

POLIO



POST

Polio Post is Published Quarterly

February, 2012

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You may visit our website at www.postpolionetwork.ca or email us at postpolionetwork@shaw.ca

President's Report February, 2012

As spring approaches, we can soon say adieu to what has been, thankfully, a mild winter and we can look forward to welcoming warm, sunny days. I am looking forward to feeling the sun on my skin, walking safely on pavement, ditching the heavy winter coat, and seeing you all at our Annual AGM in March. We have an interesting speaker, Amy Krah, Occupational Therapist, who was to be with us in October but had to cancel due to a fire next door to her office.

At that meeting, you will be electing a new President as I am retiring from the position. I have enjoyed working with the Executive and I have loved working for you - the people who make up the Network.

I have come to realize how very important our network is to us. Polio survivors represent an unique time and place in history but while our polio experience distinguishes us, it does not define us. Attending events, support meetings and conferences is meaningful to us because the issue of our polio is largely forgotten by the world. But, by being together as a group we feel comfort because we share that time and place and experience. The Post Polio Network solidifies the bond we share and maintains our specialness.

I will continue helping put out the newsletter and be involved with the group.

Our Holiday Luncheon was, as usual, a grand time of celebrating and eating and participating in the ever popular gift exchange which was fun for all. All in all, the change to the Greenwood Inn was splendidly received! The meal was lovely and the venue is a good fit for our group.

In April, we will have a Spring Tea. So if you like, bring your favorite CHINA CUP AND SAUCER. What about HATS and GLOVES? If you would like to bring dainties we would be delighted to serve them.

You will hear more about our upcoming triennial Conference in the next few weeks.

See you at the AGM my friends!

~ Charlene Craig, President ~

MEMBERSHIP IS NOW DUE

Reminder: Please renew your membership which was due January 1st, 2012.

Mia Farrow's Post-Polio Letter

WHAT ARE POST-POLIO SEQUELAE? Post-Polio Sequelae (PPS, Post-Polio Syndrome, The Late Effects of Poliomyelitis) are the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, as well as difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of "non-paralytic" polio survivors. There are about 2 million North American polio survivors and 20 million polio survivors worldwide. The existence of PPS has been verified by articles in many medical journals, including The Journal of the American Medical Association, the American Journal of Physical Medicine and Rehabilitation and The New England Journal of Medicine.

WHAT CAUSES PPS? PPS are caused by decades of "overuse abuse." The poliovirus damaged 95% of brain stem and spinal cord motor neurons, killing at least 50%. Virtually every muscle in the body was affected by polio, as were brain activating neurons that keep the brain awake and focus attention. Although damaged, the remaining neurons compensated by sending out "sprouts," like extra telephone lines, to activate muscles that were orphaned when their neurons were killed. These over sprouted, poliovirus-damaged neurons are now failing and dying from overuse, causing muscle weakness and fatigue. Overuse of weakened muscles causes muscle and joint pain, as well as difficulty with breathing and swallowing.

HOW ARE PPS DIAGNOSED? There is no diagnostic test for PPS, including the electromyogram (EMG). PPS are diagnosed by excluding all other possible causes for new symptoms, including abnormal breathing and muscle twitching that commonly disturb polio survivors' sleep, a slow thyroid and anemia. Other neurological or muscle diseases are almost never the cause of PPS symptoms.

ARE PPS LIFE THREATENING? No. But because of damaged brain activating neurons polio survivors are extremely sensitive to, and need lower doses of, gas and intravenous anesthetics and sedative medication. Polio survivors can have difficulty waking from anesthesia and can have breathing and swallowing problems, even when given a local dental anesthetic.

IS PPS A PROGRESSIVE DISEASE? PPS is neither progressive nor a disease. PPS is caused by the body tiring of doing too much work with too few poliovirus - damaged, oversprouted neurons. However, polio survivors with untreated muscle weakness were found to lose about 7% of their remaining, overworked motor neurons each year.

