

# POLIO



# POST

*Polio Post is Published Quarterly*

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## EXECUTIVE MEMBERS 2008/09

**President:** Charlene Craig, 453-6777

**Vice- President / Fund Raising:**

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**Treasurer:** Donna Remillard

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**Privacy/Fire Warden:**

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**Polio Post Newsletter Layout:** Mike Nickle

## 2009 ANNUAL GENERAL MEETING PRESIDENT'S REPORT

*2008 was a busy and exciting year for the Post Polio Network .*

*No Joke*, on a lovely summers eve , we enjoyed our Annual Barbeque with special guests. Ramesh Ferris, a polio survivor, who was cycling across Canada to raise awareness of Polio and to support the world wide eradication of Polio through inoculation, came by with his road crew and Sylvia Kusyk of CTV, who was interested in the issue, did her weather broadcast from our event. We had an excellent turnout and helped raise some money for Ramesh` s cause.

Our annual Christmas luncheon was again a time for good fellowship and a fun gift exchange facilitated by the irrepressible Elfbert.

A huge effort was made by the board and the members to accomplish a successful fundraiser with the sale of Grey Cup Raffle tickets. Funds raised cover the costs of our annual barbeque and subsidize the cost of the Christmas luncheon.

The planning for our Conference in October continues with the Conference committee meeting more frequently. We are now looking for sponsors to donate door prizes. If you have a connection to a possible donor or you have a suggestion as to whom we should contact, please speak to a Board member. We need your participation to put on a successful Conference.

We are closer to getting our website – who knew it would be so much work!! We hope that soon it will be a reality.

Happily, our recent advertising campaign to reach out to rural polio survivors has produced some interest both in phone calls and emails. We have been concerned for some time that we were not reaching folks outside the city. Hopefully, when we review the results we can make plans to include more

rural polio survivors in our programming.

Due to space and parking constrictions at SMD during the daytime hours, your executive has been meeting at the Royal Academy of Dance at the Forks. We thank the Academy for the use of the space.

I would like to talk for a minute about the future of the Network. As polio survivors age, our needs change; we are not as mobile as we once were, the weather is more difficult to deal with, and our energy level makes many aspects of our life a challenge. Where we once enjoyed coming out to an evening meeting or event we now are better able to manage an afternoon out and many of our members cannot come out at all, however we continue to need support and information and connection to people who share the same challenges as we do. But what does that support look like? Meetings with speakers? Newsletters? Social events? A website? Conferences? It all takes time, energy and lots of work to keep the network going. As time goes on the Networks role may have to further adapt to our changing needs.

As we plan for our future we need to know from you, our members, what your needs are and what your expectations are for the future.

We hear from our members that the newsletters are an extremely important support to those members who are unable to attend meetings as well as those who are able. Our newsletter, The Polio Post, is facing a major change this year as our long time editor Pat McNeill is retiring. Pat has done a wonderful job and we are going to miss her deft touch with presenting interesting articles, timely announcements and a touch of humour. We will attempt to carry on but we thank you Pat for all your excellent work.

Our long time Treasurer Dolores Horobetz is also retiring this year. We are grateful for your years of service Dolores, you have been a wonderful guardian of the Networks finances and you leave us in fine shape. Thank you so much Dolores.

We are pleased this year to welcome two new Board members, Cheryl Currie who has taken on Publicity and David Morrison who is assisting with Fund Raising and publishing the newsletter. I would like to thank David Turner our outgoing Past President for his support of the board this past year.

On a personal note, I would like to thank the board members and members for their support as I finish my first year as president.

Charlene Craig, President

***“Your living is determined not so much by what life brings to you as by the attitude you bring to life; not so much by what happens to you as by the way your mind looks at what happens.”***

*~ John Homer Miller~*

### AGM MEMBERS ELECT A NEW TREASURER

At our AGM the members elected a new treasurer, Donna Remillard, who takes over from Dolores Horebetz.

Many thanks Dolores for your years of good service to the Network and welcome Donna, we look forward to working with you.

### **THE POST POLIO NETWORK (MANITOBA)'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. If at any time you wish to opt out of these services, simply contact us by phone at 975 3037, or write us at 825 Sherbrook Street, Winnipeg, R3A 1M5 and we will gladly accommodate your request.

### **NEW CITY OF WINNIPEG DISABLED PARKING REGULATIONS**

The Winnipeg Parking Authority has announced that it is phasing out the practise of permitting up to four hours free parking at meters for persons with a valid Provincial Persons Parking Permits. It has never been the law to permit this free parking concession, only a practice.

