using a set of muscles then taking a break using different muscles, then back to the first set is helpful. Since overuse of the shoulders is a common problem among sufferers, a chair with an armrest helps so shoulders don't have to support the weight of your arms.

Remember, Post-polio sufferers must use twice as much energy to activate muscle, so the muscle fatigues more easily. ALL exercises are an overload for sufferer. The muscles will never be normal. But sufferers can use these muscles as long as they don't fatigue themselves.

#### EXERCISE GUIDELINES FOR POST-POLIO SYNDROME

- 1. Check with a post-polio clinic for analysis of muscle strength and exact guidelines specific to the results of your test.
- 2. Only muscles that test Grade 4 or 5 muscles should be considered for exercise.
- 3. Five (5) repetitions at 50% 70% of capacity.
- 4. Lifestyle considerations.
- 5. Avoid anything that causes pain or fatigue that lasts 10 minutes or longer.
- 6. Find the delicate balance between: atrophy from disuse, and destroying muscle units from overuse.
- 7. Simplify and make everyday tasks easier.
- 8. Upper extremity overuse problems are common in polio survivors. Save your shoulders: reduce reaching, support your arms, and bring work up to you.
- 9. Take pressure off shoulders: bend your elbow; bring you arm and hand closer to your body.
- 10. It is important to grieve the loss of the things you can no longer do.
- 11. Know *your* limits.
- 12. Manage your time and energy to accommodate limitations.

Suggested SIT AND BE FIT videos for Post-polio:

Arthritis Specialty Video -- good because it is slow, with a low number of repetiions

30 Minute Workout

Tone and Stretch I

Tone and Stretch II

Disclaimer: These videos are in no way intended to replace or provide medical advice. Please ask you health care provider for specific exercise guidelines for any medical conditions that you may have.

These guidelines and tips were taken from information provided by SIT AND BE FIT<sup>TM</sup> P.O. Box 8033 Spokane, WA 99203-0033 Tel: (509) 448-5078 Email: sit.and.be.fit.com www.sitandbefit.com

# ROTARY INTERNATIONAL EXPOSES THE WORLD TO POST-POLIO SYNDROME

A champion of global eradication of polio, Rotary International is bringing about world-wide attention to the eradication of polio as well as fostering an understanding of post-polio syndrome as is shown by the following excerpts from the September issue of "The Rotarian" magazine. These articles, in their entirety are available in the September issue of the magazine, or online at Rotary. org . Look for the tab "Media and News", click on Past Issues.

# Working together to improve global health

By Ryan Hyland, Rotary International News -- 17 September 2010

To increase awareness of the Global Polio Eradication Initiative (GPEI) and its successes, Rotary International organized a workshop held 30 August at the United Nations Department of Public Information/Nongovernmental Organization Conference in Melbourne, Australia. More than 2,200 representatives from nongovernmental organizations (NGOs) in 70 countries took part in the three-day conference, which aimed to build support for improving global health and achieving the UN Millennium Development Goals.

Rotary's workshop, "Coordination a Public-Private Public Health Campaign: The Global Polio Eradication Initiative," was moderated by Rotarian Jenny Horton and featured presentations by Bruce Thorley of the World Health Organization and Lieven Desomer of UNICEF.

Horton said the workshop emphasized how GPEI programs have increased routine immunization, helped with the development of disease surveillance systems, and provided a structure that has benefited other disease interventions. "Seeing and hearing just what is being done about polio eradication by many NGOs was amazing," she said. "Looking at the bigger picture to build partnerships to achieve a goal and ensure community participation is the best way to achieve the best outcome."

A registered nurse and volunteer for Stop the Transmission of Polio (STOP). Horton has led polio surveillance activities and immunization campaigns in Botswana, Ethiopia, India, Nigeria, and Pakistan.

## Polio's second act

By Kate Nolan, The Rotarian -- September 2010

...postpolio syndrome, a set of debilitating symptoms that strikes survivors at least 15 years after they've had the disease. As many as 55 percent of an estimated 775,000 polio survivors in the United States may be at risk of developing it. "We'd see more support for polio eradication if people understood the long-range effects of the disease," says Ann Lee Hussey, chair of the Rotarian Action Group for Polio Survivors and Associates. Like many Rotarians who are polio survivors, she is a strong advocate for Rotary's US\$200 Million Challenge. "There are many polio survivors who serve as their district PolioPlus chair and are active in fundraising. I traveled to Hong Kong for an event that raised \$250,000."