IS THERE TREATMENT FOR PPS? Yes. Polio survivors need to "conserve to preserve," conserve energy and stop overusing and abusing their bodies to preserve their abilities. Polio survivors must walk less, use needed assistive devices -- braces, canes, crutches, wheelchairs -- plan rest periods throughout the day and stop activities before symptoms start. Also, since many polio survivors are hypoglycemic, fatigue and muscle weakness decrease when they eat protein at breakfast and small, more frequent, low-fat / higher-protein meals during the day.

ISN'T EXERCISE THE ONLY WAY TO STRENGTHEN WEAK MUSCLES? No. Muscle strengthening exercise adds to overuse. Pumping iron and "feeling the burn" means that polio-damaged neurons are burning out. Polio survivors typically can't do strenuous exercise to condition their hearts. Stretching can be helpful. But whatever the therapy, it must not trigger or increase PPS symptoms.

IS TREATMENT FOR PPS EFFECTIVE? Yes. The worst case is that PPS symptoms plateau when polio survivors stop overuse abuse. Most polio survivors have significant decreases in fatigue, weakness and pain once they start taking care of themselves and any sleep disorders are treated. However, because of emotionally painful past experiences related to having a disability, many polio survivors have great difficulty caring

for themselves, slowing down and especially with “looking disabled” by asking for help and using assistive devices.

WHAT CAN DOCTORS, FAMILY AND FRIENDS DO TO HELP? Polio survivors have spent their lives trying to act and look “normal.” Using a brace they discarded in childhood and reducing overly-full daily schedules is frightening and difficult. So, friends and family need to be supportive of life-style changes, accept survivors’ physical limitations and any new assistive devices. Most importantly, friends and family need to be willing to take on taxing physical tasks that polio survivors may be able to do but should not do. Doctors, friends and family need to know about the cause and treatment of PPS and listen when polio survivors need to talk about how they feel about PPS and lifestyle changes. But friends and family shouldn’t take control of polio survivors’ lives. Neither gentle reminders nor well-meant nagging will force polio survivors to eat breakfast, use a cane or rest between activities. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it

Whether you had polio or not, please COPY and MAIL this letter to your doctors. With your help every doctor will learn about the cause and treatment of PPS and give polio survivors the care we so desperately need. Thank you!

Mia Farrow, polio survivor

Thaddeus Farrow, polio survivor

Co-chairpersons The POST-POLIO LETTER campaign

Mia Farrow on UNICEF's effort to eradicate polio

Jan 24, 2000 (CNN) -- Polio, one of the most feared diseases of childhood, has all but been eliminated in some countries of the world due to aggressive vaccination programs. Yet there are places where the disease still strikes the young with alarming frequency. Campaigns are underway to prevent the spread.

Actress Mia Farrow contracted polio at age nine, but was able to overcome its debilitating effects. Today, she is the United Nations Children's Fund (UNICEF) special representative for polio and is spearheading a national campaign in Nigeria to combat the disease.



Mia Farrow speaks to children in Chad about polio eradication

Chat Moderator: Welcome to CNN.com, Mia Farrow.

Mia Farrow: Hello, everyone.

Chat Moderator: When were you first approached to become UNICEF's special representative for polio?

Mia Farrow: In September of the year 2000, they asked me if I would take that title on officially. But it was in June of 1999 that I first came in with UNICEF to work with them.

Chat Moderator: Were you surprised at the number of countries that are still dealing with polio outbreaks?

Mia Farrow: No, I wasn't surprised because my son, Seamus, was born in India and was afflicted with polio -- before I adopted him -- so, I became aware the polio was still a major problem in developing countries.

Chat Moderator: What has the Nigerian government done to get out the word about polio and available vaccines?

Mia Farrow: Well, the government in Nigeria has shown tremendous support. All their TV stations have been running the announcement, and they even had town criers going to remote villages and towns -- everything possible to get the word out. They even provided money to buy vaccines.

Chat Moderator: Are there pharmaceutical companies who are involved in trying to make affordable vaccines available in poorer countries that need them?

Mia Farrow: The polio vaccine is being made by Pasteur and is affordable. It is 7 cents a dose, so they are doing that.

Question from chat room: Generally, how does it spread?

Mia Farrow: It is airborne. Lack of environmental sanitation, as well.

