

'Polio Outreach Of Washington'

State of Washington, Non-profit Corporation

"Our Mission Statement"

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

NEWSLETTER - 2005 WINTER JAN-FEB-MAR

VOLUME

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'Take Note From Your Editor'

Looking Ahead To Our 10th Annual Picnic - Mark Your Calendar for August 14th, 2005 in Richfield WA
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Welcome To Our New 12 Page Newsletter - with much more information! (SEE PAGE 3)

Vivian J. Clark, Newsletter Editor

Let's Talk About Oxygen & Polio

By Roberta Simon, RN

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From: Post-Polio Health International. Polio Network News (now Post-Polio Health) Summer 1990, Vol 6, No. 3

Many myths and truths are circulating in polio circles about oxygen use in medical crises. This is causing great apprehension for many, especially those who had bulbar polio. I think it is time to clarify some of these misunderstandings.

Let's start with a quote from the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors published by Gazette International Networking Institute (now Post-Polio Health International) in St. Louis. (As far as I'm concerned this is must reading for all polios whether they have the late effects or not!) Under "Oxygen" it states, "oxygen should be used with caution. In the face of hypercapnia, oxygen therapy may eliminate the final mechanism for maintenance of respiratory effort and thus result in apnea. Maintenance of adequate alveolar ventilation is of primary importance. (Definition: alveolar, A small cavity or pit as an air cell of a lung.) In case of severe hypoxia and respiratory failure, mechanical ventilation and oxygen may be necessary." Now that we have all of that technical information lets dissect it so we can digest and understand it!

First, we must understand hypercapnia.

Hypercapnia is excessive (more than necessary) carbon dioxide in the blood. This value can be determined by taking blood from your artery (not your vein as is usually done) when you are admitted to the hospital or when your physician sees a necessity to determine this value, such as prior to surgery.

When the carbon dioxide level in your blood is increased, it causes many symptoms including morning headache, fatigue, and confusion of thought. Unfortunately in polios that have fatigue as part of their post-polio problem, fatigue due to hypercapnia is at times difficult to sort out without testing.

Our second problem is to understand why hypercapnia may eliminate the mechanism that maintains respiratory effort.

Respiratory effort is regulated by the chest muscles and by the medulla, which is part of the brain stem. (Located at the base of your brain. The brain stem may have been affected earlier by polio.) The depth and frequency of breathing is established here.

Now here is the tricky part. If this part of your brain has been functioning at top capacity to assist your breathing since you had polio and it is suddenly assisted by OUTSIDE oxygen, it gets the message that everything is in order -- it says, "Great! I need a rest." And then it goes on vacation! Later, when oxygen is discontinued, there may be a problem getting the respiratory center to function again. Hence, the potential danger of oxygen.

Let's Talk About Oxygen and Polio

(Continued from Page 1)

Fortunately, this is not a problem with all polios! A daytime study of hypercapnia/hypoxic drive may be diagnostic for individuals at risk. The test may be done in a pulmonary function laboratory. If the test is negative, the problem may also be diagnosed by doing a sleep study to determine if you have central (brain-centered) sleep apnea (cessation of breathing while sleeping).

Sleep apnea occurs in polios if the respiratory center of the brain is weak and shuts down for brief periods during the night when the individual has lost control of his/her respirations. One difficulty that results from this is an increase of carbon dioxide in the blood. Increased carbon dioxide may also occur in polios who have chest muscle weakness and may be controlled quite adequately by resting the chest muscles at night. Chest muscles can be rested by using some type of mechanical assistance such as nasal or mouth positive airway pressure.

Because of possible chest muscle weakness, it is imperative that all sleep studies be conducted in a sleep laboratory. Their equipment monitors the movement of your chest muscles while you are sleeping.

(It should be noted that sleep apnea does occur in people that did not have polio or do not have another neurological condition. This type of apnea is called obstructive apnea and is due to airway obstruction or malformation of the jaw.) Obstructive apnea may also be caused by pharyngeal weakness or lack of coordination of muscle function in people that have had polio. These problems cause obstruction of the airway with subsequent cessation of breathing for short intervals of time several times throughout the night. Obstructive events (or apnea) may also have a central origin.

The Handbook goes on to say, "in case of severe hypoxia (decreased oxygen in the tissues) or respiratory failure (failure to breath properly to maintain oxygen in the tissues which is essential to life) mechanical ventilation or oxygen may be necessary. Maintenance of adequate alveolar ventilation is of primary importance." This is an absolutely true statement and should not be take lightly. When you reach this period of crises, you must depend on your physician to help and make decisions.

I think it is important to note that individuals with hypercapnia (excessive carbon dioxide) and apnea (cessation of breathing caused by obstruction, weak chest muscles, or the brain center shutting down) have done quite well following surgical procedures and medical emergencies by being placed in iron lungs or on some other type of ventilation assistance for a short period of time.

