

Polio Outreach Of Washington

State of Washington, Non-profit Corporation

"MISSION STATEMENT"

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

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"POLIO OUTREACH HEADLINES"

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"One Psychologists Perspective on the Polio Experience: The Perky, Plucky, Patient Persona"

By Margy Hull, Ph.D (Reprinted from PPASS Times, Newsletter of the Post Polio Awareness & Support Society of MN, 7220 York Ave. So. #520, Edina MN 55435-4461)

I think I can pinpoint the event that started it. It was October 1952, and I was eight years old. Two Air Force pilots had volunteered to use a National Guard cargo plane to fly me in my iron lung from my hometown of Plattsburgh, New York to Buffalo, New York, at the opposite corner of the state, where I was to proceed with the second stage of my recovery from acute polio at the Chronic Respiratory Disease Research Institute, or something long and complicated like that. It was a very noisy, turbulent, prolonged flight, and my two handsome pilots were concerned about how I had fared on the journey.

It was then that I learned that there was much admiration to be gained from being perky, plucky, and patient (read "not complaining")

As I recall, they broke out in relieved grins when I told them that it had been great fun, especially the bumpy parts. It was then that I learned that there was much admiration to be gained from being perky, plucky, and patient (read "not complaining") and that admiration was a great balm to my bruised and battered self-confidence, self-esteem, and sense of being safe in the world.

Thus it was that I adopted this new persona, this mask that I would present to the world, this false self that would "win friends and influence people"

(You may ask how that admiration helped me to feel safer. It gave me a sense of interpersonal power that I could use to influence all these strangers around me who had assumed such control over my life and well-being.)

Thus it was that I adopted this new persona, this mask that I would "win friends and influence people" while it protected my angry, sad, frightened real little girl self. As I adjusted to my new hospital environment, this new persona got a workout. I was the only female in a ward of about seven males ranging from six to perhaps 45 in one large room.

'More Of Christmas'

*There's More to Christmas...
There's more, much
more to Christmas
Than candle-light and cheer;
It's the spirit of sweet
friendship
That brightens all the year;
It's thoughtfulness and
kindness,
It's hope reborn again,
For peace, for understanding
And for goodwill to men!*

The Perky, Plucky, Patient Persona

(Continued from Page 1)

My new perky plucky patience got me drafted into a new version of USO, or at least so it seemed to me, and it was now my duty to cheer up these unhappy boys and men, and to be an example of the ideal patient who always smiles, was willing to try anything, and put up with all manner of discomfort and pain with minimal complaint. Now, you may say to me, surely this was all in your mind, and certainly a large part was, but I swear I recall being carried from bed to bed, even being placed on at least one of said beds next to said unhappy boys and men, and asked which one was my favorite, knowing full well what my answer should be, of course, changing from bed to bed. What can I say? It was a different time.

Fortunately for my shaky sanity, there was one of those males, Hank, I think 19 years old, whose bed was next to mine, who somehow let me know that there was no need for that mask with him, that it was OK to be myself and that he would be himself, that we would be homesick, scared, angry at our fate, whatever it was, and there was no need for us to put on an act with each other. I still felt that it would be to my benefit to get the staff on my side by being adorable and cooperative (not that there were no chinks in my persona armor, of course), but Hank kept me aware of who I really was. (We kept up a correspondence for many years thereafter.)

Three or four months late, I was moved to another larger hospital in West Haverstraw, in another corner of New York, still far from home. Here I was one of about 25 little girls all on one ward with many other such ages and sex segregated wards all over the hospital. Here I felt a strange combination of loss and loneliness, with immense relief that my mask had for the most part become irrelevant. I was no longer the center of attention, and there were far fewer people to impress with my perky, plucky, patience. The other little girls didn't give a hoot for my persona, and there was a lot of time to think and just pass time. Perhaps it was only then that I began to fully grieve for my home, my family, my former life and self. In time, my ward mates became engaging companions just like the friends I left at home.

All this is not to say that my mask was totally retired. It was fun and politic to win over new therapists and nurses with a smile (doctors in those days seem impervious to charm), and to be plucky and brave like Nancy Drew. Who wouldn't like to be admired as the "good patient"? Often today I will feel the call to put on when I'm in a medical situation. Sometimes now days it competes with the new persona of the competent, well-informed, assertive consumer, who puts up with no guff. Sometimes they struggle mightily for who will take precedence over the issue of how much to complain. For some reason, I also feel it coming on when I'm in a crowd in public, like my old stomping ground of the Atlantic City Boardwalk or in any mall.

(Continued in next column.)

