

POLIO



POST

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October, 2014

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

President's Report October, 2014

Our summer began with our annual June Picnic. There were 55 people in attendance; the food was great; but, the company was better. Thanks to all the volunteers who helped with the setup and the cleanup. There were three door prize draws and the lucky winners were: Albert Patenaude, Cheryl Currie and Marion Howard.

The May general meeting informed those present that even though we've been driving for quite a while we make a lot of mistakes when we're driving; bad habits too. There is an excellent hand book that Susan Everton handed out; "Driver's Handbook" from the Manitoba Public Insurance. It is a worthwhile read. Contact www.mpi.mb.ca.

Our autumn began with our September 30th meeting. Our speaker was from St. James Assiniboia 55+ Centre, Adele Spencer. Her talk was informative, humorous and well received. The number of programs offered by the Centre are quite diverse and of interest to most. Similar centres are found around the city.

The October meeting topic will be on Fraud and Scams and our speaker is from the Winnipeg Police Service, Constable Brent Sparrow, Community Relations. This meeting is on October 28th at 1:00 p.m.

Grey Cup is close at hand. Thanks to everyone who has been selling the pool tickets. It is the proceeds from these pool tickets that help us with our programming and luncheon costs. Thanks to Linda Wilkins for all her hard work.

Please note that we have the RSVP for the Holiday Luncheon in this newsletter issue. The Holiday Lunch will be held on November 28th at the Victoria Inn. Please get your reservation in. Looking forward to seeing everyone. Don't forget to include your annual membership fees of \$15.00. Our fees are due on January 1, 2015.

** * Cheryl Currie, President * **

OCTOBER is flu shot month – don't forget yours.

Letter to Your Doctor

Excerpts from Mia Farrow and Thaddeus Farrow Co-Chairpersons for the Post-Polio Letter campaign

POLIO SURVIVORS ARE NO LONGER POSTER CHILDREN. We are accomplished adults who are being disabled by POST-POLIO SYNDROME, new fatigue, weakness and pain, affecting the world's 20 million polio survivors. Yet most doctors don't know PPS exists. Give a copy of this letter to your doctor. With your help every doctor will learn about PPS and give polio survivors the care we so desperately need.

WHAT IS 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 difficulty swallowing and breathing—that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of 'non-paralytic' polio survivors. These are about 2 million North American polio survivors and 20 million polio survivors worldwide.

WHAT CAUSES PPS? PPS is 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 IS PPS DIAGNOSED? There is no diagnostic test for PPS. PPS is 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.

IS 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 or 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, over-worked 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 / high-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. Stretch-

ing 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.

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. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it. 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.

The Accessibility for Manitobans Act (AMA)

The Accessibility for Manitobans Act (AMA) became law on December 5, 2013. As a result, the Manitoba government will develop mandatory accessibility standards. These standards will address barriers for Manitobans as it relates to key areas of daily living. Both private and public sector organizations must adhere to these standards. Disabilities cover a wide range of impairments. These standards will address various types of disability. For example, blindness or visual impairment, deafness or hearing impairment, intellectual or developmental disabilities, mental health issues and chronic illness.

There is an Accessibility Advisory Council responsible for developing proposed standards that could become regulations under the AMA. The council is made up of members of the disability community as well as members of public and private organizations. There are 5 key areas that will be addressed:

- 1 The Accessible Customer Service which addressed business standards and training needed to provide better customer service to people with disabilities.
- 2 The Accessible Information and Communications standard which will address the removal of barriers in access to information.
- 3 The Accessible Built Environment standard will address access into and within buildings and outdoor spaces. Will include things like counter height, aisle and door width, parking and signs.
- 4 The Employment Accessibility standard will address paid employment relating to employee-employer relationships.
- 5 The Accessible Transportation standard will address aspects of accessible public transportation.

Meetings were held this past summer to discuss this legislation.

The province has begun by consultation with consumers, professionals, business and government, on the Customer Service standard. They are now in the process of taking the input from this meeting, determining what can and will work, and then a follow up meeting will take place, with an eventual plan for implementation of this standard.

The City of Winnipeg took a different approach. All 5 standards were discussed at the initial meeting, and input from the consumer groups will be considered for implementation of these standards. Again, there will be follow up meetings, but no specific timeline given.

There is a great deal of optimism regarding changes that will enhance the lives of people living with a disability. However, the commitment to achieve significant progress is slated for 2023, so these changes will take much time.

Report submitted by Esther Gill



Frederick M. Maynard, MD

ASK DR. MAYNARD

Used with permission from Post-Polio Health international

QUESTION: In 1998, I was your patient at the University of Michigan when you diagnosed my post-polio syndrome. I am preparing for a complete knee replacement on my right leg, which is the one affected by polio. My question is: Should my physical therapy after surgery be specialized to my condition or will normal therapy be OK?

