

Polio Outreach Of Washington

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Spring 2010

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"Spring has returned. The Earth is like a child that knows poems.'

- Rainer Maria Rilke

'An optimist is the human personification of spring."

-- Susan T. Bissonette



"The beautiful spring came: and when Nature resumes her loveliness, the human soul is apt to revive also. '

-- Harriet Ann Tacobs

Purple Ribbons

You know when you see a pink ribbon, it is in support of breast cancer survivors and when you see a yellow ribbon, it is in support of our troops. The Board of Directors has recently agreed to adopt the color purple ribbon to be representative of Polio survivors and their supporters. Our office manager, Lois Barber and her husband Stan, have done all the work and research into obtaining ribbons for us. There are two available: one with gold lettering for polio survivors and the other with white lettering for polio supporters. The ribbons are for sale for \$4.00 each. You may contact Lois at the office phone 1-800-609-5538 or by email poliooutreach.wa@gmail.com. There will be a good supply for purchase at the statewide picnic in August. Additional research is being done to obtain magnetic ribbons that can go on metal surfaces such as cars, wheelchairs, scooters, etc. Look for more information about this as we learn about the availability and cost.



"Every spring is the only spring.

Polio Outreach of Washington

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

Mailing address: PO Box 165, Bickelton WA 99322

1-800-609-5538

www.poliooutreach.com

A quarterly publication

Mission Statement:

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

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

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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



I hope you're looking forward to Spring as much as I am! ;-) I'm so envious when I go down to the valley and see all the tulips and lilacs and fruit trees in bloom! In Bickleton, we've actually had a couple of days about 50, but two weeks ago we also had three episodes of snow/hail - so I'm trying to contain my impatience to begin planting! ;-/ ;-D

On Tuesday, April 13th, Polio Outreach had its Spring Members/Business Meeting. There were about 20 members, leaders and Board attending. Some of the main topics on the agenda were an annual budget for the fiscal year that began on April 1st, and our annual audit of the financial books. We also discussed our annual picnic (Sunday, August 22nd) and the search for candidates for the Fall elections.

In preparing the budget, the goal is to be realistic, especially in these turbulent economic times. But there are expenses that must be met. We maintain an 800 phone line, so that anyone can call for information regarding Post Polio, be added to our data base to receive the newsletter and an information packet, ask questions and be put into contact with a Support Group Leader if possible. Of course our newsletter is our most obvious outreach to survivors and supporters, and is the major expense

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of our organization. We have also developed a website [www.poliooutreach.com] that people can go to for articles, links, and our start at archiving the past newsletters. All the labor involved is volunteer, but it still costs to print, mail and maintain the phones, newsletters and website.

Donations to POOW help us locate polio survivors and offer information and support group contacts, educate the medical field about specific needs, and remind the public that 'we are still here'. I want to give a huge 'Thank You' to everyone who has been so faithful in supporting Polio Outreach. Every dollar helps, and spending is carefully considered and scrutinized.

Every Spring Business Meeting, because it usually occurs shortly after our fiscal year end, a financial review is conducted by an independent committee comprised of members of Polio Outreach. This year the committee was headed by Larry Julius [Olympia area] and Carl Larsen [Everett Support Group]. Larry recently retired from the State of Washington, as a financial manager for DOT, and is a retired CPA. Carl, of course, is one of the founding members of Polio Outreach and still remains active with his support group and input to the Board. Due to time restraints, there is still some work to be done to finish the audit [expenditures were examined and signed off on, income records still need to be finished], and that is planned for when we get together at the picnic. Larry invites anyone [not involved in the regular financial responsibilities] who is interested in helping, to be on the committee. There is no requirement to know accounting.

Our Fall Members/Business Meeting was set for Tuesday, October 19th, so please keep that day open! ;-) Place is to be announced. We will be holding elections for the Board, and hope you can join us and consider serving a term.

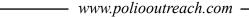
I look forward to seeing you at the picnic ("Lord willin', and the creek don't rise", as my grandmother always used to say!)