I feel a call, similar to my "USO responsibilities" in 1952, that I am somehow a goodwill ambassador from the disabled community who reaches out, in case, to the "chronically normal" * to let them know that we are quite likeably acceptable in a perky, plucky way. It no longer feels defensive, but actually quite fun, with the added challenge of not bumping into anyone when it's really crowded.

I write this thinking that many of us polio survivors have taken on personas of similar or perhaps different kinds that helped us to adapt to difficult interpersonal environment in the acute stage of our life with polio. I'm wondering if others have felt that the persona risked stifling their true selves, and that they have had to adjust it to better deal with current circumstances and new disability.

* This phrase was used by Fred Frese, a psychologist who experienced episodes of schizophrenia, to describe those people who have no obvious disability. Margy Hull Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County, New Jersey.



MEET OUR NEW POOW PRESIDENT SUE WARREN

As editor I am pleased to introduce to you our new President. Her name is Sue Warren and she comes to us from the Everett support group, being a member for almost 14 years. She contacted polio at the age of 22 months. The Post-Polio Syndrome was diagnosed approximately in 1990.

Sue has been a very busy lady. She got involved with POOW Board in October 2005. Prior to coming on the Board she worked in the following areas:

- 4 Years Accounts Payable Supervisor for a Seattle Manufacturing company.
- 30 Years involved with Early Childhood Educator (teacher/director, curriculum supervisor, trained staff, directors)
- Treasurer for Pilchuck Condo Association (non-profit).
- Past Member - Day Care Center Board Lynnwood Free Methodist Church. Also on the Trustees Committee, Pastor's Advisory Board, and Chairperson - Prayer Ministry
- Secretary Maple Park Elementary
- Second Secretary Day Care Parents Association of Washington State
- President - YMCA Parent-Child Programs in Edmonds
- Girls Softball coach 4 years

Her favorite hobbies are; Quilting, Gardening, Sewing, making Jam/Jelly, Reading and doing Photos of Birds and Wild Flowers.

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I believe that those of us who have survived Polio and Post-polio need to reach out and mentor those

"About Bananas"

Good info for prevention!

Submitted by Bob Miller

After reading this you'll never look at
a banana in the same way again

So, a banana really is a natural remedy for many ills. When you compute it to an apple, it has four times the protein, twice the carbohydrates, three times the phosphorus, five times the vitamin A and iron and twice the other vitamins and minerals. It is also rich in potassium and is one of the best value foods around. So maybe its time to change that well-known phrase so that we say, "A banana a day keeps the doctor away!"

Bananas contain three natural sugars - sucrose, fructose and glucose, combined with fiber, a banana gives an instant, sustained and substantial boost of energy. Research has proven that just two bananas provide enough energy for a strenuous 90-minute workout. No wonder the banana is the number one fruit with the world's leading athletes. But energy isn't the only way a banana can help us keep fit. It can also help overcome or prevent a substantial number of illnesses and conditions, making it a must to add to our daily diet.

Depression - According to a recent survey undertaken by MIND amongst people suffering from depression, many felt much better after eating a banana. This is because bananas contain tryptophan, a type of protein that the body converts into serotonin, known to make you relax, improve your mood and generally make you feel happier.

PMS - Forget the pills -- eat a banana. The vitamin B6 it contains regulates blood glucose levels, which can affect your mood.

Anemia - High in iron, bananas can stimulate the reduction of hemoglobin in the blood and so helps in cases of anemia.

Blood Pressure - This unique tropical fruit is extremely high in potassium yet low in salt, making it the perfect way to beat blood pressure. So much so, the US Food and Drug Administration has just allowed the banana industry to make official claims for the fruit's ability to reduce the risk of blood pressure and stroke.

Brain Power - 200 students at Twickenham (Middlesex) school were helped through their exams this year by eating bananas at breakfast, break and lunch in a bid to boost their brain power. Research has shown that the potassium-packed fruit can assist learning by making pupils more alert.

Constipation - High in fiber, including bananas in the diet can help restore normal bowel action, helping to overcome the problem without resorting to laxatives.

Hangovers - One of the quickest ways of curing a hangover is to make a banana milkshake, sweetened with honey. The banana calms the stomach and, with the help of the honey, builds up depleted blood sugar levels, while the milk soothes and re-hydrates your system.

Heartburn - Bananas have a natural antacid effect in the body, so if you suffer from heartburn, try eating a banana for soothing relief.

Morning Sickness - Snacking on bananas between meals helps to keep blood sugar levels up and avoid morning sickness.

Mosquito bites - Before reaching for the insect bite cream, try rubbing the affected area with the inside of a banana skin. Many people find it amazingly successful at reducing swelling and irritation.

Nerves - Bananas are high in B vitamins that help calm the nervous system.