All of the above can be evaluated by a knowledgeable pulmonologist and properly equipped sleep study laboratory prior to an emergency situation and should be done if warranted.

(Continued in next column.)

This is why every polio with respiratory or suspected respiratory weakness should have a complete pulmonary evaluation.

If you did not have bulbar polio and if you do not have chest muscle weakness, you are not a risk for this problem! Should you need oxygen it is not a problem. You may be treated and supported through a crisis just as any other individual. However, many people are unaware that they did have mild bulbar polio. It is possible you were never tested for it at the time of your original polio, because only the most obvious cases were diagnosed. Therefore, it is suggested that all polios should undergo pulmonary function screen. These tests should include spirometry, lung volume measurements, and a measure of respiratory muscle strength, such as negative inspiratory force.

Acknowledgements: The author wishes to thank Ann Romaker, M.D., for editing the article and for all her efforts in the past to assist polios. She has been extremely generous with her time both in the Chicago, Illinois, and the Kansas City, Missouri area, where she now resides. Dr. Romaker has a pulmonary medicine practice and is responsible for the sleep and pulmonary laboratories at St. Luke's Hospital in Kansas City, Missouri.

You may contact her at Midwest Pulmonary Consultation, 4320 Wornall Road, Kansas City, MO 64111 (816-756-2255)



LOOKING AHEAD TO AUGUST 2005 -

By Susie Koeser, President

Polio Outreach of Washington, President - Susie Koeser announces that the 10th Annual Picnic will be held in Battleground, Washington on SUNDAY AUGUST 14, 2005. Battleground is just several miles north of Vancouver, Washington. It will be held at the Lewisville Park (Section CENTRAL). The celebration will begin at 11 AM to 5 PM. We will also celebrate the 50th Anniversary of the Salk Vaccine.

PLAN AHEAD NOW AND MARK YOUR CALENDAR!!

Lewisville Park is just beautiful with trails and other things to do. The 2005 SPRING April, May, June Issue will tell you all the specifics, with the cost of motel rooms if you need them, directions and lots of other exciting things. We are hoping for a record number of Polio Survivors and their families and friends



FANTASTIC - POOW Newsletter CHANGES

Reorganization of content and number of issues!

The Polio Outreach of Washington Board of Directors recently decided to make a few changes to our newsletter. We are going from a bi-monthly to a quarterly newsletter.



The quarterly newsletter will have **FOUR** issues with 12

pages. This will give us a grand total of 36 pages of space for articles. The current published eight page issue, six times per year affords only 30 pages for articles.

Although affording minimal savings in printing and postage costs, -- by far the most important result is providing our survivors with more valuable information within a year.

If you have any questions concerning these changes please contact any of the board members. (See Page 10) 

A NAIL IN THE FENCE

A Good Story for Great Friends...

Make sure you read all the way down to the last sentence!

There once was a little girl who had a bad temper. Her mother gave her a bag of nails and told her that every time she lost her temper, she must hammer a nail into the back of the fence.

The first day the girl had driven 3 nails into the fence. Over the next few weeks, as she learned to control her anger, the number of nails hammered daily gradually dwindled down. She discovered it was easier to hold her temper than to drive those nails into the fence.

Finally the day came when the girl didn't lose her temper at all. She told her mother about it and the mother suggested that the girl now pull out one nail for each day that she was able to hold her temper. The day passed and the young girl was finally able to tell her mother that all the nails were gone. The mother took her daughter by the hand and led her to the fence.

She said, "You have done well, my daughter, but look at the holes in the fence.

(Continued on Page 7)

Polio Society Grant to Help Eradicate Polio in Africa By Charlie Preble

*Reprint Permission from OPTIONS published by
The Polio Society in Washington DC 20016.*

One of our Board members had contact with a post-polio support group in South Africa which is named the "Post-Polio Network RSA". This group is directed by a very able polio survivor, Ms. Cilla Webster. This group periodically publishes a newsletter which is distributed to other polio survivors throughout Africa. Her newsletters contain much information of interest not only to polio survivors but for the general public as well.

~~Acute poliomyelitis has been eradicated in Africa by the use of the universal vaccine program except for a few countries.~~ One of Cilla's primary projects is to spread the word to those countries on the importance of all children receiving the polio vaccine. When we learned that Cilla needed a new computer in order to get her newsletter out, the Board voted a grant of one thousand dollars for the "Post-Polio Network RSA".

Ms. Webster's response on news of her grant is quoted below:

Whew! I am so grateful I am speechless. Thank you very much. I must tell you this could not have come at a better time. Africa is going into crisis again regarding polio. As you have probably read, the Muslims in Nigeria are refusing to allow their children to be vaccinated because they believe we are trying to prevent their female children from growing up and bearing their own children because the "live" vaccine has a small amount of female hormones in it. This is going to spread to all the other Muslim communities in Africa, which are very large, and of course we have problems with polio because of refugees going into stable countries fleeing from war. Zambia has just had a large polio epidemic in the east because of the Angolan refugees. It is very sweet how their vaccines are purchased: All the British Airways passengers put their loose change in a box and UNICEF makes up the difference and the vaccines are bought with that money. *Africa is a kaleidoscope of stories about polio and post-polio syndrome and right now without a proper computer it has been a terrible battle for me.*

With a working computer this will all be done and for this I am more than grateful. My life's work is important to me because I don't want anyone to go through life without the knowledge I have to make their lives more comfortable. It is one thing to suffer, but it is another to suffer in total ignorance.

