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

# Bresident's Report May, 2016

#### Well, finally it's spring in Manitoba and I'm sure that we are all happy about that.

Post Polio Network (Manitoba) Inc. held our 29th Annual General Meeting on March 29th at the Katherine Friesen Centre. It was great to see everyone again and meet some new members. Thanks to all the executive and committee chairs for their annual reports and hard work for the past year.

The Post Polio Network works and thrives because of our volunteers and much thanks to those who have come forward. There are new directors on the Post Polio Network's Board of Directors. In February, Ms Rachelle Hebert became a member of the PPN's Board of Directors and will chair the Privacy/ Fire Safety Committee. At the AGM, Ms. Clare Simpson and Mr. Roger Currie joined the PPN Board of Directors. Clare will look after memberships and all that it entails and Roger will be responsible for publicity. We are still looking for a Telephone Co-ordinator and someone to take minutes at meetings---- any suggestions or volunteers, please. The good news is that we may not have to have a special members meeting to discuss the future of PPN.

Cheryl Currie and Donna Remillard agreed to let their names stand for President and Treasurer and were elected by acclamation.

#### Mark your calendars for our upcoming events:

- ~ For PPN's May 31st general meeting, Mr. John Thiessen of Easy Street, a physiotherapy program at the Misericordia Hospital, is scheduled to speak about the Easy Street Program.
- ~ The June "Summer Celebration Luncheon" is still in the planning stages as I write this. The location, date and time of PPN's June Summer Celebration will be announced shortly. The idea is to have a celebration party in the spring rather than in the late fall when the weather doesn't always cooperate and it is difficult to get around.

If you haven't done so, please renew your annual membership. Membership applications are located in this newsletter. It is you the members that make the Post Polio Network.

*Lastly*, I want to express Post Polio Network's appreciation to Estelle Boissoneault for her dedication and hard work on behalf of the Network for the past 18 years. We wish her all the best in her future endeavors.

May, 2016

# Post-polio syndrome

by Mayo Clinic Staff

Excerpt From www.mayoclinic.org

#### Tests and diagnosis ~ Indicators of post-polio syndrome

To arrive at a diagnosis of post-polio syndrome, doctors look for three indicators:

- *Previous diagnosis of polio.* The late effects of polio usually occur in people who were adolescents or older during the initial attack of polio and in those whose symptoms were severe.
- *Long interval after recovery.* People who recover from the initial attack of polio often live for many years without further signs or symptoms. The onset of late effects varies widely but typically begins at least 15 years after the initial diagnosis.
- *Gradual onset.* Weakness often isn't noticeable until it interferes with daily activities. You may awaken refreshed but feel exhausted by the early afternoon, tiring after activities that were once easy.

In addition, because the signs and symptoms of post-polio syndrome are similar to those commonly associated with other disorders, your doctor will attempt to exclude other possible causes, such as arthritis, fibromyalgia, chronic fatigue syndrome and scoliosis.

Some people with post-polio syndrome worry that they may be getting amyotrophic lateral sclerosis (ALS), also called Lou Gehrig's disease. But the late effects of polio are not a form of ALS.

#### Tests to rule out other conditions

Because there are no tests that confirm a post-polio syndrome diagnosis, your doctor may use certain tests to rule out other conditions, including:

• *Electromyography (EMG) and nerve conduction studies.* Electromyography measures the tiny electrical discharges produced in muscles. A thin-needle electrode is inserted into the muscles your doctor wants to study. An instrument records the electrical activity in your muscle at rest and as you contract the muscle.

In a variation of EMG called nerve conduction studies, two electrodes are taped to your skin above a nerve to be studied. A small shock is passed through the nerve to measure the speed of nerve signals. These tests help identify and exclude conditions such as an abnormal condition of your nerves (neuropathy) and a muscle tissue disorder (myopathy).

- *Imaging.* You may undergo tests, such as magnetic resonance imaging (MRI) or computerized tomography (CT), to produce images of your brain and spinal cord. These tests can help exclude spinal disorders, such as the degenerative spine condition spondylosis or narrowing of your spinal column that puts pressure on your nerves (spinal stenosis).
- *Muscle biopsy.* Your doctor may perform a muscle biopsy, looking for evidence of another condition that may be causing the new weakness.
- *Blood tests.* People with post-polio syndrome usually have normal blood test results. Abnormal blood test results may indicate another underlying problem that's causing your symptoms.