Overweight and at work? - Studies at the Institute of Austria found pressure at work leads to gorging on comfort food like chocolate and chips. Looking at 4,000 hospital patients, researchers found the most obese were more likely to be in high-pressure jobs. The report concluded that, to avoid panic-induced food cravings, we need to control our blood sugar levels by snacking on high carbohydrate food every two hours to keep levels steady.

Ulcers - The banana is used as the dietary good against intestinal disorders because of its soft texture and smoothness. It is the only raw fruit that can be eaten without distress in over-chronicler cases. It also neutralizes over-acidity and reduces irritation by coating the lining of the stomach.

Temperature control - Many other cultures see bananas as a "cooling" fruit that can lower both the physical and emotional temperature of expectant mothers. In Thailand, for example, pregnant women eat bananas to ensure their baby is born with a cool temperature.

Seasonal Affective Disorder (SAD) - Bananas can help SAD sufferers because they contain the natural mood enhancer tryptophan.

Smoking - Bananas can also help people trying to give up smoking. The B6, B12 they contain, as well as the potassium and magnesium found in them, help the body recover from the effects of nicotine

"About Bananas"

(Continued from Page 3)

STRESS - Potassium is a vital mineral, which helps normalize the heartbeat, send oxygen to the brain and regulates our body's water balance. When we are stressed, our metabolic rate rises, thereby reducing our potassium levels. These can be rebalanced with the help of a high-potassium banana snack.

STROKES - According to research in "The New England Journal of Medicine," eating bananas as part of a regular diet can cut the risk of death by strokes by as much as 40%!



2006 POOW PICNIC REPORT

By Sue Warren, Secretary

Sunday, August 13, 2006 the Everett/North King County Support Group of Polio Outreach Of Washington hosted the 10th annual picnic at Jaunita Beach Park in Kirkland, Washington. A HUGE 'Thank You' to the group and their leaders Rhonda and Lauris Whitehead for a GREAT job. The weather was beautiful and warm on Lake Washington and we had a generous amount of space assigned to us by the Parks Department with a nice shelter, and tables. About 112 people attended, -- one of our largest gatherings, and of those 6 were brand new people!

Murphy's Law -- "Anything that can go wrong, will!" -- did sort of come into play when Rhonda, fell and broke her wrist. She and her daughter wound up spending their 'picnic' at the emergency room. Then our original caterers got lost and couldn't find us. THANKS so much to everyone for your patience! Lauris was able to arrange with "SPUDS" -- which was across from the Park to make lunches for all in less than an hour! A letter of thanks will be sent to SPUDS. Our original caterers were finally able to find us, and with abject apologies, also served some nice deli box lunches. (They also agreed to waive the bill!)

We had some delightful bright spots in the day. Lots of visiting time, and our inspirational speaker Dan Miller, himself a polio survivor. He reminded us to "Risk and Persist", to 'not give up on dreaming big' and keeping our sense of humor and delight in our world. Dan has also published a book "Living, Laughing and Loving Life". If you were unable to get a copy at the picnic, his E-mail is: danmiller@telebyte.com.

I attempted to step in for Rhonda as MC, but she's one hard act to follow! Much more organized, and gracious than I will ever be! So for those items that didn't get done (like the wheelchair races) or were forgotten, I apologize profusely. Still, I hope everyone had as an enjoyable time as I did.

Thank you Everett, Marysville, Snohomish County,



Chicago's Roman Catholic Archbishop, He's Is A Polio Survivor!

Submitted by Rona Nelson. This man used to live and work with the church in Yakima.

By Judith Graham, Baltimore Sun
September 22, 2006

Janet Felde feels a connection to Cardinal Francis George, who's recovering from surgery for bladder cancer. Like Chicago's Roman Catholic Archbishop, she's a polio survivor.

George, 69 contracted polio at age 13; to this day, he wears a leg brace to support muscles ravaged by the viral illness. Felde, 58, caught the disease as an 11 month-old infant and has lived with its after-effects since. "As a fellow survivor, I'd like the cardinal to know: "you're an amazing example to us all. And please, please, take care of yourself," said Felde of Downers Grove, Ill.

Medical experts say it's advice worth heeding.

As the last Americans struck by polio advance into their senior years, the disease's residual impact is exacerbating the effects of aging and later-life illness, such as George's cancer.

That can pose new challenges to individuals who, like George, have dealt with their disability by refusing to let it define their identity or limit their sense of possibility.

"Most of my patients with polio are Type A high achievers," said Dr. Irwin Siegel of Rush University Medical Center in Chicago, who has treated polio survivors since the 1950's. "They resist anything that labels them as handicapped, and they don't want lifestyle changes like working less. "If they start getting weaker - which most do with age - their response is usually to try harder, which can backfire and make the weakness even worse. You have to convince them to back off and get some rest."

