POLIO POST

POST-POLIO NETWORK MANITOBA

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

President's Report February, 2013

I would like to wish you, your families and friends a belated healthy, prosperous and Happy New Year for 2013.

It seems that 2012 just sped by. We had a busy year and the highlight was the triennial conference, Pain and Pain Management that was held in September. The conference was a success; the program was well received. The keynote speaker, Dr. Carol Vandenakker and the panel members, Dr. B. Shay, Dr. J. Derksen and Ms. Hnatiuk, and the panel discussions were informative and interesting.

Thanks to the conference committee for all your hard work and the Winnipeg Foundation for providing us with the grant that made the conference a possibility. Other highlights this past year were the June PicNic and the Holiday Luncheon. Both events were well attended and the food and company was great. Door prize winners at the Holiday Luncheon were Marie-Anne Britton and Clare Simpson.

Thanks to all for supporting the Grey Cup pool ticket drive as this is our major funding source and a special thanks to Doug for his hard work. Looking forward to seeing everyone at the Annual General Meeting on March 26, 2013 at the Katherine Friesen Centre, 940 Notre Dame Ave. Our speaker will be a specialist on taxation who can answer your questions on disability credits, such as RDSP, medical, caregiver tax credit. Just in time for filing our 2012 taxes.

SO! Bring all your questions. A light lunch will be served. * * Cheryl Currie * *

Important Reminder

Post-Polio Network's membership is from January 1 to December 31.
If you have not already done so, please renew your membership – the fee is $10.00, which is needed to cover the cost of the newsletter sent to you 4 times a year. Check the date printed on the mailing label of your newsletter to ensure you are up to date.

C.I.A VACCINE RUSE – May Have Harmed the War on Polio
Update on Taliban

By Donald G. McNeill Jr. Published July 9, 2012 **Used with permission from PPASS BC**

Did the killing of Osama bin Laden have an unintended victim: the global drive to eradicate polio?

In Pakistan, where polio has never been eliminated, the C.I.A.'s decision to send a Vaccination team into the Bin Laden compound to gather information and DNA samples clearly hurt the national polio drive. The question is: How badly?

After the ruse by Dr. Shakil Afridi was revealed by a British newspaper a year ago, angry villagers, especially in the lawless tribal areas on the Afghan border, chased off legitimate vaccinators, accusing them of being spies.

And then, late last month, Taliban commanders in two districts banned polio vaccination teams, saying they could not operate until the United States ended its drone strikes. One cited Dr. Afridi, who is serving a 33-year sentence imposed by a tribal court, as an example of how the C.I.A. could use the campaign to cover espionage.

"It was a setback, no doubt," conceded Dr. Elias Durry, the World Health Organization's polio coordinator for Pakistan. "But unless it spreads or is a very long time affair, the program is not going to be seriously affected."

He and other leaders of the global war on polio say they have recovered from worse setbacks. The two districts, North and South Waziristan, are in sparsely populated mountains where transmission is less intense than urban slums. Only about 278,000 children under age 5 –the vaccine target population- live there. By contrast, in northern Nigeria, where polio is being beaten after years of public resistance to the vaccine campaign, children number in the millions.

Also, Durry said, vaccinators reached 225,000 Waziristan youngsters in early June, before the ban. All will need several doses to be fully protected, but each dose buys time.

And, said Dr. Bruce Aylward, the W.H.O.'s chief of polio eradication vaccination teams are posted at highway check points, train stations and bus stations. They give drops to all the children they find.

The truth probably won't emerge until the summer spike of polio cases tapers off in the fall. The virus likes hot weather, and the summer monsoons flood the sewer-choked gutters where it lurks.

Paralyzed children may also be found in neighboring countries with better surveillance, as they have been before just over the China and Tajikistan borders. Genetic testing will show whether the strains are Pakistan-based.

By contrast, if the eradicators are winning, local paralysis cases will slowly shrink to zero, as they have in India, a former epicenter which has not had a case in almost a year and a half. And the virus will no longer be found in sewage samples from Pakistani cities, as it is now.

Local anger was at its height last July, when The Guardian exposed the C.I.A. connection. It was confirmed by Defense Secretary Leon E. Panetta in January. Public outrage flared again in May after Dr. Afridi was sentenced. A coalition of aid groups protested to David Petraeus, the director of Central Intelligence.