Chat Moderator: What treatments are available for polio, and what is the success rate for these treatments?

Mia Farrow: Well, once you have been afflicted with polio, there isn't any treatment. The damage is done. There is very little one can do. In the U.S. and other developed countries, we have braces, and we can straighten out the limbs through therapy. For my own son, it took a year to get the right angle straight, so he could get his braces on. But primarily, he is in a wheelchair, and there is nothing anyone can do about that. So, the real answer is prevention.

Chat Moderator: How successful was National Immunization Day in Nigeria?

Mia Farrow: It has been very successful. Some 40 million children were immunized this time around. In the West African countries -- the combination -- it was 70 million children under 5 years of age in 17 different countries.

Question from chat room: How close are we to a cure for polio?

Mia Farrow: I don't think we talk about cures for polio; we talk about eradication. If the vaccine is given to every child three times in one year, and then every year for the first five years, then that will mean there will be no more polio on the face of the earth and no more need for immunizations. And that will save billions worldwide, billions that can be applied to HIV, AIDS and other medical emergencies. So, it is important to get this off the plate, so to speak.

Question from chat room: Is vaccination at birth not a good idea in polio-prone areas?

Mia Farrow: They give them at one month.

Chat Moderator: If individuals want to contribute to this effort, where can they send donations?

Mia Farrow: They can send donations to UNICEF, and I have seen first hand that the money there goes directly to the children and to the healthcare program. There is also Rotary and the World Health Organization. They wouldn't go wrong in choosing any of those organizations if they wish to help.

Question from chat room: Which country has the most number of polio cases?

Mia Farrow: India has the most. And in Africa, it is Nigeria.

Question from chat room: Mia, congratulations for your participation in making visible this problem, and for acting so effectively by volunteering your time for this cause --especially, considering that 2001 is the International Year for Volunteers. How would you advocate having others volunteer their time for such

campaigns in other parts of the world?

Mia Farrow: You know, if people wanted to volunteer, they could speak to UNICEF and Rotary, but they should be careful that it is an organization that is good. These organizations, I have mentioned, do tremendous work, and are very good to work with.

Chat Moderator: Is eradication of polio by 2005 realistic?

Mia Farrow: I'm not skeptical about that. I truly believe that it is possible, and more than probable, that polio will be eradicated before the year 2005. Ten years ago, for example, the numbers of cases of polio were over 350,000. And last year it was 2,000.

So, at this rate, I think anyone can see from the numbers that it's going fast. The problems have been reaching children in war torn countries, and of course, some funding still remains. A half a billion dollars is still needed.

Chat Moderator: Have any corporations committed funds to help with this effort?

Mia Farrow: Lots of corporations have committed funds. A couple of big donors for UNICEF were Ted Turner and Bill Gates. And I know that governments, too, have been tremendously supportive. The list of corporations that have donated to UNICEF is a very long list.

Chat Moderator: Thank you for joining us, Mia Farrow.

Mia Farrow: Thank you. Goodbye.

Mia Farrow joined us from CNN's U.N. studio. CNN.com provided a typist for her. The above is an edited transcript of the chat, which took place Wednesday, January 24, 2001.



Annual General Meeting

March 27th, 2012 @ 1pm

The Katherine Friesen Centre

940 Notre Dame Ave

Guest Speaker:

Amy Krahn, Occupational Therapist
Who will speak on "How to Live Better"

*The meeting is open to all polio survivors and their supporters
Lunch and coffee will be served !*

Visit our website at www.postpolionetwork.ca
or email us at postpolionetwork@shaw.ca

975-3037

Parking for Persons with Disabilities

The City of Winnipeg is dedicated to accommodating the needs of community members with disabilities.

For Drivers without Disability Permits

The provision of disabled parking facilities in the City of Winnipeg is governed by the Disabled Persons Parking By-Law. This By-Law allows for the designation of Disability Permit parking stalls and outlines the requirements for establishment of such stalls. It is an offence to park in a designated Disabled parking stall without displaying a valid Provincial Permit.

While many of these parking stalls are located on private property, many are located in public spaces and on roadways. There is a large fine for misuse of a disability space. Please watch for signage.