The currant by law actually only permits a vehicle displaying the Permit to park for up to four consecutive hours even though parking in that place is restricted to less than four hours. The by-law says nothing about the parking being free. This "practice" grew out of a recognition that, especially in winter, a disabled person might be unable to gain access to the meter and in any event would find it difficult to return periodically to feed the meter.

With the introduction of new technology that permits paying for metered parking through the use of a cell phone and credit card, a person can call a number listed on "easy to see" signs on metered areas and park for a set time. Before the set time expires the Authority will call on the person`s cell phone and ask if more time is required and the process will be repeated. It is the ultimate intention to remove all limitations on the length of time one may park in a metered area. It is also intended to increase greatly the number of metered places throughout Winnipeg designated for the exclusive use of Permit holders. This latter process is already in motion.

The Parking Authority is working on a system, similar to that used in some States, which will allow prepaying of parking by a Permit holder through the issuing of a punch card that can be displayed by those Permit holders who do not have a cell phone or a credit card.

The intention is to begin to issue on-site warnings to Permit holders once the vast majority of metered areas are cell phone accessible and the on-street designated disabled parking spots have been properly signed. This may take the form of "zero value parking tickets" delivered to windshields along with a brochure outlining the new procedures.

On the positive side, the removal of free parking for Permit holders might remove some of the incentive for people to obtain Permits. The greatest problem with parking for disabled persons is the proliferation of Permits and the consequent shortage of available designated parking spaces. There are over 30,000 Permits now issued and most of those are issued to people who do not qualify under the existing criteria of having a grave physical disability and who are unable to walk, either without a mobility aid, or more than 50 metres without great difficulty or danger to their health or safety.

Written by Art Braid

Reprinted from The City of Winnipeg`s Retiree`s Association Newsletter

## AN ORDER OF GOOD CHEER

### *DEFINITION:*

*The Order of Good Cheer: A tradition started at Port-Royal by Samuel de Champlain in 1605. The planned events of this practice helped to sustain his men's health and morale during the long, hard winters that these first colonists endured.*

The swimming pool that is found in the basement of the Misericordia Hospital is one of Winnipeg's best kept secrets. I always anticipate some mischief when telling people that I do water therapy twice a week, because in most cases, I am asked **where** this happens. Straight-faced, I respond, "At the Misericordia Hospital." Then I wait for the expected pause, which is usually followed by the puzzled query,

"There's a **POOL** at the Misericordia Hospital?"

I laugh and respond, "Indeed there is."

The pool is ancient; in fact, it is probably as old as the Wolseley wing of the hospital, where it is housed. The walls of the pool area are tiled in faded pastel pink and green 4-inch tiles; the change rooms are terribly out-dated, with broken showers and nary a locker in sight. The temperamental temperature of the water is often being adjusted by a friendly technician, even as exercise classes are in progress.

However, none of these things matter. What matters is the magic that is conjured up every Monday by Bonnie Hopps, the class's instructor... and then repeated every Thursday by Bonnie's daughter, Di. These two women have single-handedly changed my outlook on life since I joined the post-polio exercise classes they conduct twice a week at "the Misery".

Last September, I was finding that the daily pain I was enduring from a combination of severe osteoarthritis and post-polio syndrome was becoming unmanageable. Also, I was feeling mildly depressed and increasingly isolated from friends and family, who sympathized, but really could not understand what was occurring to me. Again and again, I was told, "But you **look** good." What could not be seen by my well-meaning friends and relations was the constant pain, lack of endurance and increased exhaustion that I was experiencing.

By good fortune, I decided to confide in a close friend, relating that most of the time I was merely putting on a brave face. I ended with a confession of how desperate I was feeling. After listening, she blurted out, "Bonnie Hopps! You need to join Bonnie's classes."

Although I had worked at the Misericordia part-time when I was in high school, I was unaware, like most people, that: a) there was a swimming pool at the hospital, and b) there were water therapy classes offered in the pool every week.

My friend gave me Bonnie's phone number and I screwed up my courage, feeling that I had nothing to lose. Then I gave her a call and told her my story.

The rest is history. After our conversation, Bonnie invited me to join her and her daughter Di's classes every Monday and Thursday at the Misericordia pool.