ANSWER: Exercises need to be planned out on an individualized basis based on your pre-operative muscle strength in that leg. Strengthening may need to proceed slowly to avoid overuse damage, but that is usually not an issue in the early period. It is more important later when strengthening is a major goal and is relevant if and when a protective brace can be safely discontinued.

KARACHI'S POLIO VACCINATORS IN THE CROSSHAIRS

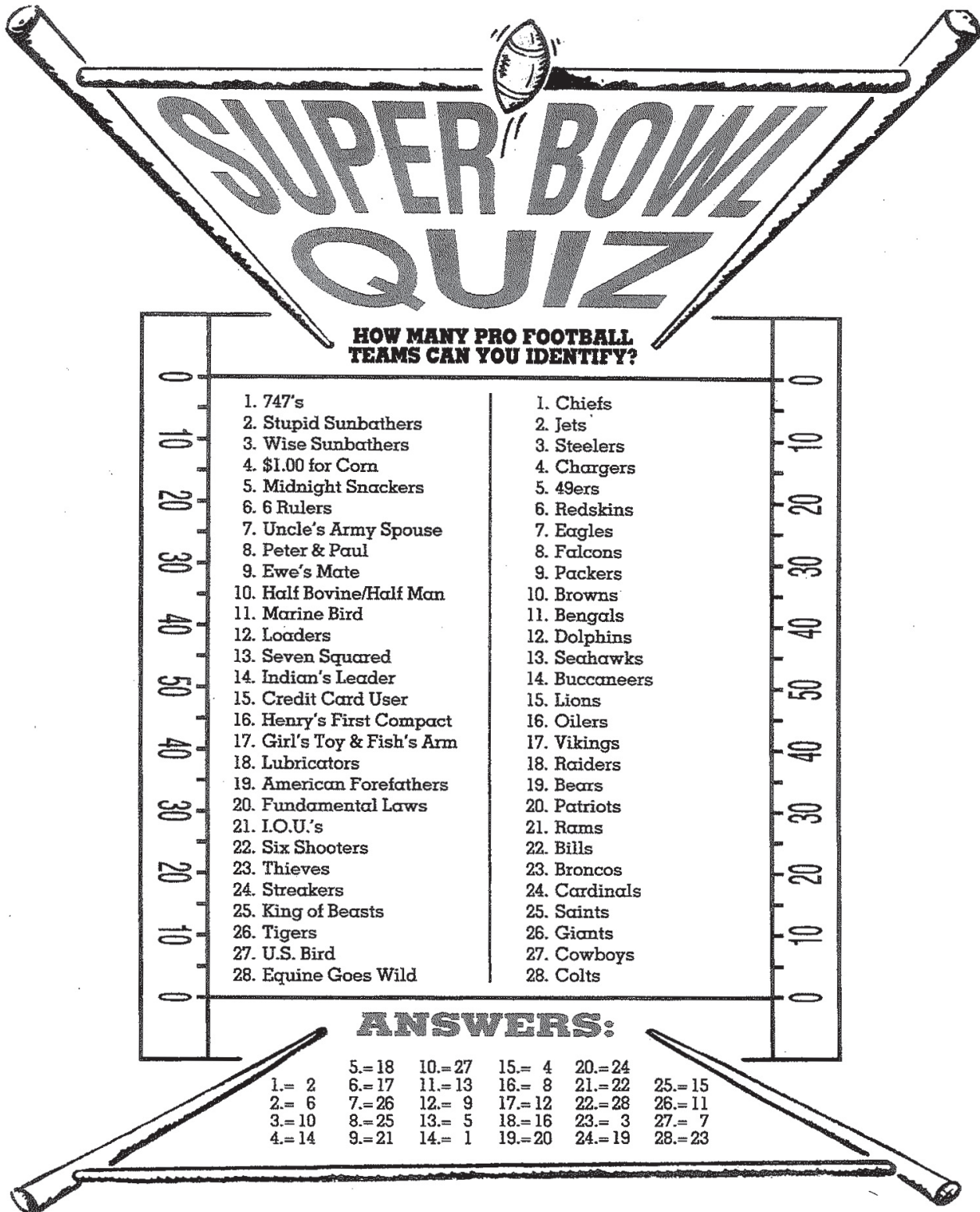
Karachi Pakistan - In the last 25 years worldwide polio cases have dropped by 99 percent, but the highly contagious disease, which is passed on through infected water and food contaminated with the faeces of an infected person and thrives in areas with poor sanitation and incomplete vaccination efforts, remains endemic in Pakistan, Afghanistan, and Nigeria.

Of those, it is Pakistan that remains the most at risk, suffering 166 cases already this year, compared to just 10 in Afghanistan and 6 in Nigeria according to the World Health Organization (WHO).