Regards, Cilla 

We Is Friends....?

"Me And You Is Friends

You Smile, I Smile ...

You Hurt, I Hurt ...

You Jump Off a Bridge ...

I'm Gonna Miss You"

TO OUR Readers -- WE NEED YOUR HELP

By Susie Koeser, President

Polio Outreach of Washington is trying to make more information available for those of you who like to have information at hand.

For those who keep everything of importance we are asking you to look in your files and see if you can locate the following newsletters:

<u>YEAR</u>	<u>MONTHS</u>
1988	September/October November/December
1989	May/June September/October November/December
1990	March/April July/August September/October November/December
1991	January/February March/April May/June
1996	January/February

Once we have copies of all our newsletters we will put them on a CD and make them available to those who want a complete copy of all the newsletters. You will not want to miss this, since these articles are not on the website and some are extremely interesting and valuable to all.

Please forward the original newsletter or a copy, to our office. We will return your newsletter to you so please note your return address. We will keep you advised as to the progress. Thank you for your help!



TUNA AND MERCURY

If you like tuna, use chunk light tuna instead of albacore. Albacore tuna has higher levels of mercury -- a contaminant that builds up in oceans and streams, is absorbed by some fish more than others.

Tuna is a healthful source of protein and omega-3 fatty acids, and low in saturated fat.

Safe fish (lowest mercury levels) are canned light tuna, shrimp, salmon, pollock (including "Fish sticks") and catfish. Highest mercury levels are found in shark, swordfish, king mackerel, and tilefish.

Source: U.S. Food and Drug Administration

TOTAL JOINT REPLACEMENT IN POST- POLIO *by Marny Eulberg, M.D.* Educational meeting, September, 1992, Mercy Medical Center - Colorado Post-PolioConnections

My qualifications are that first I am a physician, a family practice physician not an orthopedic surgeon, so I'll give you the generalities of the surgery not the nitty-gritty of how many parts there are or where the screws go. Secondly I am a polio survivor and had a total joint replacement done in March of this year (1992).

The primary reason for a total joint replacement, in fact pretty much the only reason is severe arthritis of the affected joint. Occasionally the same procedure is used for a severe fracture that cannot be fixed any other way. Several joints can be replaced; the most common are hip, knee and finger. There are some physicians who are doing replacements of wrists, shoulders and ankles. The technology for the last three is still being developed so physicians have not had as much experience but it is a possibility.

There are limitations about total joint replacement in folks who've had polio; when a joint is removed, part of the bones and ligaments holding the bones together are removed and replaced with plastic or metal parts. It now depends on your muscles to hold the joint in place and keep it from dislocating. So it is not generally appropriate nor will it be as useful and work for you if you have a joint replacement in a polio affected extremity, unless you have fairly decent muscles around that joint. If you have a very weak leg and you have arthritis in that knee or hip a total joint replacement may not be a good choice.

Fortunately joints that have not carried much weight do not get arthritis nearly as often, particularly the wear and tear of degenerative arthritis. Total joint replacement can be useful for folks who had polio if it is in their good leg, a joint that's wearing out from doing work for two legs all these years. It's not the total answer, it's not without problems and risks. We don't know how long the parts last. They have been doing total hips for 25 years, total knees for 15-20 years before they wear out. We're not exactly sure how many times it can be redone... each time some bone is removed so there's probably some limit as to how many times a joint can be replaced. In general orthopedic surgeons are going to want you to wait as long as possible, be as old as possible and still be in good health in order to survive the surgery and recover from it well. Surgeons are reluctant to do surgery on anyone less than 40 or 50 because we don't know how long the parts will last.

After the surgery intensive physical therapy is required to learn how to use the joint and to strengthen the muscles around the joint to get the range of motion back.

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There are risks as it is a big surgery: 1) 50% chance of getting blood clots, so anticoagulants are used to thin the blood; 2) there is a chance of infection and if we get infection where we have replacement hardware it is difficult to get rid of and sometimes to get rid of the infection we have to take all the parts out then wait six months to a year before another total joint replacement can be done. Surgeons do use antibiotics before and after surgery, they wear all kinds of fancy headgear, the air is recirculated through special filters in the room. 3) Joint replacement surgery is a bloody surgery so surgeons have their patients donate two or three pints of their own blood before surgery.

4) Also parts can loosen, they are put in with glue but over time normal bones around the glue tend to loosen so over the years there is a 10-15% chance of parts loosening.