Permits

The Province of Manitoba maintains a process for issuing Parking Permits for people with disabilities to eligible members of the public within provincial borders. To learn more about the permit program please contact:

The Society of Manitobans with Disabilities 1111 Winnipeg Avenue, Winnipeg, MB. R3E 0S2 Tel: 204-975-3250 Toll-Free: 1-800-836-5551 TTY: 1-800-856-7934 TTY: 204-975-3240 Fax: 204-975-3240 Web: <http://www.smd.mb.ca/>

Municipal Parking In Winnipeg (City Streets, City Owned Parkades and Lots)

The City of Winnipeg offers many services to its parking customers, including Provincial Permit holders with disabilities who wish to park in casual municipal parking lots, or at parking meters and paystations on the street. Permit holders with a disability may use spaces designated with the international access symbol, OR any other meter stall as available. Parking is offered on a “pay as you go” daily or hourly basis provided they display their permit.

The City of Winnipeg Traffic By-Law No. 1573/77 allows motorists displaying handicap permits to park for 4 hours.

This allows disabled drivers to park for 4 hours at 2 hour paystations, as well as at spaces restricted to 1 or 2 hours.

If you park with a handicap permit at a 2 hour paystation, and pay with coins or credit card for 2 hours worth of parking, you may park for up to 4 hours at no additional cost, and without penalty.

Payment for the full 4 hours of parking is required if:

- you park at a 4 hour paystation
- if you park at a 2 hour paystation and use payment methods other than coins or a credit card

FIA European Bureau The WPA recognizes Handicap Permits from other provinces, states and countries. Handicap permits from Manitoba are recognized in other provinces, states, and countries as well. The FIA European Bureau is working on a worldwide survey to develop an international guide for disabled drivers.

However, if you plan to use a Handicap Permit in another jurisdiction, **IT IS IMPORTANT** that you still check with that jurisdiction ahead of time to find out if there are any differences in regulations.

Paystations and Parking Products

Paystation technology is consistent with current City of Winnipeg Accessibility Design (link) parking standards. Paystations accept .05, .10, .25, .51 and \$2 coins as well as downtown Blue Loonie tokens and Visa, Mastercard and American Express cards. Coin charges require exact change. The machines do not accept money when parking is free or when parking is prohibited (i.e. rush hours). Please observe the signage.

All customers, including those with disabilities, may use their cellular telephone to charge parking fees to a credit card. This is a service provided by a company called Verrus; customers may sign up at home or at the curbside. Verrus will send a message and provide the opportunity to purchase another meter period by text message. For more information visit www.verrus.com

All customers, including those with disabilities, who use downtown meter parking regularly may purchase a hang tag style permit which is recognized at paystations. These permits are valid for 4 hours and can be suspended from the rear view mirror for regular daily use.

Customer Service

For customer service or to purchase parking products please contact the Parking Store.

For individuals who find that any of the options in the “Paystations and Parking Products” section above are not accessible to them, you may request a custom accommodation. Confirmation of the limitation may be requested.

The City of Winnipeg is dedicated to accommodating the needs of community members with disabilities. If we can assist, please contact us!

Post-Polio Pool Time

Aquatic programs can be fun for any age group of people. However, fun is not the only focus of the Post-Polio Aquatic Class held at Misericordia Health Centre on Mondays and Thursdays. The class tries to incorporate both physical and social activity to increase the quality of life for those who participate.

The classes are lead by Bonnie Hopps, programs coordination at the Manitoba/Nunavut division of The Arthritis Society, and Dianne Oakley, certified aquatic instructor through the City of Winnipeg. The aim of these classes is to bring together individuals throughout the city to participate in physical activity which will help any chronic conditions they are facing.

The class is an hour long and includes warm up, stretching exercises, whole body exercises, a water bicycle, a water stepping machine, and everyone's favourite, “Talk Time.”

All of this exercise is meant to help the body stay healthy while the social interaction is what keeps everyone coming back.