While the lack of uniform hygiene standards is one reason for the disease's spread, health workers told Al Jazeera that the biggest issue in Pakistan is opposition to vaccination by parents – often with the “justification” that the vaccine is part of a conspiracy to sterilise Muslims, as advocated by the Pakistani Taliban – and subsequent attacks on polio vaccination workers. The threat is more visible in Karachi, Pakistan's largest city, and one where a complex mix of ethnic, political and religious conflicts has resulted in a city where violence itself is endemic.

Since July 2012, 58 people have been killed in attacks on polio vaccination teams in Pakistan, including at least 24 health workers, according to data compiled by UNICEF. In the latest attack, on September 10, in the tribal area of Bajaur, a paramilitary soldier who was providing security to a team was killed by a group of masked gunmen.

The lack of immunisation coverage, combined with the influence of the Taliban and the constant flow of migrants into the city has turned Karachi into a reservoir for the disease. Excerpt from: <http://www.aljazeera.com/indepth/features/2014/09/karachi-polio-vaccinators-crosshairs-2014930113016107468.html>



** For your convenience the Holiday Luncheon and the Membership Application Forms are on the last page of the newsletter so you may send in the cost of the luncheon and your membership fee together **

Member's Page

Making left turns from two-way onto another two-way street

- Well ahead of the turn, look for any following vehicles, signal and move close to the centre line.
- Slow down and look both ways before starting turn.
- Enter the intersection to the right of the directional dividing line.
- Make your turn to left of the centre of the intersection.
- If turning onto a four-lane highway outside the city, town or village, move to the right after completing the turn, if traffic permits.

From Driver's Handbook

F Y I

Do you need help getting out of your chair?
Check www.liftcushion.com.

Have you cancelled your land line? Relying on cel phone alone? Please realise that you must register you cel number with the police as your addresss will not show up when you dial 911.

SMD CLEARINGHOUSE PRESENTS

"Speaking Up" A workshop on being a good advocate for yourself or for others.

- Getting organized and collecting information
- Keeping records that help tell your story
- Learning good communication skills

When: Monday, November 3, 2014. Where: Society for Manitobans with Disabilities, 825 Sherbrook St. Time: 1 – 3 p.m.

Register by emailing zjoyce@smd.mb.ca or phoning 204-975-3103

The next meeting will be October 28th

topic 'fraud and scams'



at the Katherine Friesen Centre



on Notre Dame Ave at 1 PM."

In Memory of Pat Odut who passed away on July 15th, 2014. She was a long term member of our our Post-Polio group

The Lincolnshire Post-Polio Network Host:
an information for polio survivors and medical professionals. The site is a library of full text articles on post-polio condition. <http://postpolioproblemadediscapacidad.blogspot.ca/2011/06/canadian-post-polio-clinics.html#sthash>.

2014 - 2015 Senior's Guide

is now available @ www.gov.mb.ca/shas. or call 204-945-6565 for information.

\$100,000 GRANT ANNOUNCED:

Antonio Toniolo, MD, FAME, University of Insurbia, Varese, Italy, accepted the Post-Polio International two-year grant award of \$100,000 on May 31, 2014. Dr. Toniolo's proposal, "poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs."

Used by permission from PPHI Summer 2014.

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:

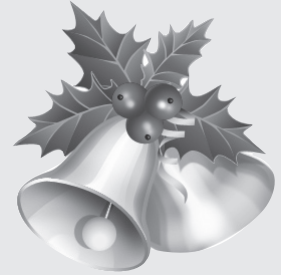
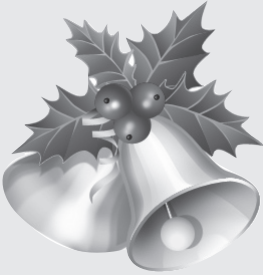
postpolionetwork@gmail.com

or mail them to:

Post-Polio Network (Manitoba) Inc.

C/O SMD Self-Help Clearinghouse

825 Sherbrook Winnipeg, MB, R3A 1M5



Annual Holiday Luncheon

Friday, November 28th, 2014

Victoria Inn @ 1808 Wellington Avenue

Doors open from 11:30 - 2:30

Cost: \$15.00/person

No gift exchange

Come join us for a traditional turkey dinner

R.S.V.P.

Please send cheque to Post-Polio Network

825 Sherbrook St. R3A 1M5

with names of member and guest and any allergies

Deadline : please reserve before November 14th, 2014

NOTE: NEW VENUE VICTORIA INN

NAME.....

GUEST NAME.....

ADDRESS.....

AMOUNT SENT.....

ALLERGIES.....

Post-Polio Network (Manitoba) Inc.
C/O SMD Self-Help Clearinghouse
825 Sherbrook Street
Winnipeg, MB, R3A 1M5
Phone 204-975-3037



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

Membership Alert

Our Post-Polio memberships are due January 2015. Please check the front of your newsletter envelope. If the date is 2015 – your membership is due.

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 or email us at postpolionetwork@gmail.com