It's not all bad. If you are hurting a lot and can't do the following items you may need surgery.

1. Can't do the things you want to do.
2. Have restriction of motion and can't bend down to get things, or sit comfortably anymore.
3. Can't get out of the car comfortably anymore.

If the surgery is successful, which it is 90 to 99% of the time, you lose the pain and gain more mobility. But you lose the ligaments that were there for stability so it's not quite the same. It's going to feel and be a little more wobbly, it's more likely it may give out in extreme positions. You also lose proprioception [which] is in a joint and also the muscles where you have nerves tell you where you are in space; tell you whether that joint is straight or bent or partially bent. You can relearn to use some of the other sensors in your muscles but you'll probably feel a little more unsteady on that leg. That can be a problem if that's been your good leg, the one you've always depended on.

Unlike some of you who had orthopedic surgery when you were children or younger, 30 or 40 years ago you were put in a cast for six weeks to six months to heal; now orthopedic surgeons are aware of how important motion is and how joints get stiff. Now, shortly after surgery, there are machines called CPM's continuous passive motion, that will start bending your knee up and down continuously for several hours a day; there also are CPM machines for shoulders and other kinds of joints. Some of the parts of joint replacement are put in with cement, some are cement-less.

There are advantages and disadvantages of both. Cemented, the joint is weight bearing much more quickly because it's pretty solid within a few days after surgery. Cementless, the bone has to grow into the metal parts and takes the same amount of time to put weight on it as a bad break - three to six months before it has full weight bearing. As smart as we think we are, we are not as good at doing anything as the Creator was when he made the parts in the first place.

(Continued in next column.)

None of the things we do work as well. We try to duplicate a joint, we try to get close, but the original parts were designed best.

QUESTION: Why don't they do as many wrist replacements?

ANSWER: A wrist is not a weight bearing joint so if it is affected with arthritis it's usually rheumatoid which can affect the whole hand. A wrist is a more complicated joint unlike the hip, which is a ball and socket joint. A knee is actually a lot harder than the hip because a knee is not just bending and straightening when you step on it each time, you also turn it in a little bit and out a little bit so it's been hard to duplicate that internal and external rotation. With a wrist you go up and down, sideways and all sorts of combinations of those movements. In the forearm there are two bones; in your wrist there are six so to duplicate that has been a difficulty.

QUESTION: Is anyone doing any joint replacements in the spine?

ANSWER: No, not that I know of.

QUESTION: What are some of the consequences of knee joint replacement surgery?

ANSWER: The major consequences despite weakened muscles, is the knee may be a little more likely to dislocate, may pop apart and not line up right. But, in three to six months after the surgery you're going to know that. You'll probably do okay unless you get into a real extreme situation where you start falling and putting unusual forces around your knee that might dislocate somebody's normal knee too.



Deadly Tsunami has a Polio Connection

...Famed Author and Polio Survivor, Arthur C. Clarke Predicted the Event...

Science fiction author, Arthur C. Clarke, is one of our more famous polio survivors. He has made Sri Lanka his adopted home and sadly lost his diving school with the deadly December Tsunami, which is an event that eerily echoes a plotline from his first book about the island.

Clarke, who predicted the establishment of communication satellites and is best known for writing *2001: A space Odyssey*, said that his diving school at Hikkaduwa, 100 kilometers (60 miles) south of Colombo was completely destroyed.

Clarke now uses a wheelchair due to his post-polio syndrome. He was not in the area at the time of the earthquake and resulting Tsunami. The 87 year-old, who is an honored guest of Sri Lanka and has a state technology institute named after him, said the island of 19 million people lacked the resources to cope with the aftermath of the catastrophe. His first book on Sri Lanka had a chapter on tidal waves hitting the southern port of Galle, he said. "Curiously enough, in my first book on Sri Lanka, I had written about another tidal wave reaching the Galle Harbor," he said. "That happened in August 1883, following the eruption Kraakatao in roughly the same part of the



ARE YOU, YOU?

Reprint Permission Granted -- By - Monica Dupont
Reprinted from Las Omigos Post-Polio Newsletter

OKAY, so you're broke or older or divorced or homeless or fatter or thinner or unemployed or drunk or lost or handicapped or really, really stressed out, but you know what? You're still YOU! You are all you've got. Relax, this is a good thing, because you know yourself better than you know anyone else.

Now, let's take a look at you. Who are YOU? Try to isolate the components. Are you stupid? You've known yourself for a long, long time and you've answered questions, filled out forms, read instructions, and escaped from burning theaters and irate landlords. A stupid person couldn't do those things, so you're certainly not stupid. Well, then, are you ignorant? Ignorant people are usually too ignorant to realize that they're ignorant, so we'll rule that one out too. Are you old? No.

Redwoods are old. Are you young? Yes. You are. In a sense we are all young, still growing and learning and searching. Deep down inside, you remember what it was like to be young -- the feeling is still with you and will never leave. Are you gorgeous and lean? Sure you are, deep down inside. Are you happy? You bet. Maybe you just don't feel it right now, but at some moment in our life you were happy and that happiness is stored inside you.