Easing up may be hard for George, who is used to overcoming obstacles and pushing himself to the limit. The cardinal plans to return to a full public schedule Oct 1 and to make a demanding trip to Rome about two weeks later. George is an extraordinarily disciplined man who exercises daily to keep muscles in his legs and trunk in shape, according to Colleen Dolan a spokeswoman for the Roman Catholic Archdiocese of Chicago.

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Chicago's Roman Catholic Archbishop - Survivor

(Continued from Page 4)

Although he "does not speak about his polio he's never wanted that to be the focus of this life ... it's very much a part of who he is," Dolan said.

One of the most feared diseases of the 20th century, polio largely disappeared from the United State after the Salk vaccine became available in the mid-1950s. There are 1.6 million American polio survivors, including 640,000 who had a more severe, paralytic form of the infectious illness, according to Dr. Julie Silver, director of the International Rehabilitation Center for Polio at Spaulding Rehabilitation Hospital in Boston. This subgroup experienced the greatest damage to nerves and muscles and is at greatest risk later in life from polio's after-effects, including fatigue and chronic pain. Those complications don't represent a recurrence of polio; instead, they are the result of long-lasting deficits the disease left behind. An illness such as cancer can compound polio-related weakness, especially for people who undergo potentially disabling treatments or need extensive bed rest that can contribute to muscle atrophy.

"A real risk for the cardinal was a significant decline in his functional status, due to the combined effect of the cancer and the earlier polio," said Dr. James Sliwa, a polio and cancer rehab specialist in the Rehabilitation Institute of Chicago. The challenge for George, the doctor suggested, will be to balance the need for activity with the need to conserve and prevent muscle overuse. Scientists are still exploring what causes the late effects of polio. In addition to the natural effects of aging, there are two main theories, said Dr. Eric Sorenson, section head of neuromuscular diseases at the May Clinic. One is that overtaxed motor neurons - cells that transmit messages to muscles - wear out over time. The other is that a continuing inflammatory reaction may slowly worsen muscle damage.

When someone is young, the body has a remarkable way of compensating for polio-related neuron loss: Unaffected neurons start doing double-duty, sprouting new shoots that activate nearby muscles. But with age, motor neurons begin to wear out and die, reducing the body's ability to adapt. Overuse may contribute to the deterioration. "If you've got a lot of neurons in reserve, like most people do, you probably won't notice much difference," Siegel said. "But if you've had polio, your bank account of neurons will be severely depleted." Then there are ailments related to the strain of compensating for a disability. "someone who has worn a brace most of their life may be more vulnerable to arthritis or more likely to fall," said Silver, whose mother, grandfather and uncle caught polio just after the end of World War II.

(Continued in next column.)

Arms that have helped a polio survivor rise from a sitting position over the years may weaken. Knees that have borne the stress of an uneven gait may begin to give out. Wear and tear on a hip may contribute to what many polio survivors describe as "deep, burning, aching" muscle and back pain, Silver said.

For some, these symptoms are sufficiently far-reaching to merit a diagnosis of "post-polio syndrome." More than 300,000 Americans may suffer from this condition, which typically surfaces 15 to 30 years after an initial episode of polio, Silver estimates. There are no proven treatments other than lifestyle modifications. Other survivors, such as George, aren't diagnosed with the syndrome but have episodes of difficulty related to their long-ago disease. Patricia Morris, 57, who was hospitalized with polio for seven months in 1943 at age 4, says re-encountering the illness later in life takes an emotional toll.

"You can't believe this is happening to you again - it can't be," said Morris of Rolling Meadows, Ill. "You fought so hard to get where you were and you feel you can't lose it, so you fight harder. And the more you fight, the worse it becomes." With years of physical therapy, Morris was able to walk with crutches and a brace, marry, have two children and work in an office. Then in the 1980s, her legs began to weaken and her shoulders began to ache nonstop. Today, she can stand only for 30 seconds and uses a scooter to get around.

"What's the point of feeling sorry for yourself?" Morris asked. "You put it behind you and you go on." Morris has watched George from afar over the years, wondering and worrying about his stamina and his very busy schedule. Now, she said she'll be paying particular attention, as the cardinal steps back into his role with the public's attention newly focused on his health.

"All I can think is, everyone is going to see him and know what he's had to go through," Morris said. "And that's something special for people like me who know what it's like." 

*The most vivid memories of
Christmases Past are usually not of
gifts given or received, but of the spirit
of love, the special warmth of
Christmas worship, the cherished little
habits of the home.*

NEW BOOK!

