

POLIO



POST

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

President's Report June, 2011

With the passing of such a difficult spring for so many of our fellow citizens, we are grateful that summer is finally coming. We are longing for warm, dry conditions and praying for all the folks who are displaced from their homes and businesses.

Our members have met twice since our last newsletter, once for our annual AGM and in April we met to hear our guest speaker Vic Kellar, a personal trainer.

The highlight of our AGM was hearing speakers from CAA Travel Manitoba speaking about travel for the disabled. How wonderful it was to hear ideas about travelling to exotic places, especially in the midst of miserable weather. Focusing on travelling on the cruise lines, we learned that the cruise ship lines are very well equipped to make travelling possible and enjoyable for those of us who need accommodation for our disabilities.

In April, Vic Kellar spoke to us about health and fitness. His presentation was interesting and informative especially regarding diet and nutrition.

We look forward to hearing Sheldon Mindell, from The Riverview Health Centre Foundation, speak at our May 31st meeting and as usual seeing lots of folks attend our annual Picnic on June 20th.

I wish you all a wonderful summer with not too many mosquito bites!

Charlene Craig, President

A.G.M. Report

as delivered by Charlene Craig to the members on March 29

“Ladies and gentlemen and special quests,

Welcome on this beautiful day to our Annual General meeting,

Hopefully spring is just around the corner and will treat us well. I thank you all for coming today and especially those who have traveled from out of town to be here. There is a hint of spring being around the corner and our long winter is almost at an end. Manitobans are an optimistic lot; someone remarked, in *The Settler's Guide to the North-West*, issued by the Northern Pacific Railway Company of New York, that: “the climate of Manitoba consists of seven months of Arctic weather and five months of cold weather.” I trust that the Arctic weather is behind us.

I would like to thank your executive, which has worked so hard on your behalf. Being a frugal lot we met throughout the year in our ‘boardroom’ at the Forks. *Don't get nervous*, we haven't purchased or leased a fancy boardroom ... our boardroom consists of a table, chairs (all free) in the skate-changing/warming area at the Forks, humble, but it works.

Thank you Estelle for always doing the minutes and all you do as secretary, membership person and newsletter creator and thank you Doug for all your hard work with the Grey Cup Ticket campaign and organizing the food for our meetings. Thank you, Cheryl for your work as Vice President and with publicity and program work and thank you Bob for making sure we are always safe. Thank you, Donna for taking care of our money and thank you David for your guidance and participation in everything we do. Thank you Clare for you and your team taking care of the Phoning. Your executive works hard to see that members enjoy varied activities and are kept informed.

I will keep my remarks brief this afternoon, but should like to highlight the fun activities we enjoyed this past year

- Our annual picnic, at the Bourekvale Community Club in June, was enjoyed by many. It was HOT- really HOT that night. I had a good time, how about you? A special thanks to our organizers for again making it such a success (the caterer also helped)
- Dr. Tapper`s presentation on Attitude and Well- being was inspiring and first rate.
- And once again, a big thanks to Doug & his helpers and all you members who sold , or bought tickets that made our Grey Cup Fundraiser another success.
- Our Holiday Luncheon was held at the Holiday Inn where turnout was terrific. Thanks to Albert and his helpers, the food was superb, the gifts interesting, the fellowship warm; personally I had a wonderful time... It was a hit.

Our finances are solid and well tended to by Donna and the Executive.

We continue to support and make others aware on the need for polio vaccination and remind people that this disease has not been eradicated.

I look forward to the special events we have planned for this year and I know you will too. Please let either a board member or myself know if you would like something included and we will do our best to accommodate your idea.

We have challenges ahead as an organization, and I would like all of you to consider whom you will want as members of your executive whom you will elect next year. Every year that passes the membership is getting older. We can't escape that reality. So what do we want to do with our organization over the next few years as we have less time and less energy to tend to its' affairs. We should be asking these questions and plan well.

Thank you again for coming!"

Salk Institute Launches Website for Polio Survivors

Reprinted with permission from the Salk Institute

The Salk has launched PolioToday.org—a resource for polio survivors intended to raise awareness of the crippling post-polio syndrome (PPS), a serious neuromuscular condition that can strike an estimated 40-50 percent of people decades after they were first infected with poliovirus.

The World Health Organization estimates there are about 10-20 million polio survivors worldwide. Characterized by extreme fatigue and renewed weakness or paralysis in the limbs, PPS is often misdiagnosed because its symptoms resemble other crippling neurodegenerative diseases. The severity of paralysis during the original polio infection (decades earlier) does not seem to play in role in whether or when PPS strikes, and the syndrome is typically gradual in onset.