UPCOMING EVENTS

April 24th Spring tea

May 29th Speaker TBA

**June 18th Picnic in the Park
Bourkevale Community Club**

Conference 2012

is on Sept.17th @ Victoria Inn

TOPIC: Pain and Pain Management

The keynote speaker is Dr. C.Vandenakker

Associate Professor and Residency Director
for Physical Medicine and Rehabilitation

UC Davis, Davis California.

COST: 35.00/person

Nostalgic Music:

Soothes the Soul, Quiets the Mind and Gets Your Feet A-Tappin'

Back in the 80s, I was drawn to the idea of entering the area of broadcasting. I think that interest stemmed from the fact that I enjoy public speaking and creative writing, which all fits into broadcasting and media in general. Well, the courses being offered at that time were beyond my budget parameters, so I put it on the back shelf, and moved on with my existing career in floral design and management.

Now, 30 years later, sitting with a friend, working on a jigsaw puzzle and listening to some fabulous nostalgic music on CJNU, 107.9 FM, came the suggestion from that friend, "Why don't you apply to be an announcer. They're always looking for new ones, and you have a great voice for radio."

I wasn't aware that they were in need, but said I would check their web site when I got home that evening. I read through a lot of the web site, checked out some bios of existing announcers and other staff members, filled out the questionnaire, then along with my resume and volunteer profile, I emailed it off that same evening.

The next morning I had a reply from the program director who wanted to meet with me for a brief interview. We met 3 days later with a positive result. I received an assignment by email that took me a couple of weeks to work on amidst everything else in my busy life. Once the assignment was complete to his satisfaction and to the standards of the station, I was invited to start training by sitting in with other seasoned announcers.

Since October 2011, I have sat in on several shows with three different announcers with three very unique styles and personalities, all of whom I enjoyed to the hilt. I learned the format of the show which is the same for all. I learned timing, where and when to fit in sponsors and

PSA's, when to announce the weather and what comes before and after everything. And, best of all, each of the announcers gave me very generous air time, helping them by reading sponsor ads, introducing songs, answering the phone, even taking requests from some of my own friends and family who called to support me. Now, officially on the CJNU staff list I, along with all the other announcers, wait to be slotted in as individual availabilities get coordinated.

Anyone who loves the good old music from 1920's - 1970's, minimal talking, chatting and bantering, will love CJNU. You will hear a complete weather report on the half hour, some PSA's letting you know what's happening around town, and some sponsor ads that will introduce you to great companies around the city. You can call in requests anytime at 942-2568. There isn't always someone there to answer the phones, so I always tell people to call while a song is playing. That way if the announcer is answering the phone he/she will be free to do so. If you get the answering machine, just keep calling. If it's important enough that you need to leave a message then please do so.

If you have trouble tuning in on your radio, then you can tune in to the CJNU web site and listen live right there. If you have MTSTV you can tune in to Galaxy 625. Now you have all the information you need to begin enjoying something new and wholesome. You will get hooked as many faithful new listeners have, two being my cousin in Milan, Italy and a friend in Blackpool, England.

This is something I will continue to pursue as I will have the joy of choosing some of my favourite oldies, taking you on a stroll down memory lane and finding myself smiling about something I haven't thought about in many years. *How good is that?*

~ Kathryn Harper ~

Member's Page

Do you have an interesting story to tell?
Or do you know any good jokes, inspirational
or humourous quotes or poems?

Then you are invited to email them to:

postpolionetwork@shaw.ca or mail them
to: Post-Polio Network (Manitoba) Inc.
C/O SMD Self-Help Clearinghouse
825 Sherbrook Winnipeg, MB, R3A 1M5

Marion's Cheese Crackers

- 1 tub of Imperial Cheese
- 1/2 cup butter
- 1 cup flour
- 2 tsp Worcestshire Sauce
- 2 1/2 cups Rice Krispies

Start with SOFT butter and cheese.

Cream the cheese and butter, add WS
sauce, add flour and mix well.

Add Rice Krispies.

1 1/2 teaspoon size balls on a cookie
sheet - press with wet fork

Bake at 350 degrees 10-12 minutes

HOW TO CALL THE POLICE WHEN YOU'RE OLD AND DON'T MOVE FAST ANYMORE.