The Post-Polio Experience:
Psychological Insights and Coping
Strategies for Polio Survivors
and Their Families

*By - Margaret Backman, Ph.D., Clinical
 Psychologist in New York City*

Margaret Backman, Ph.D., a clinical Psychologist in New York City, has written numerous articles and given presentations on the psychological aspects of post-polio syndrome. She has now published a book based on her more than 25 years of experience with those who had polio.

Today many polio survivors find themselves with new symptoms reminiscent of the earlier days when they first had polio. These new symptoms trigger frightening memories that had long been repressed, along with anxieties about what the future holds.

In **The Post-Polio Experience** Dr. Backman, examines polio survivors' psychological reactions to their earlier experiences and to their current struggles with the late effects of polio. Topics include:

- ◆ Understanding the early years
- ◆ Issues of abandonment and anxiety, loss and bereavement
- ◆ Facing the future
- ◆ The Polio Personality: Does it exist?
- ◆ Role changes from the perspective of significant others

The book also includes practical guidelines for survivors on:

- ◆ Coping with the emotional and interpersonal aspects of PPS
- ◆ Giving and receiving help, gracefully
- ◆ Managing stress and depression
- ◆ Negotiating relationships with family and friends
- ◆ Developing a positive self-concept
- ◆ Improving doctor-patient communication

Family and friends will also find **The Post-Polio Experience** of interest. In the book they learn how to deal with the changing roles that they and the survivor now face and gain insight into their own needs, which interact and sometimes conflict with the polio survivor's needs.

Mental health providers, physicians, and other health professionals gain a better understanding of their patients' psychological reaction to Post-Polio Syndrome--paving the way for more effective treatment. An entire chapter is specifically written for physicians to aid them in their interactions with polio survivors.

The Post-Polio Experience can be purchased through the publisher: www.iuniverse.com, or 800-288-4677, Ext. 501. The book is also available through Amazon.com, Barnesandnoble.com, and through special order at Barnes and Noble bookstores. The cost is \$18.95, plus shipping and sales tax, where applicable.



'NEW'
BELLINGHAM POST-POLIO
SUPPORT GROUP LEADER
MR. PATRICK EWING

Polio Outreach Of Washington is proud to introduce to you the new leader of the Bellingham Polio/Post-Polio Support Group, Patrick Ewing. Pat lives in Everson with his wife Joanne. He called the POOW office and attended our last Fall Retreat meeting in Rochester. We all got the wonderful chance to meet him. Pat and Joanne have three children and two grandchildren.

He previously worked in the parts department of a Volkswagon dealership, for Puget Sound Energy in the Purchasing Department, and is now retired from Real Estate. He retired ten years ago at the age of 44 due to health reasons.

"Goal for the Bellingham group" - to share polio survivor stories and educate each other on the late effects of Post-Polio Syndrome. Build a positive atmosphere and have fun in outreaching together to other new Polio survivors.

The first meeting will be held at St. Joseph Hospital in Bellingham on NOVEMBER 25th We will meet in the Cafeteria downstairs, in the Physicians Dining Room.

ST. JOSEPH HOSPITAL
 2901 SUALICUM PARKWAY
 BELLINGHAM WA 98225
 Phone: 360-734-5400

We can eat in the cafeteria at NOON. The meeting begins at 12:30 PM. Pat Ewing would appreciate, since it's a new meeting, if you could please R.S.V.P.

Pat Ewing can be reached at: 360-966-4253
 E-mail address: pre47airstream@aol.com



Polio Survivors' Painful Body Parts: The BIG Four - By Richard Bruno

Polio Shoulder: Because polio survivors usually have more leg than arm muscle weakness, they use their relatively stronger uppers to compensate for weaker lowers. So, when getting up out of a chair, climbing out of the bath or walking using crutches, the arms take the freight. The joint that complains most is usually the shoulder, the pain typically caused by bursitis or tendonitis. Sometimes, shoulder pain and an inability to lift your arm directly upward in front of you may be signs of a rotator cuff tear that could require physical therapy or, possibly surgery.

Polio Neck: "Polio shoulder" can also be a part of "polio neck," when the muscles that move the head and those that "shrug" shoulders upward, go into spasm due to overuse weakness and poor posture. Polio neck is also the number one cause of headaches in polio survivors.

Polio Wrist: "Polio wrist" is usually caused by carpal tunnel syndrome, the squishing of the nerves that pass across the wrist. Polio survivors have much more carpal tunnel syndrome than the general population because pain in the wrists develops in the same way as a polio shoulder - from overuse of joints - and in the case of the wrist, with repeated hyperextension (bending backward) as you push yourself upward from sitting to standing or walk using crutches.

