

# Polio Outreach Of Washington

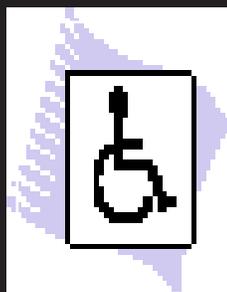
State of Washington, Non-profit Corporation

## "Our Mission Statement"

To minimize the impact and increase awareness of Polio/Post-Polio Syndrome by providing education and support to Polio Survivors, their families and healthcare providers.

NEWSLETTER SECOND QUARTER -

VOLUME 20: NUMBER 2



## "News In This Issue"

ARTICLE	PAGE
Accessible Cruising	1-2
Facts On A PPS Final Diagnosis	3,5,7,8
Alan Alda Memories	4
Not What I Say	4
Overindulgence	4
Price of Freedom	4
Homefill Oxygen	5
Chronic Pain & The Family	5
Ready For Disaster	5
Happy 14th Birthday In Memory Of Betty	6
Laughter Is the Brush	8
Can You Pass Bill Gates Speech?	8
10th POOW Annual Picnic	9
Canyon Country Historical Muesum _	9
POOW Support Groups	10
POOW Office Spanaway WA	10
POOW Library Reviews	10
ABSOLUTE Mobility Center	11-12
POOW Contribution Form	11
POOW Disclaimer	11

### **REVIEW OF CHRONIC PAIN AND THE FAMILY BOOK - SEE PAGE 5**

The price of this book is reasonable about \$10.95, not including Tax. You can order it through B & N or Borders. It is also is referred to local book sellers. You can ask for it by the author's name, Julie K. Silver M.D.

**NOTE - There is a change in the E-MAIL address for Vivian Clark, Newsletter Editor! It will be the SAME as the POOW Office E-mail address noted below:**  
[poow85jmc@msn.com](mailto:poow85jmc@msn.com)

## ACCESSIBLE CRUISING WITH PRINCESS

Authors, Mary Clarke Atwood and Grace R. Young wrote this article as a positive response to a report in the February 2005 AARP newsletter, "Taking a Cruise or Getting Taken for a Ride?" That article referenced a lawsuit filed by five people who paid premium prices for wheelchair accessible cabins on Norwegian Cruise Line ship the Norwegian Star, but found that many areas of the ship were not accessible, including the swimming pool, restaurants, restrooms, and emergency evacuation equipment. The U.S. Supreme Court is now deciding this case.

### **ADVANCE PLANNING**

Before booking a cruise, a would-be passenger needs to check with his travel agent or the cruise line to be sure that the ship he is considering has the accessible features he is looking for. Not all ships within a cruise line will have identical accessibility. According to a Princess representative, "There are one or two swimming pool life machines onboard each Princess ship. Contact the Passenger Services desk in advance to use the equipment."

When selecting a cabin, a person in a motorized wheelchair or scooter should look for a cabin that is designated not only for disabled access but is also close to an elevator. On some ships the disabled access cabins are in the bowels of the ship by the medical center or at the very far end of the deck, which seems to indicate that the ship or cruise line is not wheelchair-friendly.

### **ROUND TRIP TO HAWAII FROM LOS ANGELES**

The authors Young and Atwood have just returned from a 15-day Hawaiian cruise on the Island Princess and found it to be very accessible for passengers in scooters or wheelchairs. This ship is a newer ship, an important feature when looking for accessibility. We found the crew to be extremely helpful to all passengers and ready to meet every request.

To begin with, we selected a wheelchair accessible cabin that provided additional space and special features:

- o Entry and bathroom doors were both 35 1/2 inches wide.
- o There was additional space to maneuver a 48 inch long scooter and motorized wheelchair in the room.
- o There was an electrical outlet at the bedside as well as another pair on the opposite side of the room. (We also took along an extension cord that was used for greater flexibility for overnight charging of both vehicles.)

(Continued on Page 2)

The bathroom was large enough to roll into:

- o There were grab rails on the inside of the bathroom door, on both sides of the toilet, and on two sides of the roll-in shower.
- o The shower had a hand-held adjustable shower head and a pull-down bench.
- o There was an emergency pull-cord by the toilet.

Room stewards can provide aids to improve sleeping comfort, such as additional pillow, a foam mattress pad, or a wedge.

**ONBOARD ACCESS**

The Island Princess has three areas with banks of elevators: forward, mid-ship, and aft. These will provide access to almost all public areas of the ship. A passenger needs to learn where each set of elevators will take him, including the automatic entrances on the top decks. For example, only the forward elevators to the open entrance to the buffet on deck 14. The middle elevators on deck 14 are open to the covered pool and are the only ones that go up to deck 15, the deck which overlooks the outside pool on deck 14. In order to access deck 15, a wheelchair passenger must use the middle elevators and then ask someone to open the exterior doors because they are not automatic. In addition there is a set of glass elevators mid-ship, which only operate in the atrium area between decks 5-8.

Another thing we learned by experience was that deck 7 was the main deck to go from one end of the ship to the other; this is all public space and all main elevators can be accessed from that level. There are no staterooms on deck ; therefore, there are no cabin stewards' carts to try to maneuver past. This can be a big problem on the decks with cabins.

A very nice feature on the Island Princess is that almost all public area restrooms have one large accessible stall, which usually includes a wash basin and also a telephone. On many other ships not all public bathrooms are wheelchair accessible.

At the 24-hour buffet, crew members were always available to help; they held our plates and filled them with our choices took us to a table, and then brought us our beverages. All dining rooms on the Island Princess are accessible; however there are a few tables in the main dining rooms that are on raised platforms. The dining room captains are very conscious of handicapped passengers and will seat them in an accessible area, usually close to the entrance. Many waiters and their assistants were happy to have the opportunity to drive a scooter and would happily help the passenger sit down at the table and then drive the scooter to a nearby parking place. At the end of a meal they were just as happy to retrieve the scooter and bring it tableside.