“I have had patients who had very mild cases of polio, or don't even remember having had polio when they were young, end up with post-polio syndrome,” says Dr. Jacquelin Perry, renowned orthopaedic surgeon and world authority on gait analysis who treats PPS patients at Rancho Los Amigos National Rehabilitation Center in Downey, California.

PPS mimics other debilitating diseases, and because there is no single diagnostic test to confirm it, it is considered a disease of exclusion – meaning it requires specialized testing by well-trained physicians who rule out all other possibilities to achieve a proper diagnosis. That diagnostic complexity and confusion, coupled with the fact that the U.S. polio survivor population is now elderly (or close to it), has relegated the PPS community to relative obscurity.

“People suffering from PPS seem to exist in the shadows, far from broad public awareness of the disease and its terrible manifestations,” says Susan Trebach, Salk Institute Senior Communications Director. “Our goals are to heighten awareness and understanding of PPS, encourage people to seek proper diagnosis and treatment, and facilitate the growth of online communities of polio survivors around the world.”

PolioToday.org features video testimonials from polio survivors who share recollections of their personal battles with polio when they were young, their more recent diagnosis and management of PPS, and how they are coping with their condition. There is an expert opinion video page featuring several clips by UCLA Neurologist Dr. Susan Perlman, a PPS specialist who explains the cause of PPS and provides relevant information.

“Polio survivors have searched for a way to actively connect to one another for years,” says polio survivor Gladys Swensrud from San Diego, California. “This exciting Salk Institute site, PolioToday.org, offers not only a forum for the distribution of important polio and post-polio related information, but it also creates a much needed link for polio survivors worldwide to connect with one another using modern social networking capabilities.”

Rick Van Der Linden, a polio survivor from Hemet, California adds: “The best part of the site is that it’s been developed just for us. It allows us to communicate with and learn from one another. It’s the best thing going on the Web for the polio survivor community.”

Since going live in August, with no mainstream public announcement of any kind, the Community section of the site is already attracting attention as polio survivors, some from as far away as Australia, have signed up to participate in various discussions that have been posted. Under the Emotional Stress and PPS discussion topic, for example, members describe the ways they control the anxiety and depression associated with PPS.

“It is amazing to see people openly discuss their deepest health concerns related to PPS as well as how they found us in the first place,” says Mauricio Minotta, the Salk Communications Director leading the website project.

“It is especially gratifying to receive comments, either on Twitter or YouTube, from people who tell us how much they appreciate this new internet resource,” Minotta says.

The Resources page provides users with a growing list of polio survivor groups around the country and PPS and polio-related literature from other organizations such as Post-Polio Health International, the World Health Organization and Rotary International Polio Eradication.

Most of the activity on PolioToday.org to date has been generated through connections made on Twitter, YouTube and Facebook.

Shamed MMR Doctor in New Child Study



Dr. Andrew Wakefield

The disgraced doctor who caused public panic with his flawed research into MMR vaccine is seeking to rekindle his career in America by recruiting immigrant African children for a controversial study.

Andrew Wakefield, who was struck off the medical register last year, wants to research a technique he supports for treating autism by placing children for up to 90 minutes in hyperbaric chambers – tanks filled with oxygen-enriched air. The chambers have been linked to side effects such as lung damage and their efficacy is widely disputed.

Wakefield asked for volunteers to work with his research team when he addressed 100 families at a Somali restaurant in Minneapolis, Minnesota. Many parents have signed up. Somali refugees in the area reportedly have exceptionally high levels of autism.

Wakefield’s arrival in Minnesota has sparked some angry opposition.

Steven Miles, professor of bioethics at the University of Minnesota, has used local radio stations to challenge the Briton to “stay out of my town. Mr. Wakefield may appear plausible to the Somalis, a vulnerable and unsophisticated community....but they do not need his help” he said in a broadcast. “Their children may be suffering from autism, but alternatively their developmental issues may be related to refugee trauma and poverty.”

Earlier this month the British Medical Journal dismissed Wakefield’s 1998 study linking MMR vaccines with autism as an “elaborate fraud for financial gain”.

Wakefield’s support for hyperbaric chambers is the latest twist in a controversial career. His research, which led to plummeting rates of MMR vaccinations, was discredited by a Sunday Times investigation. Wakefield quit as a senior lecturer at the Royal Free Hospital in Hampstead, north London in 2001 and went to America.

Three years ago, he published a study of 16 autistic children treated using hyperbaric chambers and said the results were promising. The technique involves “cleaning out” the children’s systems using the high oxygen levels in the chambers. The devices are favoured by some celebrities, including the late Michael Jackson, and athletes who believe they speed up recovery from injuries.

