PARTNER WITH POLIO

We are in this together...

Dear Friends and Members,

Almost everyone knows someone - family, a friend - who has had polio. Most polio survivors are reaching ‘middle age’ or ‘senior status’, after contracting polio in the 1930’s, 40’s, and 50’s before there was a reliable vaccine. Many of these survivors are now exhibiting what is being called the ‘Late Effects of Polio’, or PPS- Post Polio Syndrome. Increased fatigue, muscle pain and weakness, additional functional disabilities are just a few of the new symptoms with which we are dealing.

Polio Outreach of Washington is currently the only organization in the State of Washington that provides education and resources to polio survivors, their support givers and medical professionals. We publish a quarterly newsletter with articles on up-to-date research, ‘what works for me’ and information to share with medical teams. Support Groups and events are listed in the newsletter and also on our new website www.poliooutreach.com.

Polio Outreach is a registered 501 (c) (3) charitable non-profit. All donations are tax exempt to the full extent of the law. We are 100% volunteer, making our administration/fund-raising and miscellaneous expenses less than 15% of our budget. That means over 85 cents of each dollar donated goes to programs for survivors. No one is denied a newsletter subscription for lack of ability to pay, nor do we charge for the information packets.

Our economy is very difficult right now, but we're asking you to Partner with Polio, so that we may continue to help polio survivors. We thank you in advance for your generosity.

Please send donation to: Polio Outreach of Washington, POB 165, Bickleton, WA 99322-0165

Sincerely,

Sue Warren
President, Polio Outreach of Washington
All POOW personnel are polio survivors or supporters and are non-paid volunteers.

SUE SAYS...

Sue Warren, President

Time passes so quickly...

I'm hoping that everyone is surviving all the crazy weather we're having, remembering to keep safe and warm and not to overdo in this hectic time of year!

This is the time of year that the Board and I begin looking at income vs. expenses and planning the Outreach budgets for our next fiscal year. At our Spring Business meeting, (currently scheduled for Tuesday, April 13, 2010 at the Paralyzed Veterans Admin. building in Burien) the proposed budgets will be presented to group leaders and members for review, amendments and approval. There is still time to submit ideas to be considered. I hope as many as possible will attend. If you plan on attending, please let your group leader know, so we can get an idea if we've reserved a large enough space.

The Board is still actively looking for a qualified person to assume the position of Treasurer. If you are interested in knowing more you may contact any Board member or email me at q3suz@embarqmail.com.

I wish to thank all the members who have so generously supported Polio Outreach, especially in the current economic difficulties. Without you we cannot continue reaching out to polio survivors. And we do get new inquiries every month.

(continued on next page)
This year, we are issuing our annual appeal for funding through our Winter Newsletter and also through our website. This helps keep our costs as reasonable as possible - we feel a very strong responsibility to use your donations to Outreach in an efficient manner. We want to be able to reach out to as many survivors and care-givers as possible!

Our Tacoma Support Group has volunteered to co-ordinate the 2010 Picnic. Marlys Tron, Group Leader, will be reserving space at the Auburn Game Farm in Auburn, WA, and will then let us know the date. We always welcome the opportunity to hold the picnic in different areas, so if YOUR group would like to attend 'nearer to home', now's the time to begin planning for 2011! ;-) We'd love to hear from you!

Have a safe and healthy winter!

Sue Warren

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SPRING MEMBERSHIP MEETING

April 13, 2010
9:30 am to 4pm (if needed)

Paralyzed Veterans Admin. Building
Burien, WA
Call a Board member for directions

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PLAN AHEAD – MARK YOUR CALENDAR NOW!

Polio Outreach of Washington
Survivors and Supporters Picnic

Sunday, August 22, 2010

Auburn Game Farm Park

Hosted by the Tacoma/Pierce County Support Group

Details about food, directions, cost, etc will be in the next newsletter and on the website.
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!

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February marks the 19th Anniversary of the Snohomish/North King County Support Group!

www.renton-postpolio.info The place to learn about what the 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...
Polio Survivors Go Surfing!

Here are the featured Websites for this quarter:

ARE YOU BREATHING OK, ESPECIALLY AT NIGHT??