**SHORE EXCERSIONS**

Shore excursions can be booked in advance on the Princess website. But, as soon as a person is onboard, he needs to confirm with the Tour Office what type of accessible transportation he requires.

**Quotes From President George Washington  
Founding Father of America**

Labor to keep alive in your breast, is called that little spark of celestial fire. *The Rules of Civility, Circa 1748*

Knowledge in every Country is the surest basis of public happiness. *January 8, 1790*



Many, but not all, ports have access to busses with lifts and tie-downs for several wheelchair users. For passengers who can step onto the bus and sit, scooters or manual wheelchairs may be stored underneath large busses.

Be aware that not all available tours are recommended for the disabled; some may require climbing steps, be on uneven terrain, or be physically demanding. Sometime final confirmation of shore excursions can only be made when onboard the ship due to available equipment and demand.

When arriving at the dock a passenger can usually arrange taxi in private car rental to do independent excursions using a manual wheelchair.

**GOING ASHORE**

When docked at a port, most passengers use a gangway on deck 5, which has steps that lead down to the dock level. However, a more level gangway is available at deck 4 for the disabled and is accessed by a regular elevator. For ports that are accessed by tenders (motorized boats), passengers walk down a set of steps inside the ship and reach the shipside platform for disembarkation. A very nice feature on the Island Princess is a special glass elevator that takes a disabled wheelchair or scooter passenger down one deck to the platform-level. Motorized wheelchairs and scooter can be lifted onto the tenders and then used while ashore.

Our first port was Kona, Hawaii, a tender port. This port was very wheelchair accessible so a passenger could go freely exploring nearby. In fact, we found a local flower shop and were able to purchase local flowers (anthurium and orchids) for our cabin.

Each port is different so each port day can be a new adventure! Each sea day is also an adventure because of the multitude of activities that are offered onboard. Sometimes it is necessary to schedule your rest periods into each busy cruise day.

**CONCLUSION**

Cruising can be a very accessible way of traveling for the disabled as long as there is adequate advance planning. Even a new ship may have accessibility problems but careful pre-planning should help the disabled traveler select a cruise line and ship that will meet many of their needs. This can be done with the assistance of a travel agent, some of whom specialize in travel for the slow walker or disabled person.



## This Article Is a Wonderful Article Submitted by: Rona Nelson

Post-Polio Syndrome( PPS), Medical name (Post-polio Sequela) has been a recognized condition more than 25 years, with reports of similar symptoms going back to the 1800's. However we still do not have a grasp of the underlying cause, or causes, of PPS!

**We do not know how many polio survivors will develop PPS, estimates range from 10% to over 80%.** -- We do not know why some polio survivors develop PPS and others do not. There is no diagnostic test and PPS remains a diagnosis arrived at after exclusion of other somewhat similar conditions.

**We do not understand why there is lag time between recovery from the acute illness and development of symptoms severe enough to compromise the quality of life.** -- It seems there is very little that we do understand about PPS. However, if we can discover the underlying cause(s) of PPS; if we can find out what is happening at the cellular and even sub-cellular level, there is promise of being able to answer all of these perplexing issues. There is also promise of being able to treat and possibly even prevent the onset of many perhaps most, PPS symptoms.

**Little research has been done on PPS, probably because many people believe polio survivors are a dying breed.** After world wide eradication of polio, the life-span' of PPS will be equal to that of the youngest living polio survivor. Or will it? Poliomyelitis continues to cause paralysis although now the virus causing the illness is not the polio virus, but the West Nile Virus, or enterovirus 71, or one of the several Coxsackie viruses. The nerve damage caused by these viruses is identical to that caused by the polio virus and therefore it is likely the PPS, perhaps by then called Post-Viral Syndrome, will continue to bring new limitations to survivors many years after they thought they had recovered. So it remains important to examine the underlying cause of new muscle weakness, central fatigue, pain, memory and word finding problems and other symptoms that accompany PPS. Fortunately, current research in other areas holds great promise for explaining what is happening with so many polio survivors.

**The cause of virtually all PPS symptoms can be explained by one word: INFLAMMATION!** Front line research in the fields of neurology, immunology, physiology and virology is coming together and the many pieces of the puzzle are being laid upon the table. A good analogy is to think about a jig-saw puzzle. When you dump a 1,000 piece puzzle out of the box, some pieces land right side up, others upside down. There is little hope of assembling the puzzle until you turn all the pieces right side up.

*(Continued in next column.)*

**Then put them in a pile and assemble the outer edge of the puzzle give you a general outline.** -- After this it is helpful to group pieces with similar patterns or colors together. This is approximately where we are today in our understanding of how inflammation is related to almost all chronic diseases; PPS-Post-polio Syndrome, MS-Multiple Sclerosis, ALS, CFS-Chronic Fatigue Syndrome and Fibromyalgia, Parkinson's, and IBS-Irritable Bowel Syndrome, arteriosclerosis and many, many others. This also gives you some idea of how far we have to go until we have a complete picture!

**Let's look at the puzzle pieces that seem to belong to PPS. Inflammation has two major causes; injury--including viral and bacterial infection, cuts, strains, operations, etc. and stress** - including major events such as death of a relative, divorce, and job loss, but also including milder, repetitive stress that is encountered everyday. In a person with PPS when the body suffers an injury, such as physically overdoing by climbing too many stairs, walking on uneven ground, etc. The first reaction is for the cells in the affected area to release a chemical messenger. This messenger, called a proinflammatory cytokine, tells specialized cells, whose job it is to protect you from invading organisms, to come to the site of the injury.