Polio Hip: Pain in the hips also is often the result of bursitis or tendonitis caused by weak muscles trying to keep you from wobbling back and forth. Polio survivors and many doctors immediately assume that all hip pain is due to arthritis. Polio survivors can have arthritis, but hip pain is almost never caused by arthritis. Again, it is irritated tendons and ligaments that are making you hurt. What's more, what you call hip pain may actually be caused by low back or butt muscles going into spasm as they try to compensate for weak leg muscles.

What do you do about the big four? Since pain is triggered by overuse, you need to take the load off of angry joints, their weakened muscles and nerves and their abused ligaments and tendons. Raising the height of chairs, using a toilet booster seat with arm/hand grips to help you stand and using a wide tub bench instead of standing in the shower or hauling yourself in and out of the tub will take the load off your upper body.

Once you are up, using lightweight Lofstrand crutches is better than using nothing or even a cane. If you have "polio wrist" crutches that have foam covered hand grips or grips that are ergonomically designed could be a big help. (See www.wakeeasy.com).

(Continued in next column.)

Crutches are also helpful for polio hip since they balance you from front to back and side to side, taking the load off of strained tendons and ligaments and weak hip, back and butt muscles. Of course, rolling in a power wheelchair is better than walking to ease all post-polio pains.

If taking the load off isn't helping enough, bursitis, tendonitis and muscle spasm can be treated by a physical or occupational therapist with ultrasound, heat (and sometimes, ice) and deep tissue massage. Your doctor may want to try a non-steroidal anti-inflammatory drug, like ibuprofen or Celebrex. However, oral steroids should almost never be used to treat bursitis and tendonitis since their side effects are very unhelpful for most polio survivors. However, a few injections of cortisone and a local anesthetic into a joint or a muscle, followed by the above therapies, can knock down inflammation and prevent spasm. Local injections of cortisone in the wrist can also help reduce inflammation and swelling in those with carpal tunnel syndrome.

Sometimes, surgery may be required to treat CTS when the nerves are being pinched and damaged - and to repair a rotator cuff. For some rotator cuff tears, therapy is recommended to increase muscle strength. Strengthening should be done without causing fatigue, muscle weakness or pain and only after pain is gone. Asking a polio survivor to strengthen an overworked joint or muscle is like trying to put out a fire with gasoline.



Reprinted from Polio Deja View, Central Virginia Post-polio Support Group, October-November 2006.



Twelve Things To Remember For the New Year

The joy of originating
The power of kindness
The improvement of talent
The worth of character
The dignity of simplicity
The virtue of patience
The pleasure of working
The wisdom of economy
The success of perseverance
The obligation of duty
The influence of example
The value of time.

Talk to Me, Doctor!

Information from June Isaacson Kailes' book "Be a Savvy Health Care Consumer, Your Life May Depend on It".

Finding your way safely through the increasingly complex health care jungle is never easy, especially if you are sick. It can be a tricky and pressure-filled business, but there are ways to protect yourself. The most important thing is to recognize that ultimately you alone are responsible for managing your own health. June Kailes, a Disability Policy Consultant, points out that consumers, especially disabled consumers, have to stand up for themselves, treating health professionals as consultants rather than as gods.

Passive consumers want providers to take charge of their health, rely totally on providers' advice, do not ask questions, offer information only when asked, are complacent and have fatalistic "what will be, will be" attitude, are not interested in thinking about options, are hesitant to disagree with or confront their healthcare will be compensated if they ask questions or disagree. In fact, research confirms that providers, often feel helpless and lost in the health care system, and worry that their people who are more active in their relationships with their physicians have more positive results.

As providers get to know you, they're able to see you as an individual rather than a textbook or theoretical case. Visiting a provider can be highly stressful. Being partially or completely undressed and addressing the doctor in a white coat can be intimidating. Some advice for getting over the "white coat" syndrome:

1. Consider bringing an advocate/friend who can listen, take notes, and help ask questions. Choose a support person who has the skill to think objectively and is able to listen and remember accurately. Ask them to assist but not take over.
2. Take notes. "The faintest ink is more accurate than strongest memory."
3. Ask open-ended questions. Avoid leading questions. Leading questions can force providers to give the answer you want, even if it's not true. Wrong or leading questions: "I'm going to be okay, aren't I?" (This implies you may not want to know any bad news.) Right or open-ended questions: What are the chances of my recovery? What's the outlook? My prognosis? What are the implications of treatment.
4. Never be afraid to say, "I'm having trouble understanding. Could you describe the problem in plain terms?"
5. Sometimes what you hear may surprise, shock or upset you. Ask how much time you can take for making a decision without endangering effective treatment.

6. Always consider getting a second opinion. When the second opinion differs from the first, you may feel justifiably confused and decide you want a third opinion. Get one or use a trusted provider to review the differing recommendations.