One of the areas polio survivors may not consider when exploring causes of fatigue, is weakness of breathing muscles. This includes the diaphragm, chest, back and neck muscles. Breathing assistance at night may be of help to survivors, especially those who use auxiliary muscles to breathe, or who have had symptoms of lung weakness, such as numerous upper respiratory infections, or those who were in an iron lung. A web site that may be helpful, particularly in explaining neuromuscular diseases’ effect on breathing issues is: POLIOTODAY. ORG

This website is from The Salk Institute in California, containing videos and information regarding PPS. I was informed of this site by Louis Boitano (pulmonary tech at the University of Washington) who is in the video on breathing equipment at the November 2009 Breathing and Sleep Symposium held at the institute. For those of us polio survivors with breathing concerns, this site offers information that is new and helpful. In addition, Dr. Joshua Benditt is the neuromuscular pulmonary specialist Louis Boitano works with at the UW. I have seen several other pulmonologists over the years, and Dr. Benditt is by far the most knowledgeable about PPS.

I see Dr. Benditt and Louis Boitano at the "Neuromuscular Respiratory Failure Clinic" at the University Of Washington Hospital. Clinic phone number: (206) 598 - 4615.

Kathy Parrish, Everett Polio Support Group

Websites in Washington State by polio survivors:

www.danmillerspeaker.com Based in Yakima, Dan Miller is a former educator, full time speaker and author. He has a powerful message of overcoming polio to reach impossible dreams.

www.just2drops.com Denny Wilford lives on the Kitsap Peninsula and has established The Denny Wilford Foundation. Its mission is “to support the rehabilitation of persons affected by polio by raising funds for equipment, facilities and procedures for the treatment of disabled children and adults.”
Supporters And Survivors

Sharing Special Tools

Almost everyone has special tools they use when nothing else will do, whether it is a kitchen knife, a wrench, a pair of scissors, or a shovel. Caregivers are no different. There are special tools that will help them deal with difficult situations they may be confronted with. Many of these special tools are designed to be shared by both the caregiver and care receiver to their mutual benefit.

Not every caregiver will be faced with difficult decisions such as: 1) becoming a long distance caregiver, 2) telling a loved one they are no longer able to stay in their home or to drive their car, 3) hire in-home help, 4) persuade a loved one that assisted devices like braces, or a power chair are needed, or 5) modify your own home to accommodate the changing needs of your spouse, parent, or other family member in your care. But it is comforting to know there are special tools to help you both through these life adjustments.

If you live further than down the street or across town, invest a lot of money and/or time traveling to see your care receiver, or depend upon neighbors to keep you informed, then you are a long distance caregiver. Not everyone will be faced with the decision of taking on the role of long distance caregiver. It is the primary responsibility of the potential care receiver to prepare in advance for this possibility. Here it is very important for both of you to work as a team. Together you should locate important documents, make a list of contacts (phone numbers, names and addresses), sign release forms, make initial contact with health services, case managers, and paid caregivers, check in to transportation and in-home meal delivery, and identify sources of financial assistance. Once done, this information should be updated as circumstances change. Knowing where important information is and who to contact for assistance will build a strong bridge between the long distance caregiver and care receiver.

Many Polio survivors are able to drive. Like everyone else, as they age responses slow, muscles fatigue, body posture declines. Driving is independence. It is the most difficult thing to give up. Safety for all concerned is the big issue. It is best if the care receiver gracefully makes the choice to stop driving rather than have it forced upon them by the family, their physician, insurance company, or the department of motor vehicles. Most vehicles can be adapted with hand controls, left foot gas pedals, or special power steering. A specially equipped van with a lift, side ramp, that kneels, has removable seats and more is a wise investment. The care receiver must also consider how the caregiver will transport them to doctors’ appointments, shopping, and social functions if
they can no longer drive themselves. It is best to discuss this subject long before it becomes an issue. Have the care receiver write a contract with you stating under what conditions they will agree to give up their driving privileges. Include what provisions will be made to ensure alternate modes of transportation will be available to them. Your local agencies on aging will provide information on transitioning from driver to passenger.