**At the same time the proinflammatory cytokines activate resident cells and cells that have migrated to the injury and all of them produce more proinflammatory cytokines setting up a cascade of events that will involve the entire body.** Two proinflammatory cytokines, Interleukin-1 and Tumour Necrosis Factor- $\alpha$ , are especially important in triggering an acute immune response, the body's first line of defense. The acute immune response involves developing a fever, fatigue, loss of appetite, sleepiness and other symptoms. It goes away within a few days. However if the injury is repeated often -- say if a person with PPS persists in exercising a stressed out muscle --- then a chronic immune response will set in. This response to chronic stress involves the entire body including the brain and it will produce central fatigue, new muscle weakness, problems with a short term memory and word finding, irritable bowel syndrome and other symptoms. Recognize them? These are the post-polio syndrome symptoms we are so familiar with. In an effort to keep this article shorter than a textbook on immunology, I have omitted the complex chain of events that takes place in the body between the original stress and the onset of PPS symptoms. There are many, many research papers that amply document what happens in the body after activation of the immune system by proinflammatory cytokines and that eventually result in symptoms identical to those of PPS.

**Let's take a brief look at how proinflammatory cytokines may be the underlying cause of new muscle weakness.** We begin with acute polio and the death of a large number of nerves whose job was to innervate muscles by telling the muscles to contract or relax and thereby allowing you to move a leg or arm. If all the nerves leading to a leg or arm died, the limb was permanently paralyzed. However, clinical paralysis

*(Continued on Page 7)*

## ALAN ALDA - MEMORIES OF POLIO

**Alan Alda, actor, director and television host recently appeared as a guest on the Tavis Smiley show, a PBS talk program.** During the interview the subject of Alda's bout with polio was brought up.

Tavis Smiley said, after talking about the research he did to prepare for the interview, and talking about Alda's humanitarian efforts, "I didn't realize that you had polio as a child."

**Alan Alda responded, "Yeah. When I was seven. There was an epidemic in those days.** That was before the vaccine. And there really wasn't any treatment except Sister Elizabeth Kenny treatments. She was a nurse from Australia who had developed a treatment which involved very hot wrappings of woolen blankets. Almost scalding hot. And massage that involved sort of bending your limbs back down behind your back -- to stretch the muscles. Extremely painful. Everybody who went through those treatments knows what I mean. They were just awful.

**"And my parents, who had no money had to administer these treatments. They had to do it themselves.** So here are your parents, torturing you against their own will. You know they don't want to hurt you. So it was an interesting experience. I don't know what it did to me to make be a better person, but I remember being aware at the ages of seven of getting ready to pound the bed in pain -- every 2 hours, you know for months -- knowing that my parents didn't want to hurt me and knowing how hard it was for them. I remember going through that feeling. I don't know really if that's the beginning."

**Tavis Smiley seemed to understand, and added,** "I suspect, though that people who suffered, if they get the lesson that can be learned ... Like my grandmother always said with every experience, you ask yourself, "What's the lesson? What's the blessing?"

*Copied from Rancho Los Amigos Post-Polio Support Group Newsletter January, 2005. By Alan Alda, an interview with Tavis Smiley, announcer.*



### 'overindulgence'

#### **Eating a lot of sugar or a high-fat high calories meal**

-- can cause inflammation in the body for up to four hours after eating. What does this mean? It means that heart disease could be in your future - in part because inflammation has been linked with heart disease. To add insult to injury, eating a heavy or high-fat meal can significantly increase the risk of heart attack. But in one small study, preceding the indulgence with an extra dose of antioxidant vitamins C and E blocked this inflammation process. Source: 2002 meeting of the American Diabetes Assoc.

### 'high blood pressure drugs'

Lowering blood pressure with a diuretic works at least as good as -- and maybe better than the newer and more expensive calcium-channel blocker or ACE inhibitor drugs, say researchers. Source: Journal of the American Medical Association, Vol. 288, Pg 2981.

## "DO WHAT I DO - NOT WHAT I SAY"

(Pride Goes Before A Fall)

*Printed from: The Tacoma Post-Polio Support  
Newsletter - By Marion Schoeller, Florida Newsletter  
(Jan-Feb 2005 Florida Newsletter)*

I find post-polio people for the most part to be highly intelligent, creative, open-minded, successful, non-judgemental, and resilient. There are too many times when we post-polios (myself included), do not practice the advice we tell other post-polios (especially new members of the group) to follow.

**I was amazed to hear the conversations around the table** at the most recent PPS meeting I attended. One lady was lamenting about having to put up Christmas decorations. It sounded as if her loving husband was even encouraging her to continue to decorate until the job was finished -- while she was standing up and as long as she was there, she may as well.

Another lady who has been a post-polio survivor for many years and has obvious problems ambulating, recently had a bad fall. She continues to try to walk outside her home in situations where she could easily but accidentally be pushed down, slip on wet floors or just stumble, trip and fall. I recall when I was still only using crutches, how terrified I was of slipping and falling especially after it rained and I had to go to the store or an office. The fear of falling began for me after, while walking with a cane, I fell and fractured my tibia and fibula (both bones of my weaker lower left leg).

**I believe that, "a word to the wise" should be sufficient.** But unfortunately, that doesn't always get through. It never fails to surprise me how stubborn we can be. *Is it our ego which prevents us from using mobility aids?*

I know that I tend to push myself and overdo activities when I feel especially rested. I also know I have a huge sweet tooth and really enjoy deserts, and will have an alcoholic drink or two. I don't believe in completely depriving myself of those things I enjoy, but MODERATION is the keyword.

**We need to use our intelligence and think what the long-term consequences** of how we may be putting our health and safety in jeopardy by our unwillingness to put into practice what we've learned.