When I arrived the first morning, Bonnie introduced me to the class and I got to meet some of the most wonderful adults that I have had the privilege to know. I felt welcomed instantly as almost everyone swam over to introduce themselves and greet me. More importantly, when I started to share information about myself with these individuals, they understood and empathized with me. I received practical advice, factual, accurate information about my ailments, and an invitation to join the Winnipeg Post-Polio Support Group which, among other things, staves off isolation for individuals who are polio survivors.

I believe that Bonnie and Di are master-class post-polio water exercise instructors with formidable skills and strategies surpassed by none. But, what really astounds me is their remarkable compassion for people as well as their uncanny awareness of what simultaneously, the whole group **and** individual members of each class need.

Ultimately, though, the magic faerie dust that enhances the entire pool experience is the shared laughter. No matter how tired, grumpy, or in pain I am when I arrive at the pool, by the time I enter the water, I am smiling. And for the next hour, while either Bonnie or Di put us through our paces, the pink and green wall tiles echo with laughter, and I feel safe, secure and hopeful in the knowledge that, like those brave settlers from our country's past, I am part of "An Order of Good Cheer".

There are 2 openings for Polio people in Bonnie Hopps classes. If interested phone Bonnie at 945 4892 or bhopp@mb.arthritis.ca?

Written by Maggie Keller

### TIMMY REACHES MIDDLE AGE

Most people are familiar with the **Easter Seals** ambassador or Timmy, named after **Tiny Tim** in **Charles Dickens' "A Christmas Carol."** "Timmy" was chosen for his tenacity, perseverance, indomitable spirit and inner strength. Timmy was to represent all children with disabilities and in 1947, the first Easter Seals campaign was introduced in Ontario with the goal of raising \$150,000; a little known fact that a "**Tammy**" was chosen to represent girls in 1979. The Ontario government had turned to Easter Seals for assistance in providing funds for children's camps. 55% of new children who attended that first camp had polio. So on in doing the math on Timmy's age, today his age would be in the early 70's. Before the days of universal health care and hospitalization, if you had a crippling disease like polio, your parents had to pay the doctors, the hospital, the rehabilitation, the braces or iron lung and many parents just couldn't afford it.

Thankfully groups like Easter Seals, March of Dimes and Rotary jumped into the breach to provide financial support for strapped families. Today we don't have the same scourge of childhood diseases to give our children disabilities. What few people realize is that our population of people with disabilities is aging. Federal-Provincial-Territorial Ministers, responsible for Social Services survey, identified in 2004 that there are 160,000 children under 15 in Canada with a disability, and 3.4 million Canadians with a disability, 15 and older. The fact is that the majority of those with disabilities are aging.

The Timmy and Tammy representative of disabilities have been replaced by characters such as **South Park's** Timmy, a student with orange hair in a wheelchair. The Timmy character in South Park was voted the greatest disabled TV character in a BBC-sponsored webzine **Ouch**. This **little** Timmy of South Park challenges the condescending disability stereotypes that are gradually fading from mainstream entertainment. But like everything else in South Park he is actually challenging preconceptions

and toppling taboos. The Timmy and Tammy funds, used to provide scholarships, are changing also and many have been renamed to make them more current in today's society.

The Timmy of many decades is being replaced by another Tim today and that is the popular Canadian institution **Tim Hortons**, which raises millions of dollars in support of children with disabilities. So as the original Timmy settles into any easy chair we can thank him for a job well done. His legacy and spirit live in on these new Timmys and their respective organizations which continue to support children and adults with disabilities.

Written by David Morrison

### **SHINGLES VACCINATION:**

#### **Should Polio Survivors Receive One?**

When polio survivors began asking about the shingles vaccination, PHI polled 19 doctors (experienced in treating polio survivors) for their recommendations. No conclusion can be drawn from their varied responses. Also, currently there is no experimental data regarding whether or not polio survivors should get this vaccine. Therefore, the most prudent thing to do is to study available information, talk with your physician about your individual circumstances, and then make your own decision.

#### **The Vaccine:**

In 2006, a vaccine Zostavax was licensed to prevent Shingles in people over 60. In the clinical Trial, the vaccine was effective in 51% of the participants 60 and older, and was most effective in those aged 60 to 69. Shingles related pain was also reduced in many of those receiving the vaccine.

#### **Precautions:**

The Centres for Disease Control and Prevention (CDC) says those who should not get this vaccine are people who have had a life-threatening allergic reaction to gelatine, the antibiotic neomycin, or any other component of the shingles vaccine. The CDC advises those who have severe allergies to inform their doctor when considering the vaccine.