#### **Treatments and drugs**

Because the signs and symptoms often vary, there's no one specific treatment for post-polio syndrome. The goal of treatment is to manage your symptoms and help make you as comfortable and independent as possible:

• *Energy conservation*. This involves pacing your physical activity and combining it with frequent rest periods to reduce fatigue. Assistive devices — such as a cane, walker, wheelchair or motor scooter

— also can help you conserve energy. A therapist can even show you ways to breathe that help conserve energy.

• *Physical therapy.* Your doctor or therapist may prescribe exercises for you that strengthen your muscles without you experiencing muscle fatigue. These usually include less strenuous activities, such as swimming or water aerobics, that you perform every other day at a relaxed pace.

Exercising to maintain fitness is important, but be cautious in your exercise routine and daily activities. Avoid overusing your muscles and joints and attempting to exercise beyond the point of pain or fatigue. Otherwise you may need significant rest to regain your strength.

- Occupational therapy. A physical therapist or occupational therapist can help you modify your home environment so that it's safe and convenient for you. This may include installation of grab bars in the shower or a raised toilet seat. Your therapist may also help you rearrange furniture or rethink certain household or work-related tasks, decreasing the number of steps you must take and increasing your efficiency.
- Speech therapy. A speech therapist can show you ways to compensate for swallowing difficulties.
- *Sleep apnea treatment.* Treatment for sleep apnea, which is common among people with post-polio syndrome, may involve changing your sleeping patterns, such as avoiding sleeping on your back or using a device that helps open up a blocked airway.
- *Medications.* Pain relievers such as aspirin, acetaminophen (Tylenol, others) and ibuprofen (Advil, Motrin IB, others) may ease muscle and joint pain.

Numerous drugs — including pyridostigmine (Mestinon, Regonol), amantadine, modafinil (Provigil) and insulin-like growth factor-I (IGF-I) — have been studied as treatments for post-polio syndrome, but no clear benefit has been found for any of them.

### **POLIO ERADICATION NEWS**

#### 2016 Update from PoloPlus (Manitoba & Saskatchewan)

Excerpts with permission from Rotary Club Fort Gary

2015 was a banner year as we saw the least number of polio cases EVER......71 cases of (WPV) Wild Polio Virus and 27 cases of cVDPV (circulating vaccine-derived poliovirus). India has not reported a case of polio for over 5 years and no cases were reported in Africa. Afghanistan (19) and Pakistan (52; 306 in 2014) are still endemic. We must not give up the battle; the war is so close to being won.

The biggest news for 2016 is that, effective in April, 155 countries and territories will stop using the trivalent oral polio vaccine (OPV) and switch to the bivalent version of the vaccine in a single 2 week period. This will be one of the most ambitious globally synchronized projects in the history of the vaccine.

By switching to the bivalent version, an inactive vaccine, we withdraw the main cause of VDPV's, target Type 1 more effectively and take the program an important step towards eradication. One reason the inactive vaccine is coming into use only now is that it is five times more expensive than the live oral type.

Taken from Report by: Brenda Banbury, District D5550 PolioPlus Chair

#### WHO's New Director of Polio Eradication

Source: Rotary International, Jan. 21, 2016

In February, Michel Zaffran took over as director of polio eradication for the World Health Organization (WHO). Most recently, Zaffran has served as coordinator of WHO's expanded Programme on Immunization. He has also served as Deputy Executive Secretary of the Global Alliance for Vaccines and Immunizations (GAVI) and represented WHO on the working group that designed and launched GAVI.

# PAIN

#### Excerpt from: PHI Comunique (No. 112), April 15, 2016

#### About Pain in Polio Survivors

Experienced physicians emphasize the "importance of diagnosing a post-polio person's pain generator and then directing the treatment (of pain) to the specific cause."

One of the best articles about pain was written by Anne C. Gawne, MD, now deceased, called Pain in Post-Polio Syndrome.

PHI recently asked physicians about marijuana use. Responses were limited since it is illegal in most states, but a few knew a patient or two who did use it for pain control and found it beneficial. It was expressed that there probably is a role for CBD/THC in the treatment of pain, etc, but the problem is that since it has been illegal no legitimate researchers have been able to conduct double-blind studies, adding that it is probably safer than high dose narcotics

#### Excerpt from: Post Polio Health Care Considerations for Family and Friends Published by Post – Polio Health International post-polio.org polioplace.org

Post-polio health care professionals describe three different types of pain in polio survivors.