**"No Price That Is Asked For Freedom  
Is Half The Cost Of Doing Without It"**

**"It's Not Hard To Make Decisions When You Know  
What Your Values Are"**

## Homefill II Oxygen Therapy System

Made by Invacare – *By Beau Jeffrey,  
March 31, 2005 - Submitted by: Susie Koeser*

**The Homefill II Oxygen system is a home oxygen therapy system made by Invacare.** This system is designed to deliver a continuous supply of stationary and portable oxygen to the patient without the need for cylinder or liquid deliveries. It works with three parts: The concentrator, compressor, and cylinders.

The oxygen concentrator filters oxygen out of room air by forcing it through a series of “filters” that traps nitrogen and allows oxygen to pass through. This filtering process purifies the room air to approximately 95% pure oxygen which is then delivered to the patient.

**Cylinder filling is accomplished with the compressor unit that sits directly above the oxygen concentrator.** Placing the cylinder on the compressor is done by mating the filling port of the cylinder to the filling port of the compressor. The cylinder will snap into place with no threading or special tools needed. Then the compressor will first test the gas to ensure its purity and then fill the cylinder with oxygen from the concentrator.

**Patients using the Homefill II home oxygen system can receive their oxygen directly from the concentrator while at home, even while filling a cylinder.** While away from the home, the patient switches to the oxygen cylinders. The cylinders, which last about 5 or 8 hours depending on size, have built in regulators so there is no need to switch regulators from tank to tank. Weighing in a 4.3 or 6 pounds, these lightweight cylinders can be carried in a specially made carrying case the’s about the size of a medium sized purse.

The homefill system is available with a doctor’s prescription and is covered by most insurance policies. Since this system is so new, it is unavailable at most suppliers, however, it can be obtained in the Portland/Vancouver area through Pacific Coast Medical Supply. For more information, call 1-866-695-5161.

The husband who boasts  
that he has never once made a  
mistake has a wife who did.  
\* \* \* \* \*

Most people would learn from  
their mis takes if they weren’t so  
busy trying to place the blame  
on someone else.  
\* \* \* \* \*

What isn’t won in prayer first  
is never won at all.

## DR. JULIE K. SILVER, MD REVIEW OF HER BOOK [CHRONIC PAIN AND THE FAMILY] A New Guide

Reviewed By: Audrey H. Baugh, April 15, 2005  
South King County, Support Group Member

This is an economically sensible book covering the causes and characteristics of chronic pain, exploring the impact on families of that pain. Acute Pain and Chronic pain are examined and defined in understandable terms.

The chapter topics include the Effect on The Couple; Intimacy Work Issues; Childbearing and Inheritance; Growing Up with Parent in Pain; Chronic pain in Children; The Extended Family; Emotional Changes and Depression; Medication Dependence and Addiction; then finishes up with Diagnosing Chronic Pain Conditions; Traditional Treatment Options and Complementary and Alternative Medicine.

Sidebar throughout the book enlighten the reader in many areas, including very complete listings of alternative therapies; Commonly Used Medications and their possible side effects; and non pharmacologic treatments, i.e., assistive devices, exercise, massage and ultrasound to mention just a few. This is a book that could be comfortably used as an ongoing reference, but it reads very well in a straight forward manner. While it is totally projected toward the person with a polio history, many of the subjects are of vital importance to the polio/post-polio population.



### READY FOR DISASTERS! By Carl Larson

**For millions of Americans with mobility problems, emergencies such as fires, floods and earthquakes present a special challenge. Protecting yourself and your family when disaster strikes requires planning ahead.**

**The following listed organizations offer information in the form of emergency checklist brochures and handbooks for people with mobility problems.**

The Salvation Army  
P.O. BOX 9219  
Queen Anne Ave North  
Seattle WA 98109

Washington Military Department  
Emergency Management Division  
Building 20, MS: TA-20  
Camp Murray WA 98430

American Red Cross  
P.O. Box 3097  
1900 25th Ave South  
Seattle WA 98114

U.S. Department of  
Homeland Security [www.ready.gov](http://www.ready.gov)

Washington Coalition of Citizens with disAbilities provides a question sheet with sample questions to ask government an community based organizations regarding a person’s preparation and safety during a disaster. Contact Good Shepherd Center at: 4649 Sunnyside Ave. No. Suite #100, Seattle WA 98103 206-545-7055. E-mail: [www.wccd.org](http://www.wccd.org)



## "HAPPY 14th BIRTHDAY" Everett, Snohomish, Seattle, North King County Polio/Post-Polio Support Group!



By: Rhonda Whitehead

The Everett Post-Polio Support Group celebrated its 14th birthday this year. Several members reflect on the roll a support group plays in their lives.

**Jack Salvadalena:** "I strongly encourage anyone who has been affected by the late effects of polio to get involved in a support group. When I first attended a meeting in the early 1990's, it immediately became apparent that I had to change my 'life style' to deal with the physical challenges that were gradually resulting in mobility reduction. Thankfully, the sound advice and sharing of experiences by other polio survivors in our fantastic support group has given me many years of comfort both physically and mentally. Being able to share my journey with other polio survivors is also a priority and I love to meet and hear the stories from first time attendees. The best thing about our group is that it is so uplifting!"

**Sue Warren:** "I have been a member of the Everett Support Group for almost 13 years. At first it was a place to get real information from people 'who knew'; who knew it wasn't just 'age' or 'all in my head'; people who could understand, would empathize, not pity. Then it was the sharing of practical solutions and lifestyle changes for common problems; the opportunity to socialize without having to mask feelings and frustrations about what you could no longer do. Now it is an opportunity to give back, to encourage, to share a sense of humor with those just starting their journey with PPS; to confirm worth, joy, and faith; to develop even deeper friendship with those who have been so helpful to me."