Throughout your life you've experienced pretty much everything that there is to experience and you will always carry those memories with you. Concentrate on the good ones and access them! They're not just there to die away in your head. You've lived those things, now wear them proudly like bright shining medals. Use them. Close your eyes and let the memories you have that can nurture you come flooding back in.

Did an idiot take your parking space? That's absolutely no different than the little wisenheimer who lived next door to you when you were eight, taking your cookie. It's no different than coming in seventy-third on your SATs and being forced to go to Clodhopper University. Can't concentrate? Try not to concentrate on it.

Can't walk? Sometimes, nobody walks. We all choose not to walk when we sit down, drive, sleep, watch TV or take a bath.

Overweight? You've been thin and you've been fat and you've been thin and you've been fat. You've been small, medium, large and extra large. It's still you. Drunk? Hey, you've been sober. You were sober an hour ago. The point is, you've been everything. **You are everthing!** You're everything you've ever been. You're a constant rerun. You're a work in progress. You're a teaching Tool!

(Continued in next column.)

Now close your eyes and remember the first humming bird you ever saw, the taste of chocolate, your favorite color. Remember great friends you've had or happy holidays or quirky cars. Take a brief second to remember those wonderful fleeting magic moments that are just a glimmer in you past. Remember feeling peaceful and looking great and having just exactly enough time to do everything? Those moments are still inside you, waiting for you to use them to cheer yourself up when you're feeling low.

All in all, things are now not the worst that they've ever been, or the best. Knowing this simple fact gives you power. You have the power of knowing that you've handled so much worse and somehow gotten through it. Be proud of yourself for that. As long as you can keep your perspective and keep on being the real you, the you that you are deep in your heart and soul, you can get through anything. It's time for you to live. Go ahead, let yourself live. And stop being so hard on yourself. Give yourself a break, you've earned it. **You can be in control of your own life if you remain true to yourself. You know who you really are.** Copyright: Monica Dupont 2004. Monica is a member of the San Francisco Bay Area Polio Survivors, and can be reached through Cotrejack Publishing: cotrejack@earthlink.net 

"MORE ABOUT MONICA DUPONT"

Source: San Francisco Bay Area Polio Survivors newsletter. Reprint Permission Granted by: Monica Dupont and Reprinted from, Los Amigos Post-Polio Rancho Newsletter

If you would like to purchase a copy of her CD "Monica Dupont - Early Eighties" go to: hoddyman@earthlink.net.

This is what the October 2003 issues of California Bay Area Blues News wrote about the author of the previous article.

"Vocalist, band leader, guitarist, and songwriter, Monica Dupont is back in the Bay Area after twenty year hiatus. She spent years hiding some of her handicaps from the world. She wanted to be judged on her own musical merits, rather than because she was handicapped. She had Polio as a child which left nerve and muscle damage. A stroke in early 1983 brought back some of her polio symptoms. Now she has Post-Polio Syndrome and is in a wheelchair. She is ready to shine forth with her song writing and recording. In fact, Hoddyman Record has issued an excellent CD of some of her songs. Her unique, deep baritone voice is evident in the CD which is entitled, "MONICA DUPONT: EARLY EIGHTIES."

And, in a review in an Austrian Blues online magazine, the writer included these comments about Monica. "For years I have played the blues song, 'Try to Find Another Man,' and have had people guess if the singer was young or old, black or white, and man or woman".

(Continued on Page 7)

No one ever guessed that the singer, Monica Dupont was young, red-haired, white, and six feet tall. I often wondered what had happened to her. Then one day, twenty years later, she contacted me. I was glad to find she was still with us.

Monica was the only girl vocalist, band leader, guitarist, and songwriter on the local blues scene from 1975 to 1983. She and her band, including people still playing the blues today, performed in a lot of different venues and played a variety of blues-based music to introduce the blues to a wider audience, and to show that there were blues in almost every type of song. The group also recorded songs, mainly written by Monica.

"Monica's deep baritone voice is what makes her unique." She has been singing most of her life. She sings with good expression and entertains audiences with her imaginative, original songs.

A NAIL IN THE FENCE - (Continued from Page 3)

The fence will never be the same. When you say things in anger, they leave a scar just like this one." "You can put a knife in a person and draw it out. It won't matter how many times you say I'm sorry, the wound is still there. A verbal wound is as bad as a physical one."

Friends are very rare jewels, indeed. They make you smile and encourage you to succeed. They lend an ear, they share words of praise and they always want to open their hearts to us.

Show your friends how much you care. Please forgive me if I have ever left a hole in your fence.



FROM OUR Readers

Dear Vivian and John - Thanks so much for suggesting I write Dr. Bruno !! I heard back already and was so relieved !!

Even though I was hoping he'd suggest certain tests, I knew there weren't specific tests for PPS. And of course he said, "There are no tests for PPS".

