

# POLIO



# POST

*Polio Post is Published Quarterly*

*May, 2017*

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Newsletter Layout: George Tataryn

Programs: Lorna Richaud

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Fire Safety/Privacy: Dolores Horobetz

Director: Bob MacAulay

Newletter: Cheryl Currie

You may visit our website at [www.postpolionetwork.ca](http://www.postpolionetwork.ca) or email us at [postpolionetwork@gmail.com](mailto:postpolionetwork@gmail.com)

## *President's Report May, 2017*

*CBC Producer, Donna Carreiro interviewed polio survivors regarding their experiences and these interviews were on CBC morning show and also on the CBC web page. As a result there have been a few responses; most agreeing with the concerns raised by our members. A link to the CBC website has been posted in Post Polio Health International Association Members Communique of April 13, 2017 (No. 123) titled From Manitoba, Canada "Polio survivors fight for proper treatment of post-polio syndrome"*

*Post Polio Network held the 30th Annual General Meeting on March 28th. Executive and committee reports were presented to those in attendance.*

*The PPN held their first general meeting at the new facility, the Caboto Centre, 1055 Wilkes Ave., Winnipeg on April 25th. Those in attendance all agreed that the facility will work well for us. The next meeting will be May 30th. Please note that the access ramp is found at the second door entrance. Many thanks to the staff at the Caboto Centre.*

*The June Summer Celebration Luncheon will be held on June 19th, 2017. This year's luncheon will be held at the Caboto Centre. There will be a general mailing regarding the luncheon; but, there is also a notice in this newsletter. Please note that we require RSVP's for this event. Please reply as soon as possible.*

*I attended an organizational meeting at SMD Clearinghouse. Introduced to attendees were the new CEO of SMD, Dana Erickson; the new COO of Services, Patti MacIntrye; Acting Manager SMD Clearinghouse, Derek Day. Representatives gave a brief outline of their organization. Over tea and cake, we all said goodbye to Natalie Mulaire who is retiring. She will be greatly missed.*

*The May executive meeting will be held in Brandon Manitoba on the 16th. Looking forward to meeting some of our WestMan members.*

*Thanks to Linda Wilkins for volunteering to chair the phoning committee and to Dolores Horobetz for volunteering to chair the Fire safety/Privacy Committee; to Merv Woodward who will be helping with Funding and Christine Portelance who will be helping with Programming.*

## *Polio survivors fight for proper treatment of post-polio syndrome*

*Excerpts from: Donna Carreiro, CBC Producer, CBC News article*

The last remaining survivors of North America's worst polio epidemic say they are living out its grim legacy — post-polio syndrome — with a medical community that doesn't know enough about the syndrome or the epidemic that caused it.

"I tell a doctor I had polio as a child, he'll just look at me with a blank stare, like 'so what?'" Altona resident Al Giesbrecht said. Giesbrecht, who contracted polio in 1952, is one of an estimated 16,000 remaining survivors across Canada living with post-polio syndrome, a neurological disorder that targets up to 60 per cent of polio survivors decades after their original bout with the virus. But those living with post-polio syndrome describe a medical community unwilling to acknowledge the syndrome or its severity.

Albert Patenaude's post-polio syndrome robbed him of his ability to walk or climb stairs. His family doctor didn't buy the post-polio explanation. Instead, he advised getting a new doctor. "The doctor said to him ... 'If you can't make it up these stairs and into the waiting room, then I can't see you,'" said Joan Patenaude, Albert's widow. "We were just cut loose."

Carol Rankmore knew something was strangely wrong when she began to fall — repeatedly, and for no apparent reason. The falls were so bad she sustained fractured bones, skull injuries and strained tendons. She later learned the falls were a common symptom of post-polio syndrome. Her doctor, however, thought she was just clumsy. "He didn't even suggest I get a walker," Rankmore recalled.

While polio ravaged communities throughout Canada in the early 20th century, Manitoba's outbreaks were among the most virulent. Six epidemics gripped the province between 1928 and 1953. The last one made headlines around the world. Winnipeg, specifically was deemed as having the worst outbreak, per capita, of any North American city. More than 3,100 Manitobans caught the virus, and 190 ended up in iron lungs. Eighty-nine people died. Despite this fact, experts concur with the survivors — polio is off the medical radar, even in Manitoba, with its infamous connection to the disease. "That is a fair description of it as it exists," said Dr. Ming Chan, the executive director of Canada's only dedicated post-polio clinic, offered through Edmonton's Glenrose Rehabilitation Hospital.

"The last group of people were infected so many years ago, polio is not an ongoing disease. People see symptoms of post-polio today, but don't think to make the link."

As a result, Chan said, it's easy for the medical community to misdiagnose the post-polio symptoms. Instead, those living with it rely on each other to learn the research and spread the word. "The next doctor I saw, I said 'I'm going to make it easy on you,'" Carol Rankmore recalled. "I said, 'I have post-polio syndrome. Here's an information pack about it.'"