Everyone should be able to stay in their home as long as they are physically and financially able. Accomplishing this is a challenge for a person with disabilities. The biggest hurdle is for both the caregiver and care receiver accepting the fact that a higher level of care giving skills is required. Hiring in-home help is a viable option. Most people do not feel comfortable with strangers in their home caring for their personal needs. The first step to take is to identify together the types of extra care that are needed. There are many areas of care: household, financial, personal, health and emotional. There are many resources to help you find the extra care you both need. Among those resources are the care receiver’s health care provider, home care agencies, seniors centers, their church, a caregivers support group, and a PPS support group.

The time may come when you, as a caregiver can no longer physically or emotionally care for your loved one. The stress of managing your own home, family, work, and personal health issues as you also age may become so overwhelming that you become unable to function productively. Telling a loved one you are no longer able to provide the level of care you feel they deserve, whether it is in their own home or yours, is a heart wrenching decision. As a caregiver and most likely a spouse, adult child, or parent, it is painful to admit internally, let alone to others that you “just can’t do it anymore”. Honest communication during the early stages of caregiving is very important. Both parties must freely express their expectations of care given and care received. Discuss the various options available such as retirement living facilities, residential care and assisted living facilities, foster homes, board and care homes, nursing homes, or continuing care communities. Get as much information as you both can. Visit the facilities, homes, and communities. Have the care receiver put together a note book of information on acceptable housing options, make a list of personal belongings they will take with them, make sure their medical needs can be met and list some the circumstances under which either of you would feel relocating would be the best for all. The need to move is not always because of the care receiver. The caregiver may develop health issues, financial problems, or a change in jobs that require making major adjustments in their own life that will prevent them from continuing to provide for the care receiver. There are many resources available to help everyone involved in the most difficult aspect of caregiving. Open and honest communication early on is the key to success.

Most Polio Survivors have, do, or will need the help of assistive devices during their lifetime. These devices range from a cane, to braces, to power scooters, to specially equipped vehicles. For many, these devices are sign of weakness, of giving up, or a loss of independence. On the contrary! These devices actually give you more independence to go and do, they relieve the fear of falling, reduce muscle fatigue, and provide a sense of security to both the caregiver and care receiver. Again, this is a subject that should be discussed, if at all possible, between the caregiver and care receiver, their physicians, therapists, and durable medical equipment providers before the need arises.
In order to become or continue being a caregiver, it may be necessary to modify your own home to accommodate the changing needs of your spouse, parent, or other family member in your care. This may be as simple as installing grab rails in the bathrooms or replacing outdoor steps with a ramp. Or it may involve more extensive and costly modifications like replacing carpet with smooth flooring, widening doorways, adding on a room, or replacing standard bathroom fixtures with a raised toilet, roll-in shower or an open vanity. In some long term caregiving situations, it is more financially beneficial to incorporate the needed modifications into a new home, rather than try to upgrade an older home. It may even be more practical to move into the care receiver’s home instead. One must consider the resale value of the existing home before and after modifications. This is especially true if the current home has multiple levels, lots of stairs, narrow hallways, or only one bathroom. If the care receiver is financially able, they should contribute to the cost of the modifications to the existing home or a new one. The caregiver should also discuss with the care receiver their contributing to the monthly household income. The caregiver cannot be expected to shoulder the financial responsibilities of the care receiver. There are various sources of financial assistance through government, health and private programs. Investigate them all.

A financial understanding between the caregiver and care receiver, even a written contract, must be arrived at before one nail is hammered or one dollar spent. Giving and receiving care in one’s home enriches everyone life, but it increases monthly expenses such as food, utilities, and transportation costs. Again open and honest communication about financial expectations as well as melding two homes into one are vital to creating a successful new home life with the caregiver, care receiver, their family and friends.

I sincerely hope that these 3 articles have been of value to some, thought provoking to others, and conversation starters for all. Perhaps having your caregiver or care receiver read this will make it easier to discuss difficult subjects. I strongly urge all caregivers to invest in a caregiver class or support group. At the very least, read The Caregiver Helpbook. It is my source. It gave me a wealth of knowledge and encouragement as a caregiver.

South Everett-Mukilteo Rotarians and Everett Polio Survivors Meet After the Itzhak Perlman Concert.
Itzhak Perlman, Seattle Symphony and Polio Survivors at Benaroya Hall

January 28, 2010

It was a memorable night of Mozart, Mendelssohn and Beethoven at the magical fingers of Itzhak Perlman, world renowned violinist. Among those filling the symphony hall to capacity were a group of people to whom this was and always will be a very memorable night. They, like Itzhak Perlman, are polio survivors. Seeing Itzhak Perlman in concert and having the opportunity of meeting with him afterwards was a moment none of them thought they would live to experience.