**Carl Larson:** "Attending support groups is a healthy and welcome forum for talking about your feeling to a peer group. After attending group meetings for over 15 years I am continually finding and sharing new information about coping strategies for aging with PPS."

**Shirley Harrell:** "I was asked to define 'support group'. First I will say what it isn't. It is not a group of people meeting and complaining and feeling sorry for themselves. Instead, a support group is a group of positive people with similar concerns who come together to learn from one another, to help each other through difficulties and to help them live life to it's fullest."

**Rhonda Whithead:** The rewards gained from being a support group leader far outweigh the responsibilities.

(Continued in next column.)

Each month brings new opportunities for sharing life-changing information with polio survivors who are searching for answers and support. Personal experiences and knowledge shared can greatly improve the quality of life for a polio survivor. I believe the bonds of caring and friendship developed between members of a support group can be among the most valuable means of coping with the debilitating late effects of polio.

***Myself and all our support group members encourage those who have not attended a support group meeting to try to do so; and for any who have tried once, to consider a REVISIT!***

### "Benefits of Belonging to A Polio/Post-Polio Support Group"

#### In Memory Of: Betty Shullenberg {Tregoning}

On Behalf of Polio  
Outreach Of Washington, We extend  
Our  
Sincerest Sympathy  
to Betty's Family and Friends.



Betty passed away on February 2, 2005 after celebrating her 88th birthday on January 16th. She was a life-long resident of Seattle. Betty grew up in Ballard and graduated from Ballard High School. She met her husband, Al, at the Tregoning Boat Co. in Ballard and enjoyed nearly 55 years of marriage. At the age of 16, she was stricken with polio and courageously rose above her disability to live a full life.

Pleasure boating was the most significant activity of Betty and Al with their many friends at Queen City Yacht Club. Betty was a life member of the Queen City Tarettes, a past President of Interclub, and a past member of Seattle Power Squadron. For several years, Betty was the secretary for the KING TV Home Economist, Bea Donovan.

Betty was preceded in death by her husband, Alvin C. Tregoning. She is survived by a son, David Tregoning (Joan) of Auburn, WA and a daughter, Vicki Ordean (Jackson) of Norwood, CO.; seven grandchildren and 23 great grandchildren. Betty was a member of the South King County RENTON Polio Support Group.

(Continued from Page 3)

may be observed when 40 per cent of the nerve supply leading to a limb has survived.

**In many people original paralysis or severe weakness eventually resolved, voluntary movement was restored and you could once again use your arm or leg.** The body developed a neat trick to allow this to happen. The surviving nerves were able to send out 'neuronal sprouts' to attach to and innervate muscles that had been orphaned when the nerve originally attached to them died off. Thus the surviving nerves were able to activate not only the muscle that they always innervated, but also surrounding muscles creating something called a motor unit. This repair was essentially stable for many years.

**However 30 or more years after recovery from polio, many people begin experiencing new muscle weakness.** Often the weakness is in the 'good' arm or leg. This may be due to the fact that the 'good' arm or leg was used more. Clearly something happened to the neuronal sprouts; either they no longer could maintain full time attachment to the motor unit or else they may have died off completely. This caused the appearance of new muscle weakness. Once again, I've simplified this a bit -- although the general picture is correct. But this is a description of what is happening.

**Enter proinflammatory cytokines. Remember them?** Researchers have well established that proinflammatory cytokines cause cells to release neurotoxic proteins. These neurotoxic proteins can damage or even kill neurons by a number of mechanisms including changing the outer membrane of the nerve cell resulting in cell death or increasing reactive oxygen inside the nerve cell which also leads to cell death. It is probable that the neuronal sprouts, that have served so well for so long, are more fragile and may be the first target of proinflammatory cytokines in the central nervous system.

**A very important fact is that nerve death only occurs in an activated immune system.** The next question is "Do people with PPS have an activated immune system? The answer is YES! There have been a number of research papers indicating that polio survivors with PPS symptoms have an activated immune system while polio survivor who do not report PPS symptoms do not have an activated immune system. (1)

**A very recent research paper (2) looked at cytokines in people with PPS, polio survivors without PPS, people with multiple sclerosis (MS),** a well known inflammatory neurological disease, and people who had no neurological problems. They found that people with PPS and MS have proinflammatory cytokines in their central nervous system, while polio survivors who do not have PPS and people without neurological problems do NOT have proinflammatory cytokines in their central nervous system. What might cause the presence of these proinflammatory cytokines in people with PPS? One hypothesis is the presence of very low levels of polio virus RNA hiding in nerve cells. This polio virus RNA is not capable of infecting

(Continued in next column.)

you or other people, but is capable of triggering the production of proinflammatory cytokines and with that, an underlying state of chronic immune system activation.

Other researchers have demonstrated a clear connection between the presence of proinflammatory cytokines and central fatigue (3). Psychological stress -- the kind that doesn't involve overdoing physically -- is perceived in the brain and the brain produces proinflammatory cytokines. This can cause profound fatigue, inability to concentrate and other symptoms (4).