## Post-Polio Syndrome

Excerpts from *The Christopher & Dana Reeve Foundation. "Today's Care Tomorrow's Cure" website* [www.christopherreeve.org](http://www.christopherreeve.org)

**The World Health Organization (WHO) estimates that 12 million people worldwide live with some degree of disability caused by poliomyelitis.**

Polio survivors are urged to take care of their health in all the usual ways – by seeking periodic medical attention, being nutrition-wise, avoiding excessive weight gain, and by stopping smoking or overindulging in alcohol. Survivors are advised to listen to their body's warning signals, avoid activities that cause pain, prevent overuse of muscles, and conserve energy by avoiding tasks that are nonessential, and by using adaptive equipment when needed.

Post-polio syndrome is not typically a life-threatening condition, but it may cause significant discomfort and disability. The most common disability caused by PPS is deterioration of mobility.

There are PPS support groups, newsletters, and educational networks that provide up-to-date information about PPS while assuring survivors that they are not alone in their struggle.

### Resources

For more information on post-polio syndrome or have a specific question, our [information specialists](#) are available business weekdays, Monday through Friday, toll-free at 800-539-7309 from 9am to 5pm ET. Additionally, the Reeve Foundation maintains a fact sheet on PPS with resources from trusted Reeve Foundation sources. [Check out our repository of fact sheets](#) on hundreds of topics ranging from state resources to secondary complications of paralysis.

- [Post-Polio Health International](#) offers information for polio survivors and promotes networking among the post-polio community.
- [Post-Polio Institute](#) is the home of Richard Bruno, clinical psychologist specializing in fatigue, pain, and stress – as well as PPS.

**Sources:** Post-Polio Health International, Montreal Neurological Hospital Post-Polio Clinic

## POLIO ERADICATION UPDATE

Excerpt from *Post Polio Health International Association Members Communique, February 16, 2017 (No. 121)*

**Facts for 2017 as of week of February 15, 2017**

- Wild poliovirus type 1: one case in Afghanistan
- Circulating vaccine-derived poliovirus: 0
- [Endemic Countries](#) (Afghanistan, Nigeria and Pakistan)
- [Outbreak Countries](#) (Lao People's Democratic Republic)
- [Key At-Risk Countries](#) (18 countries); Cameroon, Central African Republic, Chad, Democratic Republic of the Congo, equatorial Guinea, Ethiopia, Guinea, Iraq, Kenya, Liberia, Madagascar, Myanmar, Niger, Sierra Leone, Somalia, South Sudan, Syrian Arab Republic, Ukraine

## GLOBAL POLIO ERADICATION INITIATIVE

The following email was received from Ramesh Ferris. He would greatly appreciate your support regarding the request for increased funding for the eradication of Polio. Mr. Ferris was our conference speaker in 2009 when he was cycling across Canada.

On Tue, Apr 11, 2017 Ramesh Ferris wrote:

Good Morning Everyone,

I apologize for the group email but I'm trying to connect with as many people as possible from the March of Dimes and Polio Canada community (and of course as many Canadians as possible).

As you are all quite aware the Canadian Government has been a generous supporter of the Global Polio Eradication Initiative since 1988. In 1988 it was estimated that there were 350,000 new cases of polio reported annually spread out over 125 countries. Last year there were 37 cases reported in three polio endemic countries (Pakistan, Afghanistan, and Nigeria). However one new case of polio is one case to many. A case of polio anywhere in the world is threat to children everywhere in the world.

Currently there is an open online e-petition (e798) which is urging the Canadian Government to contribute an additional \$150 Million Dollars to the Global Polio Eradication Initiative. The deadline to sign this e-petition is May 30th, 2017

Here's the link to the petition:

<https://petitions.parl.gc.ca/en/Petition/Details?Petition=e-798>

## Late Effects of Polio (LEoP)

*Excerpts from Polio Oz News Autumn 2017 (Australia)*

LEoP can present as a unique cluster of biomechanical and/or neurologic features in each individual, which can be moderated if properly assessed and managed. The LEoP are essentially a 'diagnosis of exclusion', but should be considered for clients/patients who are known to have had polio themselves — or other members of their family (which may indicate undiagnosed sub-clinical damage). The LEoP refer to any of the following features.