Have a wonderful Spring!

Sue Warren

Nominations for Polio Outreach of Washington Board of Directors

It's that time of the year when we begin to look toward the Fall and annual elections of our state leaders. Consider how you can help to promote finding and educating the polio survivors and their supporters in the state of Washington. Board positions are a two year minimum commitment, reviewed each term. There are two Board meetings scheduled each year, which Directors are expected to attend. Please think about your participation in this organization. Contact Jim Fry, Vice President of the Board, for more information or to place your name in for nomination.



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 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 County

3rd Monday 5:00 - 7:00 pm City Side Cafe in Red Lion, 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 & 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 sharmancollins@msn.com

Whatcom County

Last Saturday of odd-numbered months Noon to 2:00 pm. Bellingham St. Joseph Hospital. 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!



Attention: South King County Group Change of Location

The South King County (formerly Kent Renton Support Group) has moved from Valley Medical Center to First Evangelic Presbyterian Church located at 19800 108 Ave SE; Kent. We meet the 3rd Saturday except April 2010 from noon to 2:00pm - Potluck. Mimi Sangder 206 725-8937, fuzzface7@juno.com

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...

ASOTIN COUNTY GROUP UPDATE

Jim Huetson is the group leader of the Asotin County Post Polio Support group which meets in Clarkston, Washington. Jim wrote the following about the group and himself:

"Clarkston is a city on the Washington - Idaho Border. I moved here from Everett where I had attended the Everett Group. There was no group here so I started one. We named our group the Tri-State Polio Pals when we started the group 12 years ago. We named it the Tri-State Group so that Oregon was included but have never had anyone from there attend. Our members are from Washington and Idaho. Some of our members must travel 40 to 60 miles to attend. As we <u>mature</u> we are losing some of those who can no longer make it out to the meetings. It is kind of sad as every one of them is a wonderful person. I have no one groomed to take over this group when I am taken.

I am 77 years old and one of the junior members (Heck, I don't even buy green bananas anymore.). Polio never set me back an inch after my recovery at the Idaho Elks Treatment house in 1945-1946. I hid my disability well enough to serve in the USAF and when I came out I tried to be a Telephone Lineman but my bad leg wouldn't take the strain. The company was kind enough to give me an inside job around which I made my first career. When it terminated I was a Community Service Officer for the Snohomish County Sheriff's Office for my second career. However, being a senior citizen is kicking my fanny. Every day I groan my way through the first half hour and spend the rest of the day thanking my creator that I am still here and able to be of some service. I would love to be able to attend the get-togethers on the west side of the state, but I just cannot make such a long trip anymore".

If you are in the Clarkston area and wish to visit this group, contact Jim for details about the Asotin County Group.

Happy 6th Anniversary to Kitsap County Support Group!

May 15th marks the day that this group was founded in 2004 by Luanne and Bob Miller.



A Spring Pangram

(A pangram is a sentence that contains all the letters in the alphabet) "Back in my quaint garden jaunty zinnias vie with flaunting phlox."

Books Available in the POOW office:

4 copies of <u>The Survivor Personality</u> by Al Siebert, Ph. D.

6 copies of Post-polio Syndrome by Julie Silver, MD & Anne Gawne, MD

WENATCHEE WORLD PUTS POLIO SURVIVORS IN THE NEWS

(Note of interest: Trina Adams, Don Hinman and Carol Hinman are all active attendees of the Douglas County Post-Polio Support Group)

The Disease We Dare Not Forget

By Tracy Warner

Friday, April 2, 2010

Most people know almost nothing about it. They have grown up in a world virtually free of the disease. They don't know the fear of an epidemic, when in a matter of weeks an infectious disease can paralyze hundreds of people in one small community, most children. They haven't seen every ward in the local hospital filled with people trapped in machines called iron lungs, wheezing and gasping as the gears and levers move their paralyzed chest. They haven't seen the aftermath, the children in leg braces or wheelchairs after weeks or months in the hospital, hoping they might walk again.