**Remember that 1000 piece jigsaw puzzle we have spread out on the table?** We are now able to put together some of the same colored pieces to make small pictures that are part of a larger picture. In the same way, we are piecing together what happens when a person with PPS experiences physical or psychological stress. We start to see small pictures and we can just begin to discern the larger picture coming together. We are coming to the place where it may be possible to treat PPS symptoms using anti-inflammatory medications. A very exciting trial, using intravenous immunoglobulin treatment, is currently underway in Sweden. Preliminary trials of this treatment in people with PPS have yielded dramatic improvements in fatigue and muscle strength! (5, 6)

**Other treatments to reduce PPS symptoms may be based upon traditional anti-inflammatory medicines** such as aspirin, ibuprofen, indomethacin and others. All treatments would have to be done under the supervision of your doctor, but in the meantime, there are some things you can do that are known to minimize inflammation to your body -- and with that you might have a reduction of PPS symptoms. **You might try meditation. Yes it works... if you do it consistently.**

Appropriate exercise, under the guidance of a knowledgeable physiotherapist, will definitely lower inflammatory cytokine levels. Pace yourself and don't overdo. This is easier said than done but if you understand that seriously overusing muscles will start the proinflammatory cascade of events and with that bring on or intensify PPS symptoms, perhaps you will be able to justify resting before you go too far.

**Adipose tissue -- commonly known as FAT -- is also a producer of inflammatory cytokines.** If you needed a good reason to lose weight, here it is. Finally there are a few things you can try. Drinking green tea encourages weight loss and it has neuro-protective qualities. There are also reports that undenatured whey protein may be beneficial. These things are probably not as effective as direct medication to lower proinflammatory cytokine levels, but as we incorporate them into everyday life, they will bring positive benefits. ***And let's keep working on that jigsaw***

## A FINAL DIAGNOSIS OF POLIO/POST-POLIO SYNDROME

(Continued from Page 8)

### REFERENCES:

1. **Dalakas**, **Pro-inflammatory cytokines and motor neuron dysfunction:** Is There a Connection in Post-polio Syndrome? *J Neurolog Sci.* 205:5-8, 2002
2. **Gonzalez et al.** **Prior Poliomyelitis - LVLG treatment reduces proinflammatory cytokine production.** *J Neuroimmunol.* 150:139-144, 2004
3. **Patarca, R.** **Cytokines and chronic fatigue syndrome.** *Ann NY Acad Sci.* 933:185-200, 2001
4. **Black, PH.** **Stress and the inflammatory response: a review of neurogenic inflammation.** *Brain, Behavior and Immunity* 16:622-653, 2002
5. **Farbu et al.** **Intravenous Immunoglobulin in Post-polio Syndrome.** *Tidsskr Nor Laegeforen.* 124:2357-2358, 2004
6. **Gonzalez et al.** **Study in Progress (Copyright: Marcia Falconer,**

PhD.) [marcia.falconer@sympatico.ca](mailto:marcia.falconer@sympatico.ca)

Reprint request should be addressed to Marcia Falconer.

**Maria Falconer met Hilary online many years ago and became a Life Member.** She also visited and spoke at our 2000 AGM. Here are just a few facts from her extensive C.V.

### Polio History: Non-paralytic polio at age 7 (1949).

Quarantined for about 1 month. Symptoms included fever, leg and back pain, weakness in both legs and right arm, also generalized weakness for a period of months, followed by complete recovery. Led a very active life swimming, ice-skating and cross country skiing. PPS symptoms first noticed (in retrospect) in 1985 with fatigue, and leg weakness becoming severe by 1996. Received a diagnosis of "probable PPS" in 1997 B.Sc in biology, Simmons College, Boston, Massachusetts USA 1964.

**Research Assistant in cell biology laboratory at M.I.T.** Worked with human tissue cultures, polio virus (strain3) and various pesticides. 1964-1966

**M.Sc. in plan cell biology,** Carleton University, Ottawa, Ontario Canada 1985.

**PhD. in Neuronal Cell Biology,** Carleton University, Ottawa, Ontario, Canada 1990.

**Post-doctoral studies in molecular biology,** M.I.T. (Center for Cancer Research), Cambridge, Massachusetts, USA 1990-1992.

**Co-author with Professor Eddie Bollenbach MA in biology** -- also a LincsPPN Member.

**'Non Paralytic Polio and PPS'** - A Lincolnshire Post Polio Publication January 1999.

**'Late Functional Deterioration in Non Paralytic Polio'**  
AM J Phys Med & Rehab Jan/Feb 2000



"Laughter Is The Brush  
That Sweeps Away the  
Cobwebs Of The Heart"

## CAN YOU PASS BILL GATES

### HIGH SCHOOL SPEECH?

From: Charles Sykes, Author of  
Dumbing Down on Your Kids

Love him or hate him, he sure hits the nail on the head with this! To anyone with kids of any ages, or anyone who has ever been a kid, here's some advice Bill Gates recently dished out at a high school speech about 11 things they did not and will not learn in school. He talks about how "feel-good, politically-correct" teachings have created a generation of kids with no concept of reality and how this concept has set them up for failure in the real world.

**Rule 1:** Life is not fair - get used to it.

**Rule 2:** The world won't care about your self-esteem. The world will expect you to accomplish something BEFORE you feel good about yourself.

**Rule 3:** You will NOT make \$40,000 a year right out of high school. You won't be a vice-president with a car phone until you earn both.

**Rule 4:** If you think your teacher is tough... wait till you get a boss.

**Rule 5:** Flipping burgers is not beneath your dignity. Your grandparents had a different word for burger flipping they called it opportunity.

**Rule 6:** If you mess up, it's not your parents' fault, so don't whine about your mistakes... learn from them.

**Rule 7:** Before you were born, your parents weren't as boring as they are now. They got that way from paying your bills, cleaning your clothes and... listening to you talk about how cool you are. So before you save the rain forest from the parasites of your parents' generation, try delousing the closet in your room.

**Rule 8:** Your school may have done away with winners and losers... but life has not. In some schools they have abolished failing grades... they'll give you as many times as you want to get the right answer. This doesn't bear the slightest resemblance to ANYTHING in real life.

**Rule 9:** Life is not divided into semesters. You don't get summers off and very few employers are interested in helping you find yourself. Do that on your own time.