"There could hardly have been a more stupid venture, and there was bound to be a backlash, especially for polio," said Dr. Zulfiqar A. Bhutta, a vaccine specialist at Aga Khan University in Pakistan.

Dr. Bhutta, who also heads the government's research ethics committee, said both Dr. Afridi and the C.I.A. could be "sued or worse". To establish their credibility, Dr. Afridi's teams vaccinated whole neighborhoods in Abbottabad without permission. The setback was just one more in the endless war on

polio, which was supposed to have been over by 2000. The fight is against the last 1 percent of cases. Paralysis cases worldwide have shrunk from 350,000 in the 80's to about 600 now.

Victory gets tantalizingly close, and then recedes, forcing health authorities to appeal for another $1 billion, as they did recently in Geneva.

Nigeria had only 62 cases last year; Pakistan had 198. For every known case, there are about 200 carriers with no symptoms, experts believe. Thus far in Pakistan this year, only 22 confirmed cases have been found. But the virus is still in sewage samples, meaning people are still shedding it. Paradoxically Dr. Afridi was not offering polio vaccine but hepatitis B vaccine.

Exactly why has not been elucidated, but there is a possible explanation: Hepatitis vaccine is injected, while polio vaccine is oral drops. If the objective was to gather DNA-- which Dr. Afridi's team apparently failed to do-- it would be easy to aspirate a little blood into each needle.

Also "hepatitis B could be kept under the radar," said Dr. Bhutta "For polio, there are too many players and agencies," he said.

But polio is the vaccine with a long history of controversy among Muslims in many countries, so Pakistanis who were not familiar with the difference turned on polio vaccinators.

From the Vancouver Sun, Dec. 12, 2012

Gunmen shot dead five women working on UN-backed polio vaccination efforts in two different Pakistani cities on Tuesday, officials said, a major setback for a campaign that international health officials consider vital to contain the crippling disease but which Taliban insurgents say is a cover for espionage.

Pakistan is one of only three countries where polio is endemic. Militants, however, accuse health workers of acting as spies for the U.S. and claim the vaccine makes children sterile. Taliban commanders in the troubled northwest tribal region have also said vaccinations can't go forward until the U.S. stops drone strikes in the country.

Read more:

http://www.vancouversun.com/news/Five+polio+campaign+workers+killed+while+providing+vaccines/7719087/story.html#ixzz2HVOOTrXD

UPDATED POLIO STATISTICS

Year to date 2012

COUNTRY	WPV1	WPV2	WPV3	TOTAL	date of most recent case
Pakistan	55	2	1	58	30 nov 2012
Afghanistan	35			35	25 nov 2012
Nigeria	100	19		119	03 dec 2012
Chad	5			5	14 jun 2012
Niger	1			1	15 nov 2012
TOTAL	196	21	1	218	
Total in endemic Countries	190	21	1	212	
Total outbreak	6	0	0	6	

Post Polio Syndrome - An Overview of Current knowledge

This lecture was presented by Dr. Frans Nollet M.D. PHD. Academic Medical Centre, department of rehabilitation Amsterdam Netherlands

Dr. Nollet was the Dr. who came to my rescue when I fell in the elevator before the conference even started. I had an instant goose egg on the side of my knee. Joan and Donna wanted it looked at by a Dr., so Dr Nollet was asked by the conference coordinator to come and see me. He very kindly came to my room and examined my knee and felt that I should have it x-rayed. He was questioning maybe a cracked patella blood clot or bursa damage, so off we went to hospital for x-rays. It turned out that the x-rays showed nothing, so after 4 hours we headed back to our hotel. The next morning when the conference began I found out that Dr. Nollet was one of the keynote speakers and was on the board that organized the conference.

He spoke on post polio syndrome in regards to our current knowledge. He firstly spoke about pps as the decline in muscle function many years after the recovery from polio. He also commented on the fact that pps can only be diagnosed when every other disease has been excluded. Post polio is felt to be established in about 40-60% of polio survivors, with a 2% decline every year. Another interesting fact that Dr. Nollet mentioned was that pps was higher in females than males, why they don't know. The cause of pps is not known, but the most widely excepted hypothesis is that the neurons age prematurely due to high metabolic demands and lose their ability to maintain the large motor units, that were formed in the recovery phase after the acute polio. In recent years they have suggested that pps is an inflammatory disease, based on the raised concentration of cytokines in the cerebrospinal fluid. There has been no pharmacological therapy that has been able to stop the decline in pps patients. Researchers have been studying the effectiveness of a new procedure, intravenous immunoglobulines, but it needing further study. Even though we need some physical activity we must be very careful not to overload ourselves. We must make changes in our life style, such as the use of mobility assistive devices, and make modifications to our homes.