7. If you have a disability, be sure to find doctors who are "disability-aware." Being a savvy health care consumer does take time and planning. If you do not follow any of these visit strategies, at least remember this: You have the right and responsibility to ask: Why? Why not? How? When?

Reprinted from Polio Deja View, Central Virginia Post-polio Support Group, October-November 2006.

Sinus Infections and PPS

By Joyce Insley printed from
Polio Connection Of America

I wanted to say a little something about sinus infections. I used to stay on antibiotics for sinus infections. I even had sinus surgery. As soon as I was off the antibiotics from the surgery, I got "another" sinus infection.

I stayed in the doctors office, getting shots and different kinds of antibiotics. As soon as I would go off the antibiotics, I would get another sinus infection. I went through all the tests (twice) and four different specialists.

It wasn't until the late Dr. Anne C. Gawne diagnosed me with PPS that I finally found out what was causing the sinus infections. Dr. Gawne let me watch a video and then she explained "why: the infections. I was told that you have four very small tiny gland pockets at the top of your throat. Food goes into the tiny pockets when we eat. It is a normal process for humans.

The problem for PPS'ers is that our throat muscles are weakened by PPS. When we eat, the food is not squeezed from those tiny glands and swallowed. Food stays in them, thus letting bacteria grow, causing infection to "back up" into your sinus cavities. I was taught how to eat and swallow my food so the tiny glands would not retain food. I was told to take small (not tiny) bites, followed by several swallows of water. Tuck your chin down to your chest or turn your head to one side when you swallow.

(Continued on Page 9)

Sinus Infections and PPS

(Continued from Page 8)

This will clear the food from the tiny glands.

Do not chew meat too much, as it tends to get larger the more you chew. I was told to stay away from potato chips, corn bread, and rice. These foods tend to stick in the glands worse than most foods.

It is important that you get use to tucking the chin or turning your head sideways and drinking plenty of fluids with your food. I was taught this method of eating in October 2001 and I have only had one sinus infection since I started using "this method" to eat.

I had been having sinus infections, back to back for approximately 6 years before I saw Dr. Gawne. I think this is a problem that you need to speak to your doctor about.

It was such a simple change in eating habits that change my health problems. The bites that you take of your food can't be so small or they will go into the glands. Drinking plenty of fluids will keep the glands washed out. I hope this information helps some of you.
The Seagull July, 2005



PRESIDENT - SUE WARREN

(Continued from Page 2)

I believe that those of us who have survived Polio and Post-Polio need to reach out and mentor those who are just starting the journey. Adjustments must be made in life-styles, but life and life quality can still be enjoyed and fulfilling.



My wife, who recently passed away, was a polio victim who was suffering from Post-polio syndrome.

I have 2 walkers, 2 canes (1 collapsible) and 2 toilet "booster seats" (1 for round bowls and 1 for Elongated bowls).

If you can use any of these items please let me know and I will be more than happy to deliver them locally.

Contact Mike Jewitt: 253-941-3487
Federal Way, Washington
KB7WBL@hotmail.com



"From The Board Column"

The POOW Fall Retreat and Council Meeting was held at the lovely Eagles Landing Hotel near Rochester (West of Centralia). Usually there are guest speakers to address concerns and educate our members. This year Lisa Willts of Southwest Washington Medical Center (Outpatient Neurological Rehabilitation, spoke. She gave a very up-beat, informative presentation on "Living with Post-Polio Syndrome, "It's All About Quality".

Our next retreat is the April Spring Retreat which will be held at the same site as the Fall Retreat in Rochester, Washington on April 17, 18, 19, 2007. Watch for registration information.

The twice yearly Council Meetings are an opportunity for Support Group Leaders and up to two delegates from each State Support Group to be involved in setting goals and electing officers or be on one of our committees.

At the Fall Retreat several Support Groups were represented: Marlys Tron and Sandra Morley of Tacoma -- Patrick Ewing, new from Everson (Bellingham area) -- Carol and Ray Moline of Lacey -- Carl Larson and Ann Wickstrom, Everett/Seattle. Board members represented Bremerton, Bickelton, Vancouver, Renton, Allyn, and Covington areas.

POOW is a 100% volunteer organization -- no paid staff. This means that more than 87% of donations goes into providing information and resources to polio survivors and their families/caregivers.

They get together to plan and work on various projects, to benefit all our State's polio survivors. Being on a committee is a great way to get to know other survivors and help guide our organization. We'd love to welcome new people on the Committees. Any Board member would be happy to talk with you and answer any questions. The Committees are: Administration, Newsletter, Public Relation, Outreach/PPS Support, Fundraising, Picnic, Retreat Planning, Finance, Nominations.