George Phillips of Meridian Mississippi was going up to bed when his wife told him that he'd left the light on in the garden shed, which she could see from the bedroom window. George opened the back door to go turn off the light but saw that there were people in the shed stealing things. He phoned the police, who asked, "Is someone in your house?" and he said "no." Then they said that all patrols were busy and that he should simply lock his door and an officer would be along when available. George said, "Okay," hung up, counted to 30, and phoned the police again. "Hello, I just called you a few seconds ago because there were people stealing things from my shed. Well, you don't have to worry about them now because I've just shot them." Then he hung up. Within five minutes three police cars, an Armed Response Unit, and an ambulance showed up at the Phillips' residence and caught the burglars red-handed. One of the policemen said to George, "I thought you said that you'd shot them!" George said, "I thought you said there was nobody available!"



(True Story) **Don't mess with old people!!**

George Carlin's View on Aging

Do you realize that the only time in our lives when we like to get old is when we're kids? If you're less than 10 years old, you're so excited about aging that you think in fractions. "How old are you?" "I'm four and a half!" You're never thirty-six and a half. You're four and a half going on five!

You get into your teens and you jump to the next number, or even a few ahead. "How old are you?" "I'm gonna be sixteen!" You could be 13, but hey, you're gonna be 16! And then the greatest day of your life... you become 21. Even the words sound like a ceremony.... You become 21.... Yesss!!!

But then you turn 30. Ooooh, what happened there? Makes you sound like bad milk. He turned so we had to throw him out. There's no fun now, you're just a sour dumpling. What's wrong? What's changed? You become 21, your turn 30, then you're pushing 40. Whoa! Put on the brakes, it's all slipping away. Before you know it, you reach 50....and your dreams are gone.

But wait!!! You make it to 60. You didn't think you would! So you become 21, turn 30, push 40, reach 50 and make it to 60. You've built so much speed that you hit 70! After that it's a day by day thing, you hit Wednesday!

You get into your 80s and every day is a complete cycle; you hit lunch, you turn 4:30, you reach bedtime.

And it doesn't end there. Into the 90s and you start going backwards; "I was just 92." Then a strange thing happens. If you make it over 100, you become a little kid again. "I'm 100 and a half!"

May you all make it to 100 and a half!

Post-Polio Network (Manitoba) Inc.
C/O SMD Self-Help Clearinghouse
825 Sherbrook Street
Winnipeg, MB, R3A 1M5



Membership Application Form

Name: _____

Address: _____

City: _____ **Province:** _____ **Postal Code:** _____

Telephone: _____ **Fax:** _____ **E-mail:** _____

Please check one or more of the following options:

- ☐ **New Membership - \$10/year**
- ☐ **Membership Renewal - \$10/year**
- ☐ **I wish to make a charitable donation of \$** **Tax deductible receipt will be issued.)**
- ☐ **I would like a copy of the newsletter sent to:**
(My doctor, therapist or other individual at the address below)

Name: _____ **Profession:** _____

Address: _____ **City:** _____ **Province:** _____

Postal Code: _____ **Telephone:** _____

Please make cheque payable to the Post-Polio Network (Manitoba) Inc. and mail to the address listed above.

Membership Renewal

2012 is here and we should be renewing our memberships. The fee is \$10.00/ year. Please check your mailing label on your envelope. If your mailing label indicates 2013 or greater, your membership is up to date.

If the date is 2011 or 2012, please renew.

Thank you ~ The Polio Post editorial team~

Post-Polio Network's Privacy Policy

The Post-Polio Network (Manitoba) Inc. respects your privacy. We protect your personal information and adhere to all legislative requirements with respect to protecting privacy. We do not rent, sell or trade our mailing lists. The information provided will be used to deliver services and to keep you informed and up to date on the activities of the Post-Polio Network (Manitoba) Inc. including programs, services, special events, funding needs, opportunities to volunteer or to donate.

You may visit our website at www.postpolionetwork.ca or email us at postpolionetwork@shaw.ca

If at any time you wish to opt out of any services, simply contact us by phone at (204) 975-3037, or write us at 825 Sherbrook Street, Winnipeg, MB R3A 1M5 and we will gladly accommodate your request.