I briefly outlined what my problems were and he made suggestions for further reading, etc. He also suggests "chances are this is not a back problem but a back muscle problem", which I tend to agree with at this point. His suggestions gave me some strong reassurance that I was headed in the right direction. And interestingly enough he said, "There aren't doctors we can recommend in other states", which I can understand.

This is a very interesting journey, to say the least!! Thanks again for all your help! It does make a big difference and both your dedication to helping others on this journey DOES MAKE A DIFFERENCE !! *Becky Montrenes, Yelm WA*



(Continued on Page 10)

Positive Attitude!

The 92-year-old, petite, well-poised, and proud lady, who is fully dressed each morning by eight o'clock, with her hair fashionably coiffed and make-up perfectly applied, even though she is legally blind, moved to a nursing home today. Her husband of 70 years recently passed away, making the move necessary.

After many hours of waiting patiently in the lobby of the nursing home, she smiled sweetly when told her room was ready. As she maneuvered her walker to the elevator, I provided a visual description of her tiny room, including the eyelet sheets that had been hung on her window. "I love it," she stated with the enthusiasm of an eight-year-old having just been presented with a new puppy.

"Mrs. Jones, you haven't seen the room... just wait."

"That doesn't have anything to do with it," she replied. Happiness is something you decide on ahead of time. Whether I like my room or not doesn't depend on how the furniture is arranged... it's how I arrange my mind. I already decided to love it. It's a decision I make every morning when I wake up. I have a choice; I can spend the day in bed recounting the difficulty I have with the parts of my body that no longer work, or get out of bed and be thankful for the ones that do work. Each day is a gift, and as long as my eyes open I'll focus on the new day and all the happy memories I've stored away... just for this time in my life."

Old age is like a bank account; you withdraw from what you've put in. So, my advice to you would be to deposit a lot of happiness in the bank account of memories. Thank you for your part in filling my memory bank. I am still depositing.

Remember the five simple rules to be happy!

1. Free your heart from hatred
2. Free your mind from worries
3. Live simply
4. Give more
5. Expect less

Source Unknown



this 'n' that

If you have a penny and I have a penny and we exchange pennies, you still have one cent and I still have one cent. But if you have an idea and I have an idea and we exchange ideas, you now have two ideas, and I now have two ideas.

Hope Health-Boeing - Summer 2004

"The Marine"

By: Corporal, Aaron Gilbert
US Marine Corps USS SAIPAN, Persian Gulf

Aaron served in the Persian Gulf, and Iraq. He is the author of other poetry and writings.

gilbertam@2mawnr.usmc.mil



Hey Dad! Do me a favor and label this "The Marine" and send it to everybody on your email list. Even leave this letter in it. I want this rolling all over the U.S. I want every home reading it. Every eye seeing it. And every heart to feel it. So can you please send this for me? I would but my email time isn't that long and I don't have much time anyway.

You know what Dad? I wondered what it would be like to truly understand what JFK said in His Inaugural speech. *"When the time comes to lay down my life for my country, I do not cower from this responsibility. I welcome it."*

Well, now I know. And I do, Dad, I welcome the opportunity to do what I do. Even though I have left behind a beautiful wife, and I will miss the birth of our first born child, I would do it 70 times over to fight for the place that God has made for my home. I love you all and I miss you very much. I wish I could be there when Sandi has our baby, but tell her that I love her, and Lord willing, I will be coming home soon. Give Mom a great big hug from me and give one to yourself too.



THE MARINE

We all came together,
Both young and old
To fight for our freedom,
To stand and be bold.

In the midst of all evil,
We stand our ground,
And we protect our country
From all terror around

Peace and not war,
Is what some people say.
But I'll give my life,
So you can live the American way.

I give you the right
To talk of your peace.
To stand in your groups,
And protest in our streets.

But still I fight on,
I don't bitch, I don't whine.
I'm just one of the people
Who is doing your time.

I'm harder than nails,
Stronger than any machine.
I'm the immortal soldier,
I'm a US MARINE!

So stand in my shoes,
And leave from your home.
Fight for the people who hate
you,
With the protest they've shown.

Fight for the stranger,
Fight for the young.
So they all may have,
The greatest Freedom you've
won.

Fight for the sick,
Fight for the poor.
Fight for the cripple,
Who lives next door.

But when your time comes
Do what I've done.