As polio survivors, they overcame the crippling effects of this terrible disease. They have become husbands, wives, parents, grandparents and even great-grandparents. They became accomplished musicians, teachers, business owners, community volunteers and more. They drive their cars, own homes, travel, swim, hike and enjoy the activities of living that we all do. Polio may have robbed them of the use of their legs or arms, the ability to walk or breathe without effort; but Polio did not rob them of their determination to live their life to the fullest.

Merilyn Boyd, a polio survivor and co-founder of the Everett Post Polio Support Group 19 years ago, and her daughter, Lynne Hollister’s concert evening was made possible by members of the South Everett – Mukilteo Rotary Foundation, Kathleen Stratton Zunkel and her husband David Zunkel. Also guests of the Zunkels’ for the evening were Past District Governor for Rotary District #5050, Mr. John Bosch and his wife Maxine Bosch. Other members of the Everett Post Polio Support Group enjoying Mr. Perlman’s performance were Judy Johnson, Norma Nickols, Scott Stahr, and Joan Stocker.

Itzhak Perlman, in his black oriental designed silk top and jaunty dark red scooter, met with the group after his mesmerizing performance. David Zunkel introduced Mr. Perlman to Mr. and Mrs. Bosch. They both explained Rotary’s mission to promote polio awareness. Norma Nickols asked Mr. Perlman about traveling with his metal canes and scooter in light of all the new restrictions. He, laughing, admitted that it was a little more difficult than in the past.

Tips on how they all stay active as they enter their 60’s, 70’ and 80’s were exchanged. Everyone agreed carrying around those extra pounds from desserts did not help walking or breathing. Merilyn Boyd and Mr. Perlman talked about how the use of scooters and power chairs has enhanced the lives of polio survivors and other people unable to walk on their own.

Mr. Perlman graciously autographed programs and posed for pictures. As he left, he took time to give tips and encouragement to a young violinist. He was very generous with his time after giving us a wonderful concert. Later as the Polio Group came off the lobby elevator, they met Mr. Perlman again. They all said their “Good Nights” and thanked him again for a wonderful evening. Mr. Perlman zipped off to his hotel room and a well deserved night of rest. The music of Itzhak Perlman and the company made for a wonderful experience!
Have One? Want One?

House to accommodate the needs of the mobility impaired for sale in the Granite Falls WA area.

One of our members is selling a home suitable for a disabled veteran and their family, or any family with a disabled adult or child. It is also great as a starter or retirement home. The ramps from the house lead to the gravel and barked yard. To see the listing of the house check the computer listing at

John L Scott Listing # 3932 or MLS # 31979 at www.andrabyrnes.com or www.johnlscott.com

My mom, Merilyn Boyd no longer has space to keep her back-up powerchair. This item has been placed on Craig’s List with photos of it.

If you know any one in or out of the Polio Circle who could use a good powerchair, please have them call me.

We are more interested in finding someone that needs more independence than getting money for it.

Thank you for your help.

Lynne Hollister

If you would like to place your items available or request for items on this page, please submit your information to Linda Fry by the newsletter deadline at frydaze3@comcast.net.
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 for the newsletter. 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 address

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

Itzhak Perlman (born 1945) is accepted and celebrated by many as one of the greatest classical violinists of the twentieth century. Overcoming polio and its crippling effects, Perlman was a distinguished musician in his native Israel prior to entering his teens. He travels around the world performing and teaming with other great musicians and he has brought a new style, individuality and technical ability to classical music and the violin.

from Answers.com

Merilyn Boyd, Itzhak Perlman and Norma Noble visit in “the Green Room”

Newsletter Deadline:
The deadline for the next issue of POOW newsletter is April 15.
If you have any articles, information or suggestions for items you would like to see printed in this publification, please send an e-mail with that information to me at: frydaze3@comcast.net

Thank you! Linda Fry, Editor
Our website is now ready for you! www.poliooutreach.com

March 31st - End of Fiscal Year

April

12th - Salk vaccine anniversary
13th - Spring Member Meeting

August 22 - Annual picnic

MMX

Twenty - ten