Most of us have forgotten about the epidemics of the early 1950s, forgotten about polio — poliomyelitis, aka infantile paralysis — but there are people in Wenatchee who can't. They live with its effects every day. Some of them remembered their ordeal Thursday at a meeting of the Wenatchee Rotary. Rotary is in a campaign to raise \$200 million for its longstanding worldwide effort to eradicate the disease.

Don Hinman was 23, just out of the service, working at Alcoa, when he came back from a hunting trip feeling tired. Then, he was more tired, and every nerve in his body felt like it was exploding. "I was so weak I couldn't even go up one step." He spent 59 days in Deaconess Hospital. He still walks with crutches, and says he feels fortunate. His wife Carol (she and Don met at a polio survivors' picnic in Ellensburg in 1998) was a child in Wenatchee during the epidemic in 1953. She felt like she had a cold, a fever, then pain in her legs and arms — "a lot," she said. Her father had to carry her into the hospital.

Karen Lunt was 6 when polio struck her father. She remembers the ambulance attendant who said, "I hope we can get him there in time." Then, in Seattle in 1952 she was 10 years old. "I said my legs really hurt." Her mother said it was growing pains. It was not. She spent weeks, months in Children's Hospital and recalls being alone at night, singing to herself the song from the musical "Carousel" — "You'll Never Walk Alone." Eventually her paralysis subsided.

Trina Adams was a former Apple Blossom queen, who had one polio vaccine and was due for a booster when she was struck in 1958. She spent 9 1/2 months in Deaconess Hospital, not leaving until her son Mark was born. She contracted the disease when she was two months pregnant. Now she persists with the help of her family, a motorized wheelchair and her beloved service dog Eon.

The worst year in Wenatchee was 1952. There were 171 polio patients received at Deaconess Hospital. Eight died. Across the state there were 1,320 cases. Polio is caused by a virus, often spread through water. Only five in 100 develop symptoms, most of those flu-like, Ford Barrett told the Rotarians. One in 100 are paralyzed.

"It was a real epidemic," recalled Deaconess physical therapist Carmen Bossenbrock. Polio would lock muscle fibers. They had to be stretched or be forever frozen. That was her job, but it was long-term agony for the patients. They still speak of the "torture" even in their gratitude for Bossenbrock's persistent efforts. "I'm so glad we haven't had to fight this in recent years," Bossenbrock said.

The turning point was 1955. A vaccine developed by Dr. Jonas Salk, the result of a massive national fundraising campaign called the March of Dimes, became available. Later came an oral vaccine developed by Dr. Albert Sabin. It was a great medical miracle. The disease has disappeared from the Western Hemisphere and the developed world. It persists in pockets of poverty — in India, Africa Asia. Rotary has set the goal of eliminating it entirely.

When the Rotary worldwide anti-polio campaign began, there were 350,00 cases worldwide. Now it is conceivable the disease could be wiped out. The effort has been called one of the greatest private health initiatives ever. It started in 1985, instigated in part by Dr. Ed Cadman, the new president of Rotary International, who saw the impact of polio firsthand in that terrible year of 1952 as an attending physician at Deaconess Hospital in Wenatchee.

The effort is not finished, but close. Don't forget.

Tracy Warner's column appears Tuesday through Friday. He can be reached at warner@wenatchee-world.com or 665-1163.

MAKE RESERVATIONS FOR THE ANNUAL PICNIC

The Tacoma/Pierce County Support Group is planning a-better-than-ever event for the Annual Polio Survivors and Supporters Picnic to be held Sunday, August 22, at the Auburn Game Farm Park. There will be a catered chicken picnic lunch for \$10 per person. Your reservation and money are needed ahead of that day in order to have enough food available. There will be entertainment, door prizes, a raffle as well as games. More details will be in the July newsletter...but we would like to start having reservations made now. Please invite your family and friends, then let us know how many will be there!