**Musculoskeletal features:** Decreased muscle endurance and muscle fatigue, Overuse of compensatory muscle groups, Muscle pain and/or spasms, Joint pain and/or degeneration such as arthritis, Biomechanical deformity such as kypho-scoliosis, Muscle contracture, Osteopenia or osteoporosis

**Neurological features:** New muscle weakness, Muscle atrophy, Preservation of sensation irrespective of muscle loss, Muscle twitching/fasciculation, Compression neuropathy

**Respiratory features:** Shortness of breath due to chest deformities, Respiratory insufficiency due to sleep apnea, Weakening respiratory muscles, Hypoventilation due to early damage to the respiratory control centre

**Bulbar features:** Impaired thermoregulation, Dysphagia/swallowing problems, Dysphonia/vocal dysfunction, Dysarthria/unclear speech, Chronic fatigue, headaches, poor concentration

**Additional considerations:** Biomechanical problems, Bladder dysfunction, Weight gain due to decreased mobility, Oedema, Psychosocial concerns due to increasing disability, Pre and post-planning for surgical procedures

## Members Page

### Upcoming Events

#### PPN General Meeting

May 30<sup>th</sup>, 2017  
between 1:00 & 2:30 pm

Caboto Centre  
1055 Wilkes Ave. Wpg

Speaker: B.Konantz of Hearthwest -  
Orthotics

#### Summer Celebration Luncheon

June 19<sup>th</sup>, 2017  
between 11:30 & 2:30 pm

Caboto Centre  
1055 Wilkes Ave. Wpg

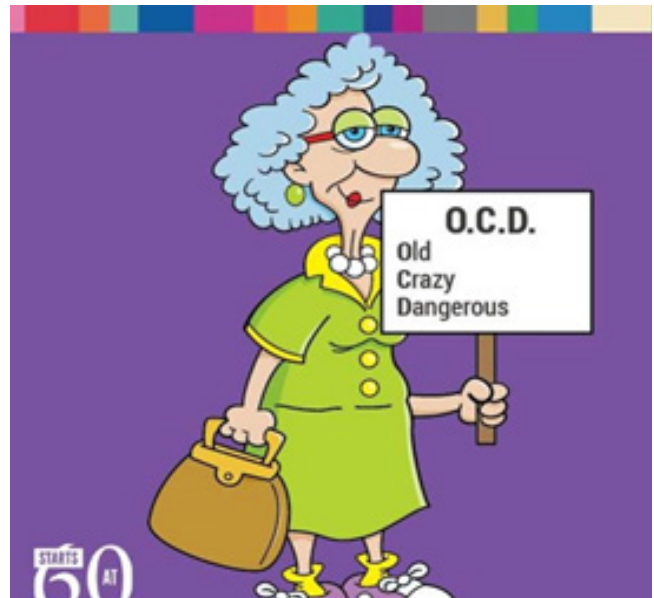
NOTE: RSVP

### Passages

The Post Polio Network (Mb) would like to express our condolences to the family and friends of Victor Palsson of Arborg, Mb. who passed away in April 2017.

#### Jokes of the Day:

My wife was hinting about what she wanted for our upcoming anniversary. She said, "I want something shiny that goes from 0 to 150 in about 3 seconds." I bought her a bathroom scale. And then the fight started.....



***Do you have an interesting story to tell?***

*Or do you know any good jokes, inspirational or humorous quotes or poems?*

*Then you are invited to email them to:*

[postpolionetwork@gmail.com](mailto:postpolionetwork@gmail.com) or mail them to:

Post-Polio Network (Manitoba) Inc.

C/O SMD Self-Help Clearinghouse

825 Sherbrook Winnipeg, MB, R3A 1M5



# SUMMER Celebration Luncheon

**DATE:** June 19th , 2017  
**TIME:** 11:30 a.m. – 2:00 p.m.  
**WHERE:** CABOTO CENTRE  
1055 Wilkes Ave., Wpg



*RRSP by June 12th, 2017 (need to advise caterer number of attendees)*  
*EMAIL: [postpolionetwork@gmail.com](mailto:postpolionetwork@gmail.com) or*  
*TELE: 204 975-3037 or*  
*MAIL to: Post Polio Network, 825 Sherbrook Ave.,*  
*Winnipeg MB R3A 1M5*



**COST:** \$5.00 for MEMBERS \$10.00 for GUESTS

Name:

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No. of persons attending: \_\_\_\_\_ member(s) \_\_\_\_\_ guest(s)

Please list any food allergies:

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Payment enclosed: \_\_\_\_\_yes \_\_\_\_\_no





## Membership Application Form

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **Province:** \_\_\_\_\_

**Postal Code:** \_\_\_\_\_

**Telephone:** \_\_\_\_\_ **E-mail:** \_\_\_\_\_

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

**New Membership - \$15/year**

**Membership Renewal - \$15/year**

**I wish to make a charitable donation of \$**   
*(Tax deductible receipt will be issued.)*

***Please make cheque payable to:***

***Post- Polio Network Mb. Inc. and mail application form and cheque to:***

***Post-Polio Network, 825 Sherbrook St., Wpg. Mb. R3A 1M5***

***For further information please phone 204-975-3037***

### 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.

You may visit our website at:

[www.postpolionetwork.ca](http://www.postpolionetwork.ca) or email us at [postpolionetwork@gmail.com](mailto:postpolionetwork@gmail.com)