TIPS & TECHNIQUES FOR TREATING CHRONIC FATIGUE

by Richard L. Bruno

QUESTION: *I read a newspaper column about health that two drugs can treat post-polio weakness. Mestinson was one. The other was a Parkinson's disease drug that wasn't named. I have weakness and pain. I have been on narcotics and Soma for a long time but I built up a tolerance and I'd like to switch to Nembutal for Pain. Should I take Nembutal and one of these other drugs, too?*

Answer by Dr. Bruno: Mestinson? Narcotics? Soma? Nembutal? My, oh my. Where to begin? First, there are no drugs that decrease post-polio weakness. An international, double-blind, placebo-controlled study found that Mestinson did not improve muscle strength in polio survivors. The same is true for insulin-like growth factor (which is similar to growth hormone), prednisone (a powerful steroid) and amantadine, a Parkinson's disease drug. In 1995 we did a double-blind, placebo-controlled study of bromocriptine, which is a more powerful Parkinson's drug than amantadine. But we used bromocriptine to treat fatigue, not muscle weakness. Patients on bromocriptine reported a noticeable reduction in fatigue and "brain fog:" difficulty with attention, concentration, word finding, mind wandering, memory and thinking clearly.

Is bromocriptine then "the" treatment for post-polio fatigue? Not at all. We don't recommend drugs, even bromocriptine to treat fatigue in polio survivors or those with CFS. Fatigued folk shouldn't pump themselves up with any drug, be it caffeine or, heaven forbid, "pep-pills" like amphetamines, Ritalin or Adderall. Actually our study's most important finding was that nearly 90% of our patients were not eligible as subjects since their daily fatigue decreased markedly after they had applied all of the PPS symptom management techniques. Post-Polio Institute patients' muscle weakness and pain also significantly decrease when they conserved to preserve.

REMEMBER OUR TROOPS! **Write -- Send Pkgs -- Pray**

(Continued on Page 9)

BRUNO TIPS & TECHNIQUES (Continued)

That's why we also don't use narcotics or muscle relaxants, like Soma, to treat pain. Pain is your body's way of telling you to slow down.

As for nembutal, that's a 1960s sleeping pill, not a pain pill.

Polio survivors and those with CFS who have insomnia shouldn't be taking nembutal; neither should those who have pain. If you have trouble sleeping or have daytime fatigue, you should get a sleep study to find out why you can't sleep, not use a pill - be it nembutal, amitriptyline, Ambien -- or over-the-counter pills like Tylenol PM, to drug yourself into oblivion. Polio survivors and PWCs are very sensitive to any drugs that are sedating, sleeping pills as well as antihistamines and some medications or high blood pressure, like beta blockers. And of course drugs intended to sedate you knock polio survivors for a loop. "Mild" anesthetics used for "twilight sleep" during a colonoscopy, endoscopy or before major surgery -- fentanyl, Versed, propofol -- and certainly the gas anesthetics that keep you under during major surgery, can make polio survivors sleep for hours longer than they should and make you groggy and unsteady for days. See the "Preventing Surgical Complications" articles in The Post-Polio Library at postpolioinfo.com/postpolio.

Unfortunately, there's lots you can read on the Internet concerning pills that are said to either hurt or help polio survivors. The buzz in the post-polio community is that muscles break down in polio survivors taking cholesterol lowering "statin" drugs like Lipitor. There have been no specific studies of the effects of statins in polio survivors. Only about one-half of 1 percent of anyone who takes statin develops rhabdomyolysis, a condition where muscles do indeed break down. We have seen a few of these cases which are diagnosed by measuring an increase in CPK (or CK), an enzyme that is released when muscle breaks down. However, the one study looking at CPK in polio survivors found that the average level is elevated to 225 (normal is less than 150) in those with muscle weakness who are not taking statins. So polio survivors should have CPK measured before taking a statin. If you are on a statin drug and you feel any muscle pain or weakness, especially in your calf muscles, stop the drug immediately, call your doctor and have your CPK measured. If you don't want to take a statin at all, ask your doctor if you can try changing your diet, taking slow acting niacin or a bile acid sequestrant drug to lower cholesterol.

Finally, there have been no studies showing that herbal remedies -- carnitine, cysteine, or coenzyme Q10 -- reduce PPS symptoms. Polio survivors shouldn't think that they can run themselves ragged, pop a pill and make PPS disappear. Self-care -- not medication -- is the prescription for post-polio fatigue, weakness and pain.



Dr. Richard Bruno, Director, The Post-Polio Institute and Fatigue Management Programs, Englewood NJ Hospital and Medical Center Post-Polio Task Force
 Telephone: 201-894-3742 Toll-free: 1-877-POST-POLIO;
 FAX: 201-541-6491; E-MAIL: postpolioinfo@aol.com

Keeping Polio Bodies Warm

Reprinted from Polio Deja View, Central Post-Polio Support Group, February - March 2005, www.cyppsg.org

COLD INTOLERANCE

It is well known that cold intolerance is a common feature of surviving polio. It is also well documented that this can become an increasing problem as we get older. This appears to happen in at least 41% of polio people. Why does this occur and what can we do about it.

First, we go to some basic physiology, looking at the action of muscles, we can see that muscular actions is necessary to return venous blood up the leg to the heart. This is called the skeletal muscle pump. When the muscle contracts blood is squeezed up the vein and one-way valves stop it flowing backwards. Where there is muscle wastage from polio this contraction is less effective. If we stand or sit still without moving, blood collects in your feet and lower legs causing swelling and a drop in blood pressure (even fainting).