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

PICNIC RESERVATIONS

Please RSVP by August 13, 2010

Your name
Your Phone
Total reservations
Total amount (\$10 ea. person)

I/we plan to attend but choose not to purchase a lunch:

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 endo Howard Rd, turn right onto R Street

4. At the endo Howard Rd, 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.

Make your check payable to POOW.
Return this information to: POOW
PO Box 165
Bickleton WA 98322

Walter C. Stolov, MD

By Paul Jeganathan Snohomish/North King County Polio Support Group.

Dr. Walter C. Stolov joined the University of Washington School of Medicine in 1960, which is just a year after UW Hospital admitted its first patient in 1959. He will retire in June 2010. Prior to joining UW Hospital, Dr. Walter C. Stolov worked as a physicist at the United States Naval Gun Factories. He has a master's degree in physics to his credit. Deciding on a career change, he obtained his M.D. from the University of Minnesota Medical School in 1956. He was a resident in Physical Medicine and Rehabilitation at the University of Minnesota Hospitals under a National Foundation Fellowship, from 1957 until he joined UWMC in 1960. During his illustrious career at UWMC spanning close to six decades, he has served in various capacities and has established advanced clinical programs. He has written several publications and books and has received national recognition. He is the recipient of numerous awards.

I have been a patient of Dr. Stolov for the past 15 years. I am thoroughly impressed by the confidence with which he treated me. Beneath his tough exterior, he is a doctor with genuine concern and care for his patients. Let me explain this by sharing my personal experience. As a polio survivor, I have been using crutches since 1946. This prolonged use of crutches had taken a toll on my arms. I was experiencing excruciating pain in arms and consulted Dr. Stolov. After examining my elbow and shoulder joints, he suggested that I stop using crutches in order to make my arms last for the next 15 to 20 years. This transition required other changes such as making the house wheelchair accessible, buying a van, etc. At that time, I was not prepared to tackle these issues. Therefore, I ignored his advice and kept using crutches. A few years later, with the pain in my elbow becoming worse I went back him for care. He gave me an intense stare, held my shoulder and said, 'Four years ago you chickened out. Now I won't let you go". I did not bother explaining why I chickened out. However, following his advice and switching from using crutches to using a motorized wheelchair saved my arms. Thanks to Dr. Stolov!

The Polio Outreach of Washington wishes Dr. Walter C. Stolov a happy retirement!

Some Thoughts About Polio

The majority of patients seen in the Post Polio Clinics throughout the nation are those who contracted polio during 1950 – 56, the time of the last major epidemic before the vaccines were developed. The current age range of the group, assuming polio was contracted before age 25, is 54 to 85 years of age. There are now 6-7,000 people from this group in the state of Washington.

The concerns expressed by these patients in almost all of the cases center around a decrease in function compared to function skills they achieved two to five years after the attack, sometimes up to 10 years later. The function decreases experienced for some began to occur about 20 or more after initial attack.

The areas of function that are diminished might include walking, stair climbing, posture maintenance, transfer skills (e.g. getting out of bed, on and off chairs), personal hygiene skills (e.g. bathing, toileting), dressing skills, eating skills, swallowing, breathing, avoidance of falls, and performance of responsibilities at home, work, school, and the community. The symptoms associated with these function losses can include fatigue, reduced endurance, pain, and a perception of weakness.

The cause of the function losses is multifactorial in most patients. These factors include: (1) the severity and location of muscles completely or partially paralyzed; (2) the degree of joint destruction and deformity secondary to the lost muscle strength at the joints, particularly at the knee, ankle, foot, hip, shoulders, hand and spine.

Additional factors include diseases acquired over time that are not directly related to the original polio but which can magnify the functional losses. These factors include: (3) thyroid disease, (4) heart disease, (5) pulmonary disease, (6) cancer, (7) diabetes, (8) other neurological and muscle diseases, (9) osteoarthritis, (10) significant weight gain, (11) stroke, (12) the effect of injuries, and (13) depression. For some patients, the polio residual is not the primary factor in causing function losses and associated symptoms.