Because the shingles vaccine contains the live though weakened chickenpox virus, the CDC does not recommend the vaccine for individuals with the following: a weakened immune system due to HIV/AIDS or another disease that affects the immune system; a history cancer affecting the bone marrow or lymphatic system, such as leukemia or lymphoma; treatment that affects the immune system, such as steroids for organ transplants, or radiation/chemotherapy for cancer; and untreated tuberculosis.

Individuals who are moderately or severely ill( including those with a temperature of 101.3 or higher) should wait to get their vaccine until they are well.

#### **The Disease:**

Approximately one million cases of shingles( also known as herpes zoster) occurs in the United States each year, generally in people over age 50. Varicella-zoster virus (VZV), the same virus that causes chickenpox, causes shingles. Anyone who had chickenpox is at risk of contracting shingles because the chickenpox virus remains in the nervous system for the rest of one's life. Certain circumstances, such as stress or immune deficiency, can cause the virus to reactivate move back down the nerve fibers to the skin, causing the rash of blisters that is the hallmark of shingles.

Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain nerve on one area and one side of the body. Shingles blisters then form for a number of days before

they pop, finally crust over and heal. The entire process can take several weeks.

**Symptoms and Complications:**

Fever, chills, upset stomach and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis or death. A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as postherpetic neuralgia, which occurs in more than 40% of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

**Interesting Facts:**

People who have had shingles can get it again. Only people who had chickenpox or chickenpox vaccine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chickenpox or the chickenpox vaccine can get chickenpox from someone with shingles.

**Feeling Better with Shingles**

See your doctor at the first sign of shingles. It often begins as burning or shooting pain and tingling or itching on one side of the body, followed by a blistering rash. Early treatment can help shorten the length of infection and reduce the risk of other problems.

**Your doctor may prescribe:**

- Antiviral drugs to help kill the varicella- zoster virus.
- Steroids to lessen the pain and shorten the time you are sick.
- Antidepressants, anticonvulsants or analgesics to reduce pain.

**Things you can do:**

- Get enough rest and eat well balanced meals.
- Try to relax. Stress can make the pain worse.
- Dip a washcloth in cool water and apply to your blisters to ease the pain.
- Do things to take your mind off your pain. Watch TV. Read books, talk with friends, or work on a hobby.

**Note::** Article reprinted with permission of Post-Polio Health International.

**Editors note:** This vaccine has been approved for use in Canada and should be available sometime this year.

**DATES TO REMEMBER**

**May 19<sup>th</sup>**

**Winnipeg Police Officer Gernie McIntyre will speak on the topic of Personal Safety**

Time: 1:00 pm – to 3:00 pm

Place: Holiday Inn South – Deer Room 2<sup>nd</sup> floor

Coffee will be served

**June 15<sup>th</sup> Annual Barbeque**

Time: 5:00 pm

Place: Bourkevale Community Club, 100 Ferry Rd.

**Oct 13<sup>th</sup> Conference:**

**Building Better Tommorows:  
Living Healthier Lives**

Time: 8:30 am - 3.30pm

Place: Victoria Inn, Winnipeg

More Information to come.

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



## Membership Application Form

<b>Name:</b>			
<b>Address:</b>			
<b>City:</b>		<b>Province:</b>	
<b>Postal Code:</b>		<b>Telephone:</b>	
<b>Fax:</b>		<b>E-mail:</b>	

**Please check one or more of the following options:**

<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<ul style="list-style-type: none"> <li>• <b>New Membership - \$10/year</b></li> <li>• <b>Membership Renewal - \$10/year</b></li> <li>• <b>I wish to make a charitable donation of \$</b> <input style="width: 50px;" type="text"/>  <i>(Tax deductible receipt will be issued.)</i></li> <li>• <b>I would like a copy of the newsletter sent to:</b>  <i>(My doctor, therapist or other individual at the address below)</i></li> </ul>
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<b>Name:</b>			
<b>Profession:</b>			
<b>Address:</b>			
<b>City:</b>		<b>Province:</b>	
<b>Postal Code:</b>		<b>Telephone:</b>	

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

Phone: (204) 975-3037 | Fax: (204) 975-3027  
 Email: [postpolionetwork@shaw.ca](mailto:postpolionetwork@shaw.ca)  
 Website: [www.postpolionetwork.ca](http://www.postpolionetwork.ca)