Lecturer: Dr. Kristian Borg, a researcher from Sweden
We had a lecture from Dr. Kristian Borg who is a researcher from Sweden.

They have been treating patients with PPS with an experimental drug called intravenous immunoglobulin, but with varying results. Dr. Borg introduced us to a 67 year old women, Ester Boserup, who spoke about her experience with polio. Her symptoms were the same as many other polio survivors, muscle weakness, pain, fatigue, and were diagnosed as PPS. In Sept 2009 she was treated with 900ml of immunoglobulin intravenously for 4 hours a day for 3 days, at the Danderyd Centre for PPS, in Stockholm Sweden. Her mental and physical tiredness decreased considerably and the "fog" in her head decreased. Her pain was gone and her muscles became stronger. Her concentration and focus increased dramatically. She could sleep! Lack of concentration and poor memory, and her out-look on life became positive – it was great! She went into this situation anticipating relief of her symptoms, but got a lot more. It improved her general attitude and her quality of life dramatically. This treatment lasted 10 to 12 months. Then her PPS symptoms started to reappear and she was back where she started. In Dec 2010 she was to have a second treatment, this treatment had now been cancelled, due to the lack of funding, and she was back where she started. Due to the fact that there was a waiting list, they decided to fulfill their obligations for patients on that list. This treatment is still being researched and is still in the experimental stage, it is very expensive, and not available to all. Dr. Borg explained that 1/3 of patients respond very well to this treatment, 1/3 only marginally and 1/3 negatively. He is now able to identify and treat the 1/3 that falls into category one. This treatment would be a wonderful break through for not only PPS, but many other like diseases.

~ From the Aug 2012 issue of PPASS BC ~

Accessibility Legislation / Province of Manitoba

What is it?

Accessibility legislation lays out the vision of the Manitoba that we all want – one where everyone can live, work and play free from barriers. While the rights of people with disabilities and seniors are laid out in our human rights codes, the path to achieving full accessibility is not always as clear. Legislation will set out the process to come up with that plan – using the input from all Manitobans and the businesses and public services that affect them.

Who will it affect?

Virtually all Manitobans live with a disability or know someone who does. Many of us will become disabled as we age or as the result of an injury. For businesses, making products and services more accessible can increase customers. Attracting and keeping skilled employees, including people with disabilities and older workers, is important to our economic success. Promoting Manitoba as an accessible destination can increase tourism. Making Manitoba more accessible ultimately benefits everyone.

Why do we need it?

The Manitoba Human Rights Code ensures that people with disabilities have the right to the same services as everyone. Complaints to the Human Rights Commission are a result of public and private sector services not meeting this obligation. While the complaints process will remain an important tool to protect these rights, most Manitobans would agree that preventing the barriers that lead to these complaints is a better option than only increasing accessibility in response to complaints. Legislation will lay out a plan to eliminate these barriers based on the advice of everyone affected, including business, government, people with disabilities and seniors.

When will it come into focus?

Building an accessible Manitoba is a long-term goal. Many businesses and public services have already committed to this goal and are working towards it.

How does it work?

The commitment to make Manitoba accessible must be shared by all – governments, businesses and public services. The final design of the legislation will be guided by what we hear through consultation and/or through groups which include people with disabilities and others who will be affected by these standards.

Don't just 'IMAGINE'

(new words via John Lennon's song)

Imagine there's no stairways
It's easy if you try
No steps below us
Above us only sky
Imagine all the people
Living in equality

Imagine there's no prejudice
It isn't hard to do
No reason to judge or hate
And no name calling too
Imagine all the people living life in peace....

You may say I'm a dreamer
But I'm not the only one
I hope someday you'll join us
And the world will be as one

Imagine accessible transport
I wonder if you can
No broken lifts or moody drivers
A brotherhood of man
Imagine all the people
Sharing all the world.....