New officers are: Sue Warren, President; Susie Koeser, Vice President; Larry Christensen, Secretary and Susan Harter, Treasurer.

I look forward to getting to know you!

Sincerely, Sue Warren

"When The Power Of Love Overcomes
The Love Of Power,
Then, and only Then, Shall We Have Peace"

Polio Outreach Of Washington State Polio/ Post-Polio Support Groups

Contact the LEADERS of the PPS Support Groups for further directions, time and place and other details. If you have any further questions about our Support Groups please contact the Polio Outreach Of Washington's Central Office - 1-800-609-5538 or
Local - 253-847-8114.

Bellingham - New Leader - Patrick Ewing 360-966-4253
First meeting November 26, 2006 is at St. Joseph Hospital the 4th Saturday of each month, from Noon to 2:00 pm.

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

Clarkston, Idaho: Tri-State Polio Pals
Jim Hueston, 208-790-3805, rockinnj@clarkston.com

Ellensburg Call 800-609-5538

Everett, Marysville, Snohomish County, & Seattle, & North King County Rhonda Whitehead 425-488-0219 lauriswh@comcast.net (2nd Saturday of each Month.).

King County (South) Renton, Seattle, Maple Valley, Auburn, Federal Way 3rd Saturday of each month. 12:00 NOON to 2:00 pm - potluck call leader.
Mimi Sangder 206-725-8937, fuzzface7@juno.com

North Central Washington - Wenatchee & other Cities
Don and Carol Hinman, 509-884-2176, 3rd Monday 5:00 - 7:00 pm City Side Cafe in Red Lion
dchinman@charter.net

Olympia, Washington - Ursula Schmidt, 360-456-8097, bobuschi@msn.com

Olympia, Capitol (DOT) State Capitol Employees
Larry Julius, 360-426-0100, LJulius600@aol.com

Port Angeles, Washington Paul Tucker, 360-452-6487 paulavr@olympus.net

Richland-Kennewick-Pasco Washington
Norma Peters, 509-946-5485, nevers@televar.com

Spokane, Washington Sharman Collins, 509-448-8517 SharmanCollins@aol.com

Tacoma, Pierce County & Surrounding Cities
Marlys Tron, 1-253-863-9556 & Flo Anrud 253-588-0655, anrud11444@foxinternet.com 1st Monday usually 1:00-3:00 pm (Do not meet in January or July.)

Vancouver, Washington Susie Koeser & Stan Nelson
Co-leaders 360-574-4523, vipsusie@msn.com or Stan stanor@juno.com (Call for information details.)

Oak Harbor, & Whidbey Island WA 1-800-609-5538

Yakima Lower Valley
Bev Nading, 509-837-4265 or 1-800-509-5538
cubfarms@bentonarea.com

Polio Outreach Of Washington CENTRAL OFFICE

4704 235th St. East
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1-800-609-5538 or 253-847-8114

BUSINESS HOURS

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Office Manager - John M. Clark
Newsletter Editor - Vivian J. Clark
OFFICE E-Mail: poow85jmc@msn.com

PRESIDENT - Sue Warren
509-896-5333

E-Mail: gcsuz@earthlink.net

VICE PRESIDENT - Susie Koeser
vipsusie@msn.com

SECRETARY - Larry Christensen
360-613-0783
lchristensen@wavecable.com

TREASURER - Susan Harter 425-277-7663
E-Mail: hsuzi@aol.com

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"Polio Outreach Of Washington" 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 Polio Outreach Of Washington Newsletter Editor.
Vivian J. Clark, at: E-mail: poow85jmc@msn.com
Phone: 1-800-609-5538

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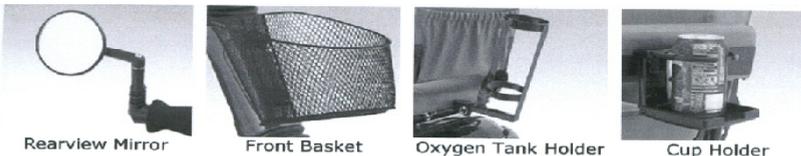
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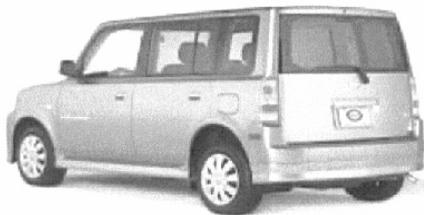
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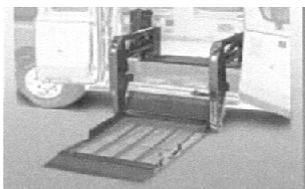


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