The tanks have been used to treat carbon-monoxide poisoning and decompression sickness. Side effects include lung damage and among premature babies, retinopathy – burst retinas resulting in blindness.

Wakefield is recruiting volunteers and running the program, but is not doing the research. Last week, Mary Catherine DeSoto, associate psychology professor at the University of Northern Iowa, confirmed she was talking to him about joining the program.

DeSoto, who suspects environmental toxins and vitamin D deficiencies may help explain the 600% rise in reported cases of autism over the past two decades, said she was still preparing the research. She said this would include asking Somalis if they were willing to try hyperbaric treatment. Its methods have yet to be approved by her university.

On his visit to Minnesota, Wakefield was accompanied by Jennifer VanDerHorst-Larson, a businesswoman. She has set up a foundation, the Holland centre, to promote education and treatments for autistic children, including her son Cade, 9.

From the same offices, she runs the Minnesota hyperbaric treatment centre, which markets treatments for a range of maladies, including autism.

Shlomo Shinnar, professor of neurology at Montefiore medical centre in New York, said: “There is no evidence hyperbaric chambers make any difference, nor is there any real scientific reason why they should”.

Some Somalis, who have felt neglected by health officials, are listening to Wakefield. “I know there was something bad written about Dr. Wakefield but at least he is listening to us,” said Shukri Osman, a community figure, whose child is autistic. “I am thankful he is here and helping us.” Wakefield did not respond to requests for comment. ~ thesundaytimes.co.uk/mmr ~

Ask Dr. Maynard



Frederick M. Maynard, MD

Question: I read with great interest the question and answer about knees collapsing in the Vol. 26, No. 2 (www.post-polio.org/edu/pphnews/pph26-2sp1Op7.pdf). I had polio at age 1. I'm told that I made a full recovery and that our local doctor used me as an example of a "miraculous" recovery.

A graduate of the U.S. Naval Academy, I am now 63 and have had a normal, active life. Several years ago I noted a weakening in my right leg that has slowly gotten worse. I attributed it to sciatica. I had surgery for a ruptured disc in 2002. Last summer after about a year of relative inactivity (just got lazy), my right leg started to buckle and deteriorate rapidly. It even looks smaller.

I saw a neurologist and first heard about post-polio syndrome (PPS). He felt it could be PPS combined with my back problem and with myopathy caused by my mild type 2 diabetes. I went through a period of rehab and regained some strength. I decided to do exercises at home and walk every day. The buckling frequency has decreased, but I have fallen a time or two. A recent MRI of my legs was shocking. My right leg muscles are almost gone, and the space filled in with fatty tissue. I am amazed that my life has been so normal. My body must have compensated incredibly without my realizing it.

The question is ... Can I regain some muscle mass and strength through exercise? I would love to work my legs harder, but have heard that I could damage my muscles since they

may not have the capacity to recover. Should I experiment with a strenuous routine to see if I can improve strength, or do I risk doing damage and further deteriorating my legs?

A: Thank you for describing your history of polio and recent changes so clearly. Here are some thoughts about your situation and what you can do about it.

The large amount of fat seen in your thigh suggests a chronic gradual loss of muscle mass and is an expected result of muscle atrophy. It does not explain if the new atrophy is a result of nerve loss from your lumbar disc problem or from nerve loss due to PPS. Reduced activity will also lead to muscle atrophy from "disuse weakness," and this happens more quickly and dramatically in people who have recent and old nerve losses. Exercise can usually reverse much of the loss of muscle mass from disuse atrophy.

I would not recommend a "strenuous routine" of exercise. Instead, I would recommend you try a low-intensity, non-fatiguing exercise program to strengthen your thigh muscles. However combine this with a careful monitoring (keeping a written record) of your walking activity, including a record of your "maximum walking capacity" done once weekly. This is best done on a level surface and done either as a timed test (how far you can walk in 6 minutes) or as maximum distance walked before there is muscle fatigue (muscle not as strong as when activity started or aching pain in muscle develops). The former is better from a time management standpoint if walking distances are fairly long.

Walking is an activity that does require repetitive strong use of the thigh muscles and does lead to slow strengthening of these muscles in and of itself. A walking program alone may

be best for strengthening your thigh muscles. One has to be careful that strengthening exercises don't interfere with, or necessitate a decrease in, your functional walking. Over-use weakness can occur in polio-involved muscles, especially such as in your weakening and atrophying thigh muscles.

If you experience increased ache and/or burning discomfort/pain in the thigh muscles, or increased/ frequent involuntary twitching in these muscles or increased weakness (even of a temporary nature) then you **MUST** significantly reduce, but not stop, the intensity and/or duration and/or frequency of the exercise and/or walking. Given the relative complexity of the decision-making involved in the above rehabilitative steps, I would recommend seeking professional advice from a physical therapist or exercise physiologist who is familiar with post-polio issues. A professional can support and guide you through the above steps and help you plan for regaining as much strength as possible in your leg muscles.