You may say I'm a dreamer
But I'm not the only one
I hope someday you'll join us
And the world will live as one.....

PAIN-FREE COOKING

Preparing a meal: no simple job

Many tasks are involved in making a meal:

- Deciding what you're going to make
- Making a grocery list
- Shopping: transportation, reaching/lifting/lowering items in and out of your grocery cart, carrying bags full of groceries, unloading groceries
- Pulling out ingredients for a recipe: lifting, searching, bending, reaching
- Using various cookware and appliances: chopping, pouring, stirring
- Setting the table
- Eating
- Cleaning up

This is a large amount of work. If your joints are stiff and painful, that will make the job harder and more tiring. The following general tips and on how to work smarter in your kitchen will make cooking easier. For recommendations specifically tailored to your abilities, please seek an assessment from an Occupational Therapist.

TIPS

Pace Yourself:

- Be well rested. Cook extra on 'good' days and freeze.
- Take rest breaks before you get too tired. No one is timing you. (sit, take in some deep breaths, mentally scan your body and notice any feeling of discomfort/tension/swelling/ warmth or pain and rest that particular joint. Change positions or switch tasks and return later).

Posture:

- Maintain a good, supported posture. If you can, sit on a stool at the counter or on a chair at your kitchen table so that you can rest your arms comfortably.
- Alternate tasks (cut some veggies, wash a few dishes, set the table) so you are not doing the same task for a long period of time (e.g every 5-10 minutes)
- When standing, avoid locking your knees – this puts stress on your back
- Try placing one foot on a stool. This can help prevent back pain.
- Minimize the need to lift: arrange your kitchen tools and appliances with easy reach, ask for help with the groceries, use wheeled trolleys.

Kitchen organization:

- Keep most used items, especially the heavier ones out on the counter, in top drawers, or the lower shelf of overhead cupboards (between eye and hip level).
- Lazy Susans allow you to use the full depth of the cupboards but prevent you from having to reach far.
- Stacking shelves allow you to separate your dishes so you never have to lift the lunch plates for example, for example, to get to the large dinner plates.
- Peg boards allow you to hang pots individually (to avoid retrieving a pot from underneath a stack of them), and frequently used utensils (instead of rummaging through a full drawer).
- Vertical storage racks hold your pot lids and pans individually so you don't have to stack them.
- Store items (flour, sugar, rice) in small containers to avoid bending and lifting. Fill these containers by scooping (not lifting and pouring), or have someone fill them for you.
- Line cans up in rows of the same product so you don't have to rummage at the back of the cupboard.

- Continuous counters are better for sliding pots/dishes to where you need them. If you have to lift and carry, a trolley would be useful. A small table in your kitchen is also helpful. Pass dish from counter to table, walk, pass dish from table to other counter and walk.

Kitchen cleaning:

- One dish meals allow for fewer dishes to clean up.
  Line pans with foil or parchment paper, and use a cooking spray for easy clean-up.
- Squeezing a sponge with your palm to release excess water is easier than wringing out a dish-cloth. If you do use a dish cloth, try draping it over the faucet and pressing the cloth between your palms to squeeze out the excess water.
- It may be helpful to raise the level of your sink bottom by using a basin in the sink raised by a couple of blocks of wood.

General tips:

- Use your palms rather than your fingers when possible (e.g. to carry plates, to push down on spray cans, when using a rolling pin, when holding mugs).
- Use your forearms when possible (e.g. Place straps on handles to the fridge or cupboards. Place your forearm through the loop of the strap and pull).
- When carrying groceries hold the bag close to your body with both arms.

Excerpts from:

'Aging Well with Post-Polio: The Weight of the Matter'

Published by:
'Rehabilitation Research and Training Center (RRTC) on Aging with Physical Disability'

There has been little research on the weight of people who were aging with a chronic condition. People with post-polio syndrome (PPS) who participated in our survey may recall answering a question about weight, height and waist circumference. The RRTC studied this data and recently published findings in the Disability and Health Journal.

Based on the answers received, we calculated Body Mass Index (BMI) which is weight divided by height, that results in a number commonly used to categorize if a person is underweight, normal, overweight or obese. In our research, we compared the data we collected to a larger sample of the general population from National Health and Nutritional Examination Survey (NHANES) that assesses the health and nutritional status of U.S. adults and children. We also looked at BMI by chronic condition (multiple sclerosis, post-polio syndrome, muscular dystrophy, and spinal cord injury), age group and gender.