Problem	Ideas to Improve Alignment
Knee pain from "back knee" in the weak leg or in the "good" leg from overuse	Brace for "back knee"; use of cane to unload stress on "good" knee
Low back pain due to abnormal leaning to one side when walking (result of one-sided hip weakness)	Cane held in opposite hand to increase stability and reduce leaning
Carpal tunnel from using a cane	Use ergonomic handles or two canes to minimize stress on painful wrist
Poor sitting posture due to hip muscle imbalance (one side is smaller than other)	Small portable pad placed under buttock when sitting

#### **Biomechanical Pain**

#### **Overuse Pain**

Example	Problem Activity	Ideas to Reduce Pain
Shoulder (rotator cuff) injury from pushing up body weight using arms	Getting up/down from chairs, toilets	<ul><li>Elevate seat height</li><li>Install/use grab bars</li></ul>
Upper arm muscle pain (biceps tendinitis) from pulling body weight up stair rails (due to leg muscle weakness)	Climbing stairs, e.g., to bedroom	<ul> <li>Move bedroom to first floor</li> <li>Install stair lift</li> </ul>

Treatment for overuse pain includes rest and support for the overused body part. Physical agents such as ice or heat, ultrasound and transcutaneous electrical nerve stimulation (TENS) may help reduce the symptoms. Modification of the activity that causes the pain is the best way to provide long-lasting relief. Often rest is not possible since many survivors rely on upper extremities for both getting around and self-care.

#### Post-polio Muscle Pain

Survivors describe post-polio muscle pain as burning, cramping or a deep ache. This type of pain is usually associated with physical activity and typically occurs at night or at the end of the day. Muscle cramps and/or fasciculations (muscle twitching) are indications of overuse of polio muscles. In the table below, you will find a few examples of how to reduce post-polio muscle pain.

Muscle	Problem Activity	Strategies
Front of the thigh (quadriceps)	Standing for long periods	<ul> <li>Alternate sitting and standing</li> <li>Evaluate for orthotics, assistive devices, etc.</li> <li>Do stretching exercises to help change position</li> </ul>
Calf (gastrocsoleus) twitching or pain	Walking long distances	<ul> <li>Reduce walking distances</li> <li>Evaluate for orthotics, assistive devices</li> </ul>

#### Post-polio Muscle Pain

Survivors and health professionals use a variety of medications to treat post-polio muscle pain. The most common ones tried are of little use. Examples include the nonsteroidal antiin-flammatories (NSAIDS – aspirin, ibuprofen and naproxen), acetaminophen (Tylenol), benzodiazepams (Xanax, Valium) and narcotics.

Experience shows that tricyclic antidepressants (TCAs), especially amitriptyline, can help with easing pain and decreasing fatigue.

Decreasing activity of the painful muscle(s) throughout the day is the best way to manage post-polio muscle pain. An evaluation for the need for orthotics (braces) and/or assistive devices (canes, crutches, scooters) and their appropriate use may also help to reduce post-polio muscle pain.

#### A woman on the phone to her friend;

I feel like my body has gotten totally out of shape, so I got my doctor's permission to join a fitness club and start exercising....

I decided to take an aerobics class for seniors. I bent, twisted, gyrated, jumped up and down, and perspired for an hour. But, by the time I got my leotards on, the class was over.



# Hooray Winnipeg!!

From the Winnipeg Press, Feb. 13, 2016

The Intelligent Community Forum named the top seven intelligent communities for 2016. And with an IQ popping three Canadian cities on the list, it's time for us to stop being modest.

The non-profit think tank, based in New York, announced the winners this week, recognizing seven of the world's most gifted metropolises. Of the three Canadian cities on the list, all were from a different province; Montreal (Quebec), Surrey (B.C), and Winnipeg (Manitoba). Meaning that the country's intellect isn't just concentrated in one area – there are geniuses from all across the land.

The Intelligent Community Indicators used six pointers to define the critical success factors, which provides the framework for understanding what goes into making an intelligent community. Broadband, Knowledge Workforce, Innovation, Digital Equality, Sustainability and Advocacy

#### From National Geographic Travel, Nov. 2015 as reported by CBC Nov. 19, 2015 and the only Canadian City to make the list.

The Canadian Museum for Human Rights, Arctic Glacier Winter Park at the Forks and the Downtown Spirit bus. Those are three of the reasons National Geographic Travel named Winnipeg one of the best places to visit on earth on their list, Best Trips 2016.

"Winnipeg is a whistle-stop on rail and road trips across Canada; polar bear and beluga whale enthusiasts know it as the starting point for their journey north to Churchill," Kimberley Lovato wrote in the article. "But this unpretentious prairie city proves itself worthy of more than a glance from a train window."