SEND YOUR QUESTIONS FOR DR. MAYNARD TO INFO@POST-POLIO.ORG.

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Laughter is the Best Medicine

EXERCISE FOR PEOPLE OVER 50.....

Begin by standing on a comfortable surface, where you have plenty of room at each side.

With a 5-lb. potato bag in each hand, extend your arms straight out from your sides and hold them there as long as you can. Try to reach a full minute, and then relax.

Each day you'll find that you can hold this position for just a bit longer. After a couple of weeks, move up to 10-lb. potato bags.

Then try 50-lb. potato bags and then eventually try to get to where you can lift a 100-lb. potato bag in each hand and hold your arms straight for more than a full minute.

When you feel confident at that level, you can then put a potato in each bag.

General Meeting

Katherine Freisen Centre

940 Notre Dame Ave

May 31st 1pm- 3pm

Speaker: *Sheldon Mindell*,

(manager of the Riverview Health Centre Foundation)

They would like to hear stories from people who were in the Municipal Hospitals during the Polio Epidemic

Lunch will be served!

“Mark Your Calendars”

**Annual Post Polio Network
Barbeque**



Monday June 20th, 2011

Join us at the Bourkevale Community Centre
100 Ferry Road

turn south off Portage Ave at Ferry Road towards the Assiniboine River

All the food will be catered by

Tailgator's BBQ Pit

Bourkevale is wheelchair accessible with adequate parking. We will use the clubhouse in the event of inclement weather.

Hope to see you there!

Doug will have Grey Cup Tickets for sale.

Member's Page

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@shaw.ca or mail them to:

Post-Polio Network (Manitoba) Inc.

C/O SMD Self-Help Clearinghouse

825 Sherbrook Winnipeg, MB, R3A 1M5

Charlene's Favourite Charity Unicef Canada

2200 Young St Suite 1100,

Toronto ON M4S 2C6

1 888 777 0380

unicef.ca/life

Polio vaccines

Protect children from a dreaded virus.

Your thoughtful gift of \$45.00 vaccinates 228 children against Polio.

Web sites for the Accessible Accommodations Project

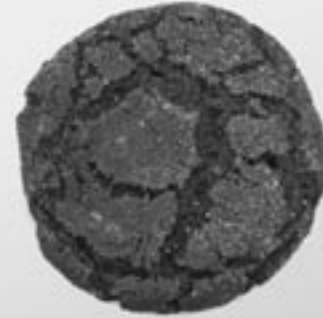
If you decide to travel this Summer, here are some web sites that offer accessible accommodations.

This is a UK site, but click on the link to open the site, then scroll down on the left to find the country you might be interested in visiting. <http://www.disabledholidaydirectory.co.uk/>

This one, <http://www.disabledtravelers.com/>, has lots of great links within; even accessible cruise specialists.

Also you can go to <http://www.travelintelligence.com/luxury-hotels/north-america/canada/wheelchair-accessible-hotels>. From here you can click on any city within North America.

Kathryn Harper scotlass@mymts.net



Ginger Cookies

2 cups (500 mL) all-purpose flour

1 tbsp (15 mL) ground ginger

2 tsp (10 mL) baking soda

1 tsp (10 mL) ground cinnamon

1/2 tsp (2 mL) kosher salt

3/4 cup (185 mL) unsalted butter, at room temperature

1-1/4 cups + 2 tbsp (310 mL + 30 mL) granulated sugar

1 large egg

1/4 cup (60 mL) fancy molasses

In medium bowl, whisk together flour, ginger, baking soda, cinnamon and salt. In large bowl using electric mixer on medium, cream butter and 1 cup (250 mL) plus 2 tbsp (30 mL) sugar until light and fluffy. Beat in egg, scraping down sides of bowl. Add molasses; beat well. In three additions, beat in flour mixture just until incorporated.

Shape dough into 24 balls, each about 2 tbsp (30 mL). Roll balls in bowl with remaining 1/4 cup (60 mL) sugar. Place several inches apart on large, parchment-lined baking sheets. Bake 15 to 17 minutes in preheated 325F (160C) oven until just golden. (Cookies will spread to about 4 inches/10 cm.)

Makes 24 large cookies.

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

REMINDER: It's time to renew your membership for the year 2011 due on January 1st. \$10.00 covers the cost of our newsletter published 4 times a year. A tax receipt will be issued for any other financial donations, as membership fees are not tax deductible.

Thank you. Estelle, secretary

Post-Polio Network's Privacy Policy

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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.