Our findings:

- The average BMI for both men and women with PPS across all age groups was greater than 25, which is the standard for overweight.
- In comparison to people with multiple sclerosis, spinal cord injury and muscular dystrophy, people with PPS on average has a higher BMI.
- In comparison to the NHANES Survey Group on average people with PPS had lower BMI except for women in the youngest age group (45-59). In other words people aging with PPS are in better shape compared to the general population aging in the United States.
- To calculate your BMI go to www.cdc.gov/healthyweight/assessing/bmi/.

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YOU ARE INVITED !

WINNIPEG TRANSIT TRAVEL TRAINING

Winnipeg Transit has changed over the years and offers many new features for accessibility and safety. Please join a representative from Winnipeg Transit to hear about the changes that include:

- Easy-Access Low-Floor buses
- Priority seating, extending ramps for persons with mobility issues
- Navigo, teleBUS
- GPS tracking, onboard cameras for added safety

Where: Room 203 – 825 Sherbrook
When: Thursday, February 28, 2013
Time: 1:00 p.m. – 2:30 p.m.

PRESENTATION INCLUDES A RIDE ON A NEW BUS – WE HOPE YOU WILL JOIN US

smd CLEARINGHOUSE

PLEASE RSVP by February 18, 2013 by calling Kathy at 204-975-3037

Any Communication Supports will be provided upon request

Member's Page

Update on the 2009 conference keynote speaker:

On July 1, 2012 (Canada's 145th birthday) Ramesh Ferris was married to his sweetheart, Dagmar. Dagmar was born in and still has a large family living in Czechoslovakia, but now is teaching math in Whitehorse. The ceremony was presided over by Ramesh's father Bishop Ron Ferris, so it was a big family affair here in Canada. This would be followed by a second celebration in Prague.

Since last reporting on Ramesh's work , he has been extremely busy as an advocate for polio eradication. He has flown many thousands of miles, and met many influential people during the past year and is definitely leaving his mark on the world. In a period of 8 days he flew from Whitehorse to Vancouver, then to Seoul, Korea and on to Mumbai, India, eventually arriving at his destination a further couple of hour's flight away. Most recently he has travelled to South Africa and France.

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Fund Raising Report

A sincere appreciation goes out to all members who supported our Grey Cup Pool—either through purchasing or the actual selling! This year we came very close to meeting our goal, raising close to $3400.00. Please remember monies raised go towards the following:

- rental cost related to the Katherine Friesen Centre
- rental cost related to SMD facilities
- printing and photocopying, costs related to and the mailing of newsletters and notices
- the subsidies for the June Picnic and the Holiday Luncheon
- lunches at the general meetings.

In order for our organization to continue the status quo of services, the executive and the fundraising committee asks more of our members become active in selling these pool tickets.

ANNUAL GENERAL MEETING

March 26th AT 1:00 PM

Place: Katherine Friesen Centre,
940 Notre Dame Avenue

Necessary Business:
Under section 3 of By-Laws it reads:

"For the first year, the President and Vice-President shall be elected for a 2 year term....."

This needs to be changed to read:
"The President and Vice-President shall be elected in alternating years for a 2 year term....."

Due to previous confusion, the President's position will be extended to 2015.

This issue and others need your vote.
NOTE: **Only members who are up to date with their membership dues are eligible to vote.**

Resources—Post—Polio

The following links are very helpful for updates and new developments in the fields in interest most often requested:
http://www.post-polio.org/edu/pphnews/index.html (2012 current year)
http://www.post-polio.org/edu/pphnews/topic1.html
(all other years alphabetically)

Other noteworthy websites:
www.polioplace.org
http://www.polioplace.org/living-with-polio/living-polio
Programs, services and contacts across Canada (Disability WebLinks):
www.disabilityweblinks.ca

IN MEMORIAM

We have recently lost these long term members.

Helen Redden,	November 30th	aged 75
Audrey Carlson,	December 2nd	aged 80
Helene Blais,	December 14th	aged 95
Enid Kaake,	December 29th	aged 81

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

2013 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

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.