Many people have not heard of postpolio syndrome. Compared with the 20th-century epidemics that spawned a national movement in the United States led by President Franklin D. Roosevelt, it's an understated illness. Many patients who have postpolio syndrome – an under-diagnosed, under-researched condition without broad-based advocacy from patients – don't even know it's related to the disease.

It has been 26 years since postpolio syndrome was identified, but often doctors don't know how to diagnose or treat it, Hussey says. Because polio is viewed as a conquered disease in the United States, its aftermath has been relatively unexplored in the research and in medical schools. (*continued on page 10*)

(continued from page 9)

Post-Polio Health International, a St. Louis group that works closely with the Rotarian Action Group, addresses the dearth of information through a network on its website, www.post-polio.org. It connects patients with each other and the few health professionals experienced in treating the condition.

Most of the people who lived through the U.S. polio epidemics will die in the next 40 years – a fact that may offset the irony that the final phase of the most studied virus in history now gets modest public notice. But even greater resources may be needed in the future, as a new tide of potential patients rises in the developing world. "They're going to have horrible lives. Who will address their pain and mobility issues?" Hussey asks. Some work continues. The John P. Murtha Neuroscience and Pain Institute in Johnstown, Pa., is exploring nonfatiguing exercises and stress-reduction behaviors at its polio-survivors clinic. Studies in Canada, France, Norway, and Sweden show that the immune system may have an influence on postpolio syndrome, and interest in a long-term U.S. clinical trial to replicate them is growing. Research may lead to a gamma globulin shot to reduce symptoms.

"It is just now becoming an issue in India, and it will be eventually in all areas of the developing world as the average lifespan increases," says Hussey, of the Rotarian Action Group. While Rotary's eradication efforts have dramatically slowed the rate of polio infection, the World Health Organization estimates that survivors number between 10 and 20 million worldwide. "Long after the last polio case, postpolio syndrome will persist as a significant personal, social, medical, financial, and political challenge," Hussey says.



#### Be Thankful

Be thankful that you don't already have everything you desire, If you did, what would there be to look forward to?

Be thankful when you don't know something For it gives you the opportunity to learn.

Be thankful for the difficult times. During those times you grow.

Be thankful for your limitations
Because they give you opportunities for improvement.

Be thankful for each new challenge Because it will build your strength and character.

Be thankful for your mistakes They will teach you valuable lessons.

Be thankful when your're tired and weary Because it means you've made a difference.

It is easy to be thankful for the good things. A life of rich fulfillment comes to those who are also thankful for the setbacks.

GRATITUDE can turn a negative into a positive.

Find a way to be thankful for your troubles and they can become your blessings.

~Author Unknown~



#### 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)

| First contact with Polio Outreach of Washington. |
|--|
| ☐ Name and/or address change.                    |
| ☐ Donation(Includes newsletter) \$               |

| First Nam | ne .   | Initial | Last Name   |
|-----------|--------|---------|-------------|
|           |        | at      | Last Haille |
| Mailing a | ddress |         |             |
| City      | State  |         | Zip code    |
|           |        |         |             |

Please make checks payable to: Polio Outreach of Washington. Mail your check and completed form to: PO Box 1876, Kingston, WA 98346



# Happy Holidays to All



- 1) You believe in Santa Claus.
- 2) You don't believe in Santa Claus.
- 3) You are Santa Claus.
- 4) You look like Santa Claus.



#### **Newsletter Deadline:**

The deadline for the next issue of POOW newsletter is November 29. We appreciate any articles, information or suggestions for items you would like to see printed in this publication. Please send an e-mail with that information to me at: frydaze3@comcast.net

Thank you! Linda Fry, Editor

#### Polio Outreach Of Washington, a 501(c)(3) Non-Profit Corporation



PO Box 1876 Kingston WA 98346

**Return Service Requested** 

NON-PROFIT ORGANIZATION U.S. POSTAGE PAID

PERMIT NO. 2169 Seattle, WA

# What's Inside

| Board of Director News  | 2  |
|-------------------------|----|
| With Appreciation       | 3  |
| Support Group Locations | 4  |
| Salk Symposium          | 5  |
| Pícníc Review           | 6  |
| Pícnic Information      | 7  |
| Exercise Tips           | 8  |
| Rotary and Polio        | 9  |
| Be Thankful             | 10 |
| Donation Form           | 11 |

## Calendar

Our website is now ready for you! www.poliooutreach.com

October

19 - Fall Membership Meeting ~ begins new term of officers

~fundraising awareness month

~new mailing address

November

~ Happy Thanksgiving

December ~ Enjoy the Holidays!

> MMX Twenty-ten