The National Geographic profile provides information on the public transit system, including the Downtown Spirit, a free bus with three routes at the center of the city. Winnipeg's Alt Hotel is named one of the best places to stay while vacationing in Winnipeg, whether it be in the winter when there are lots of opportunities for ice skating and tobogganing or in the summertime, when farmers markets are a popular way to spend time.

No Artificial Sweeteners

lauthor unknown)

Have you ever wondered how effective hugs are? You rarely give a hug that is not appreciated, or receive one that does not make your day a little brighter.

- © Can you think of any medication that has such pleasant side-effects?
- © Hugs are good for you. They're not fattening and they don't cause disease or give you cavities.
- © They're all-natural, contain no preservatives, artificial sweeteners or other chemical additives.
- © Hugs are cholesterol-free and contain100% of the recommended daily allowance of hope and happiness.
- © They're a completely renewable source of energy and they're available without a prescription.
- © Hugs don't require any special instructions.
- ☺ They don't need batteries, tune-ups or X-rays.
- © They're non-taxable, fully returnable and energy-efficient.
- © They can be safely used in all kinds of weather as a matter of fact, they work especially well during cold or rainy days.
- © They are particularly effective in treating everyday problems like stress, worry, anger, frustration, sadness or sorrow, and even the occasional nightmare.
- © The best thing about hugs is you can use them without special training or prior experience.

# But....a word of caution for those of you trying it for the first time: you should never wait until tomorrow to hug someone who needs it today.

## Once you realize how good it feels, you'll want to do it all over again tomorrow! Yes, hugs are extremely addictive!

# This and That

#### Upcoming in June Summer Celebration Luncheon\*

Celebration details are in the planning stages



May 31<sup>st</sup>, 2016 between 1:00 & 2:30 pm

The Katherine Friesen Centre 940 Notre Dame Ave

Speaker: Mr. John Thiessen, Physiotherapist

Topic: Easy Street, a physiotherapy program at the Misericordia Hospital that is designed for clients specific needs

Lunch and coffee will be served !

On the first day at the new seniors complex, the manager addressed all the new seniors pointing out some of the rules: "The female sleeping quarters will be out-of-bounds for all males, and the male dormitory to the females. Anybody caught breaking this rule will be fined \$20 the first time." He continued, "Anybody caught breaking this rule the second time will be fined \$60. Being caught a third time will cost you a fine of \$180. Are there any questions?"

A t this point, an older gentleman stood up in the crowd inquired: "How much for a season pass?"

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

# FYI

A Private Member's BILL C239 – The Fairness in Charitable Gifts Act. Ted Falk, MP for Provencher, is proposing that Federal tax credits for donations to registered charities be raised. Contact your member of parliament and lend your support to this bill.

**NOTE:** federal tax credits for political contributions far exceed the federal tax credits for charitable donations.

**New Co-operative Living Development** of 60 units is scheduled to begin in June 2016 in the Wolseley District (located at the Old Grace Hospital site at Arlington and Preston). Occupancy for early 2018. One to four bedroom units available. Already 60% occupancy confirmed. Contact: <u>oldgracehousingcoop@gmail.com;</u> www.oldgracehousingcoop.ca

Manitoba 55+ Games will be held in Brandon, June 14 -16, 2016. Registration is open. Lots of fun and things to do. Cards/games/sports. Contact: <u>manitoba55+games@gmail.com;</u> (204) 261-9257 or 1-855-261-9257

**British Polio** has just published, Jan 2016 "Post-Polio Syndrome: A Guide to Management for Health Care Professionals"

Excerpt from Polio Oz News, March 2016, Volume 6, Issue 1.

"Research conducted by the British Polio Fellowship in 2012 determined that only 55% of GPs were able to diagnose the symptoms and 18% of GPs did not know how to manage PPS when diagnosed. The aim of this publication is to assist GPs and other clinicians in recognizing and managing PPS."

If you would like a copy of this comprehensive guide, the cost will be \$8 to pay for postage and copying. Contact PPN at 204 975 3037 or email <u>postpolionetwork@gmail.com</u>

## \*Membership Alert\*

Our Post-Polio memberships were due January 2016. Please check the front of your newsletter envelope. If the date is 2016 – your membership is due.

**Membership Application Form** 

Name:		
Address:		
	Province:	
Postal Code:		
Telephone:	E-mail:	
Please check one or	more of the following options	s:
New Membershi	p - \$15/year	
Membership Rei	newal - \$15/year	
	a charitable donation of \$ 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.

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