Climatic temperature also influences size of blood vessels. Heat opens them up allowing more blood to reach the skin surface areas giving a redder hot look, also sweating and evaporation that helps to cool the body. Cold closes the vessels restricting the flow to capillaries to conserve heat giving a paler appearance to the skin. This function is controlled by the sympathetic nervous system. In polios the nerves that control this sympathetic function may have been damaged by polio thus not allowing them to shut off the blood supply when it is cold. So precious heat is lost, the cold decreases what muscle activity there is and the "purple cold foot/leg syndrome" appears. In fact cold constricts all nerves and muscles. 75% of your muscle strength is lost when the temperature drops to below 20 degrees C.

WHAT CAN WE DO ABOUT IT

Obviously the first requirement is to get some warmth back. Creating a warm environment achieves this. Warm yourself up by external heat, i.e. warm bath/shower/foot bath; electric blanket or thermo mattress or just getting into bed. Most polio limbs are warm once they have been in bed long enough. The secret is to keep them warm when you get up. Polypropylene is a silk-like plastic material that holds heat in but allows sweating out. Wrap up well to keep heat in. Socks, leggings, long-johns, track pants made of this and similar materials help. Be warned you must be warm first, when you put them on.

Cold sensitivity can also be increased if your thyroid gland is not working well. Poor thyroid function will make you sluggish, tired and result in a tendency to put on weight. If your magnesium is low we get cold extremities too.



**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

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

Ellensburg Daisy Stevenson--509-968-4280, ldsarah@aol.com

Everett, Marysville, Snohomish County, & Seattle, & North King County Rhonda Whitehead--425-488-0219

King County (South) Renton, Seattle, Maple Valley, , Auburn, Federal Way Mimi Sangder--206-725-8937

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

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

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

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

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

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

Vancouver, Washington - Susie Koeser, 360-574-4523, vipsusie@msn.com

++ Whidbey Island, Washington & Surrounding Cities
Dee Michel, 360-675-4727, deejaymichel56@comcast.net
Co-leader: Betty Whittaker, 360-675-7503

Yakima Lower Valley - Bev Nading, 509-837-4265 cubfarms@bentonarea.com

++ Yakima Valley Polio Network - Sarah Doyle--509-469-0348, ldsarah@peoplepc.com

**"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.
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Office Director - John M. Clark

E-mail: poow85jmc@msn.com

Newsletter Editor, Vivian J. Clark

poownewseditor@msn.com

PRESIDENT, Susie Koeser 360-574-4523

E-mail: vipsusie@msn.com

VICE-President, Sarah Doyle 509-653-2189

E-Mail: ldsarah@aol.com

Secretary, Barbara Ellis 360-574-1864

E-mail: barbara41509@msn.com

++ Treasurer, Susan Harter 253-887-0123

E-Mail: hsuzi@aol.net

FROM OUR Readers (From Page 7

January 2005 -- We have been receiving your Polio-post/polio newsletter for a few years and have not contributed. Now we feel we must. We have learned so much from your newsletter. Thank you so much for everything your newsletter has taught us and informed us about post-polio. *Sincerely, Ted and Jan Meinders, Milca MN*

POOW Thanks you for your contribution!

November, 2004 -- I so much look forward to the newsletter each month. I find it very informative and keeps you up on the latest info on PPS. *Clint Potter, Covington WA*

May 2004 -- I just finished reading the May-June 2004 issue of POOW. As a reader of your publication for many years let me say that this issue was by far the most helpful and informative. I am currently living just outside of Charleston, SC, but I am a native of Washington State. I had always known of the Nordstrom policy of not charging customers with different size feet for the second pair. However, I was unaware of the real reason... the "original" Mrs. Nordstrom had polio. As they say here in the South, "Bless her heart for her generosity and thoughtfulness.

Susan Preston Raybon, Summerville SC



'GLADDEN THE HEART'



Life is short and we do not have much time to be a Blessing to others. So be quick to GLADDEN THE HEART of those who travel the way with us. So be swift to LOVE and make haste to be KIND!

Submitted by: Norma Nickols



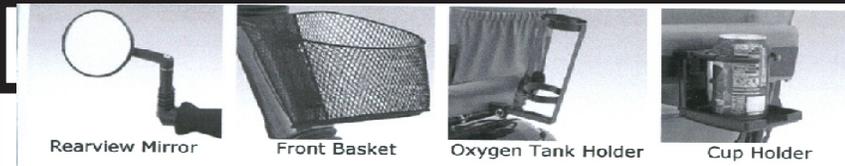
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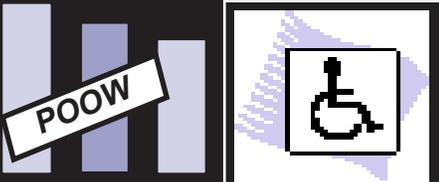
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