A major additional factor contributing to the development of function losses is: (14) the normal aging process that begins at about age 25 to 30, and affects all of us whether we had polio or not.

The effect of this aging process for those with significant polio muscle weakness can lead to a profound effect on these muscles causing added function loss. The explanation for this is as follows.

The nerve fibers that cause muscle contraction originate in the spinal cord. Each muscle is served by many of these nerve fibers. Within a muscle, many individual muscle fibers attach to each individual nerve fiber. The number of nerve fibers per muscle and number of muscle fibers that are attached to each nerve fiber varies with the size and location of the muscle.

In acute polio, the virus attacks the cell bodies of the nerve fibers. Some escape the attack, some cease to function but then recover and some die. Therefore the muscle involved can end up totally paralyzed, partially paralyzed or fully recover. The partially paralyzed muscle ends up with less than the normal number of nerve fibers and hence less working muscle fibers. It is this group that is affected by the normal aging process.

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The normal aging process causes all of us to lose about 1% of the nerve fibers to a muscle per year. In a partially paralyzed muscle that already has a reduced number of nerve fibers, such additional losses can lead to a reduced ability to perform ordinary daily functional activities, and the appearance of fatigue and pain when performing activities that were not fatiguing or painful before.

The therapeutics used in post-polio clinics vary from patient to patient, but all are directed at reestablishing or delaying the losses in the functions enumerated above. The therapeutics may include:

- 1. bracing as needed to substitute for weakened muscles or correct deformity with appropriate design, fitting and training
- 2. appropriate prescription of walking and ambulation aids
- 3. suggestions to modify the environment to reduce energy costs of an activity
- 4. surgery recommendations for some deformities
- 5. referrals to other specialists to decrease the influence of non-polio related diseases
- 6. education about what polio is and what it is not
- 7. teaching a maintenance home-performed active range of motion, a stretching program, and aerobic conditioning
- 8. exercise to strengthen muscles that were not involved initially may be prescribed

Strengthening polio involved muscle should usually not be done as they are likely to be already at maximum strength. Such exercises may enhance fatigue. Any exercise that produces fatigue should be avoided or performed at a lower intensity. Any activity that one enjoys except for the fatigue that occurs can usually be managed by interspersing short rest periods and then resuming.

The polio group from the 1950's is a proud bunch. They have been highly productive. They have great pride in the fact that they "beat polio". They understandably are disappointed to find out that the polio is still with them. As long as they maintain their focus on function and come in time to worry less on how they now need to do some things differently, they will be able to say, "I beat it a second time".

You may have noticed that I have not used the term "post-polio syndrome". I dislike it because it suggests a whole new disease, which it is not, and also implies that everybody with it are alike, which they are not. I prefer to say "post-polio, late effects as modified by the normal aging process and health status".

Walter C. Stolov, MD Professor and Chair Emeritus Stepping down Director of the UWMC Post Polio Clinic University of Washington Department of Rehabilitation Medicine Seattle, WA

Polio	Outreach	Of Wash	nington

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 Name	Initial	Last Name
Mailing addres	ss	
City	State	Zip code

Please make checks payable to: Polio Outreach of Washington. Mail your check and completed form to: PO Box 165, Bickelton, WA 99322



To all of our generous financial contributors who donate money to Polio Outreach of Washington to help in our effort to find polio survivors and to share our resources to educate and inform them, their support people and the medical community about living with the late effects of having had polio.

To all of you who thought about the polio survivors of the State of Washington, and others who read this newsletter, and took the time and effort to contribute articles, information and ideas for this issue of our newsletter!

Newsletter Deadline:

The deadline for the next issue of POOW newsletter is June 7.

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

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Calendar

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

May - Woodland Lílac Festíval and Garden Tour

June - POOW established (1996)

August 22 - Annual pícnic

October 19 - Fall Membership Meeting

MMX