**Rule 10:** Television is NOT real life. In real life people actually have to leave the coffee shop and go to jobs.

**Rule 11:** Be nice to nerds. Chances are you'll end up working for one.



# "10th Annual Picnic" Lewisville Park, WA

AUGUST 14, 2005 - 11:00 AM to 5:00 PM  
Lewisville Park -- Battleground WA  
OFF of HWY 503, North of Battleground

By: Susie Koeser, President

The picnic is catered. In order for us to do this we need your help. Please complete the form below and send it to the POOW Office, along with a donation of \$10 - per adult, and \$5 for children 12 and under. **This way we know how many are attending and how much food to get ready, so we don't over purchase.** If we count you and you do not show up, we will have the cost covered. If this is a hardship for you please let us know - that you want to attend but cannot contribute; but be sure and send in your form.

Arrangements have been made with the following motels who are giving POOW a special rate for the weekend\*\*. Please remember to let them know that it's for the Polio Outreach Of Washington's Annual Picnic on August 14th

help us show everyone how many we are and make them aware of Post Polio Syndrome while you are having fun at the 10th Annual Picnic.

Any further questions please contact Susie Koeser, at: 360-574-1520. We hope to see all of you there!

The picnic committee is planning a very exciting picnic for our 10th Annual Picnic and the Celebration of the 50th Anniversary of the Salk Vaccine.

We have received a lot of donations from various people and businesses for the raffle. Some of the prizes that have been donated are: A fishing rod and reel, chiropractic exam, tulip bulb, quilt, brunch at the Oak Tree Restaurant in Woodland, WA. A stay at a hotel in Astoria Oregon, Cross-Stitch-Sweatshirt (special made for POOW), a cooler, and various baskets plus many more exciting prizes.

**Entertainment includes** - Debbie Wooten who graciously agreed to do a presentation for us. If you have not heard her yet, you are in for a treat. If you have - you know what I am talking about. We are hoping to have some other special speakers.

**Lewisville Park is a County Park with lots of trees, grass and the Lewis River.** There are paths all over the park and restrooms close at hand. We are looking to have a lot of volunteers helping us. If you are "lucky" you may see some wild animals, (rabbits).

## POLIO OUTREACH OF WASHINGTON (PICNIC) MOTEL LISTING

\*\* Holiday Inn Express -- Vancouver WA  
360-576-1040

\*\* Ferryman's Motel -- Vancouver WA  
360-574-2151

Comfort Inn -- Vancouver WA  
360-575-6000

Best Western -- Woodland WA  
360-225-1000

Polio Outreach Of Washington  
10TH ANNUAL PICNIC  
Sunday AUGUST 14, 2005  
RESERVATION CARD

Name \_\_\_\_\_

Pho \_\_\_\_\_

### NUMBER ATTENDING

ADULTS: \_\_\_\_\_ CHILDREN: \_\_\_\_\_

\$ AMOUNT ENCLOSED:

RETURN YOUR R.S.V.P FORM TO:  
John M. Clark, Office Manager  
POOW OFFICE  
4704 235TH ST. EAST  
SPANAWAY WA 98387-6162

## OPENING OF CANYON COUNTY HISTORICAL MUSEUM - NEW POLIO/POST-POLIO EXHIBIT IN NAMPA (ID)

By: **Vivian J. Clark, Newsletter Editor**

I was travelling from Boise, Idaho on an airplane several weeks ago, I sat next to a lady who told me about the Canyon County Museum's newest exhibit on Polio/Post-polio that opened up in their museum on May 3, 2005. I will be putting in a longer article about this Exhibit in our next issue. If you are travelling in that direction, you might want to drop by Nampa and see the Exhibit.

Karma, Office Manager Canyon County, Historical Museum stated that the hours are:

Tuesday through Friday from 1:00 pm to 5:00 pm.

You can contact her at 208-467-7611 or E-mail: [canyonmuseum@netzero.net](mailto:canyonmuseum@netzero.net)

Address is: 1200 Front Street,  
Nampa, ID 83651-3931



## Polio Outreach of Washington

### Polio/Post-Polio Syndrome Support Groups

Please contact the leaders of the PPS Support Group for further details. **1-800-609-5538 or 253-847-8114.** Revised: ++

Bellingham - Joan Fortune--360-738-0707

Bremerton & Kitsap County LouAnn Miller--360-692-1381, [rmiller@wavecable.com](mailto:rmiller@wavecable.com)

Clarkston, Idaho: Tri-State Polio Pals - Jim Hueston, 208-790-3805, [rockinnj@clarkston.com](mailto:rockinnj@clarkston.com)

Ellensburg Daisy Stevenson--509-968-4280, [theflower1950@yahoo.com](mailto:theflower1950@yahoo.com)

Everett, Marysville, Snohomish County, & Seattle, & North King County Rhonda Whitehead--425-488-0219, [lauriswh@comcast.net](mailto:lauriswh@comcast.net)

King County (South) Renton, Seattle, Maple Valley, . Auburn, Federal Way Mimi Sangder--206-725-8937, [fuzzface7@juno.com](mailto:fuzzface7@juno.com)

North Central Washington - Wenatchee & other Cities Don and Carol Hinman--509-884-2176,

Olympia, Washington & surrounding cities. Ursula Schmidt, 360-456-8097, [bobuschi@msn.com](mailto:bobuschi@msn.com)

Olympia, Washington State Capitol (DOT), State Capitol Employees - Larry Julius, 360-426-0100, [LJuliu600@aol.com](mailto:LJuliu600@aol.com)

Port Angeles, Washington - Paul Tucker, 360-452-6487, [paulavr@olympus.net](mailto:paulavr@olympus.net)

Richland-Kennewick-Pasco Washington Norma Peters, 509-946-5485, [nevers@televar.com](mailto:nevers@televar.com)

Spokane, Washington Sharman Collins, 509-448-8517, (no meetings), [sharmancollins@msn.com](mailto:sharmancollins@msn.com); Website: [www.polionet.org](http://www.polionet.org)

Tacoma, Pierce County & Surrounding Cities Marlys Tron, 253-863-9556

Vancouver, Washington - Susie Koeser, 360-574-4523, [vipsusie@msn.com](mailto:vipsusie@msn.com)

Whidbey Island, Washington & Surrounding Cities Dorothy Michel, 360-675-4727, [deejaymichel56@comcast.net](mailto:deejaymichel56@comcast.net)

Yakima Lower Valley - Bev Nading, 509-837-4265 [cubfarms@bentonarea.com](mailto:cubfarms@bentonarea.com)

Yakima Valley Polio Network - Sarah Doyle--509-469-0348, [ldsarah@peoplepc.com](mailto:ldsarah@peoplepc.com)

### VIDEO REVIEW - VIDEO NO. 15

**TITLE:** Post Polio Challenges **SUBJECT SKILLS:** Post-Polio Basics **PRESENTER:** Dr. Jackquelyn Perry

**Review** -- Gives a good overview on what Post-polio is. Dr. Perry is a well known doctor in the field and answers some very good questions. Even for those who have had a lot of prior knowledge. **Subject Valid:** YES  
**Library Rating:** GOOD **Reviewer:** Susie Koeser

"Polio Outreach Of Washington"  
**OFFICE - 4704 235th St. East**  
**Spanaway WA 98387-6162**

1-800-609-5538 or

253-847-8114 Fax No: 253-846-0973

#### BUSINESS HOURS

Mon-Fri 9:00 AM to 3:00 PM

**Non-business hours:** Leave message.  
We will return your call as soon as we can.

Office Director - John M. Clark

Newsletter Editor, Vivian J. Clark ++  
E-mail for: POOW Office, John and Vivian  
[poow85jmc@msn.com](mailto:poow85jmc@msn.com)

PRESIDENT, Susie Koeser 360-574-4523  
E-mail: [vipsusie@msn.com](mailto:vipsusie@msn.com)

VICE-President, Sarah Doyle 509-653-2189  
E-Mail: [ldsarah@peoplepc.com](mailto:ldsarah@peoplepc.com)

Secretary, Barbara Ellis 360-574-1864  
E-mail: [barbara41509@msn.com](mailto:barbara41509@msn.com)

++ Treasurer, Susan Harter 253-887-0123  
E-Mail: [hsuzi@aol.com](mailto:hsuzi@aol.com)

### REVIEW OF LIBRARY INFORMATION

By: Newsletter Editor

The Polio Outreach Of Washington Board are reviewing the videos in our Library. After reviewing, they decide if the video works and if the content makes it a good video for polio survivors. Periodically we will put the Review of Library Information statements throughout the newsletter. If you want to see one of them, contact the central office at:

1-800-609-5538, or local 253-847-8114  
or E-mail the office - [poow85jmc@msn.com](mailto:poow85jmc@msn.com).

**VIDEO NO. 14 Subject Skills: Survival Skills - Lifestyle Changes.**

**TITLE - Surviving But Not Always Thriving with PPS. Presenter: Dr. Halstead**

**Review:** Dr. Halstead, a polio survivor tells what new medications are helping and gives examples of what he is doing and using to help him survive PPS. It has a good example of how other polio survivors can help.

**Subject Matter Valid?** YES  
**Library Rating:** GOOD

**Reviewer:** Susie Koeser





**Polio Outreach Of Washing-  
ton**

Please cut out on broken line and use this form when you are submitting any information. Always write your name, address, phone and E-mail etc. This will help us get it posted to the correct person. Thank You!

Since we are an independent, non-profit organization we rely on our readers and membership for support. We appreciate and thank all of you who have sent donations. 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**

- This is my first contact with Polio Outreach of Washington. (Washington State)
- This is a NAME and/or ADDRESS CHANGE
- I would like to receive your newsletter.
- I am making a donation. (Suggested \$20.00)  
\$ \_\_\_\_\_
- E-mail: \_\_\_\_\_
- Phone: \_\_\_\_\_

— LAST NAME	FIRST NAME	M.I.
MAILING	ADDRESS	
CITY	STATE	ZIP

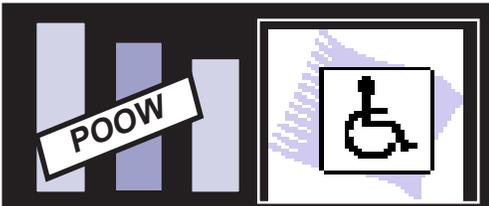
**Please make checks payable to: >>>>**  
Mail Check with complete form to:>  
E-mail: [poow85jmc@msn.com](mailto:poow85jmc@msn.com)

**Polio Outreach Of Washington**  
4704 235th St. East  
Spanaway, WA 98387-6162

**PHONES**  
1-800-609-5538  
253-847-8114

**POOW DISCLAIMER** -- People who had polio and are experiencing new symptoms need to be assessed by medical professionals who are experienced in Post-Polio to determine what is wrong and to give correct advice. Take what you believe to be relevant to your Medical Professional. 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 need to have prior approval of the Polio Outreach of Washington (State) Newsletter Editor, or Susie Koeser, President. See PAGE 10 of the newsletter for phone/e-mail addresses.**



4704 235th St. East  
Spanaway, WA 98387-6162

Return Service Requested

Non-Profit  
Organization  
U.S. Postage Paid  
Permit No. 96  
Seahurst, WA

PRINTED BY:  
CAPITOL CITY PRESS  
SECOND QUARTER 2005



[ ]  
[ ]

