POLIO POST

POST-POLIO NETWORK MANITOBA

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President's Report to the 2010 AGM

The Post Polio Network has had an exciting and productive year. Notably, our Conference in October was a highlight. We were gratified with the number of folks who attended and so pleased with the response. The conference evaluations told us that people were moved and inspired by our keynote speaker Ramesh Ferris` story and his courage. His message, that work still needs to be done to vaccinate children who are at risk, compels us to think outside ourselves.

The presentations of Ron Jersak, physiotherapist and our own Bonnie Hopps who provided much needed practical information on post polio and arthritis were very well received. People were inspired by Bonnie; her spirit, her knowledge and her humour were greatly appreciated.

The conference was a financial success as well. We recovered all monies from entrance fees and generous donations from private sources, the Manitoba Government and The Winnipeg Foundation. The silent auction raised monies which will be donated to the purchase of a new lift for the swimming pool at the Misercordia Hospital where many of our members participate in aquatherapy.

A big thank you to the board members and the many other volunteers who gave so freely of their time and energy; with their contribution the conference went beautifully.

As you know, we hold a barbecue every June and this year we are going to have it catered, as schlepping the barbeques and shopping for and hauling the food is too labour intensive for our poor old bones.

The food will be great and as usual it will be a wonderful time. Mark your calendars for June 14th.

This year we are losing a valued board member who has been a huge part of the heart and soul of the Post Polio Network. Albert will remain as a member but is unable for health reasons to remain on the board.

Albert has provided us with speakers for several meetings a year as well as booking the hotels for our meetings, our AGM and our Holiday Lunch. We are grateful for his involvement on the board and his excellent work as Program chair.

Doug has been our vice president and chair of fundraising committee for several years. While he is retiring from his position as VP, he will continue to be involved primarily in fundraising, in a consulting role. He needs to pass on his knowledge and his wisdom this year to others. His motivation, his determination and his hard work in the Grey Cup Ticket campaign has meant that ticket sales have exceeded all expectations year after year.

The post polio network is facing a fundamental crisis of existence. We are coming to that time when groups such as ours must revaluate our purpose and our ability to continue, as we have been. As numbers and age take their toll we must get creative. Did you know that you don`t have to have had polio or have post polio syndrome to become a member or board member, you need only have a desire to serve the organization?

This is the clarion call to you all – if you can be of service or if you know of someone who can, please come forward to a board member. We need people to volunteer time and energy to our group. *We need new board members.*

I want to thank my fellow board members for two great years. We`ve had a lot of fun, we`ve worked really hard, but your dedication, spirit and energy has kept the network going. Thank you Doug, Estelle, Bob, Cheryl, Donna, Albert, David and Clare - you are spectacular people.

Thank you so much Clare, for your coordination of the phoning committee. It is important work.

And, thank you also to David Turner for going to the Donwood Manor to speak about the Network to the residents there.

And a special thank you to Natalie and Kathy of the SMD Self-Help Clearing House. We appreciate your support more than words can say.

Respectfully,
~ Charlene Craig - President ~

Do you have a physical disability and enjoy gardening?

Go to: www.envirolandscaping.org. This is a website which explains how gardening can be adapted for people who have a physical disability and would like to maintain this leisure activity.

In case we forgot, this happened this month!

Russia Confirms First Polio Case in 13 Years

EthiopianReview.com | May 15th, 2010 at 1:25 p.m.

The 9-month-old girl was diagnosed with the disease after arriving in the Siberian region of Irkutsk from the Central Asian state, where at least 12 people have died from a polio outbreak, said Rospotrebnadzor spokeswoman Lyubov Voropayeva.

"All the necessary epidemiological measures have been taken. There is not currently any threat the disease will spread," Voropayeva said.

Tests in a Moscow hospital found that a second girl from Tajikistan, also 9 months old, was carrying the polio virus but had not developed the disease, Voropayeva said. The last case of polio was confirmed in Russia in 1997.

Polio, which spreads in areas with poor sanitation, attacks the nervous system and can cause irreversible paralysis within hours of infection. Children under the age of 3 are most vulnerable.

The disease was practically eliminated as a public health problem in industrialized countries in the 1960s, but remains endemic in seven countries, including India, Nigeria and Pakistan, according to the World Health Organization (WHO).

At least 12 people have died of polio since January in Tajikistan, WHO figures show. "It is a huge outbreak," WHO spokeswoman Sona Bari told Reuters in Geneva.

She said at least 83 cases of polio had been registered in Tajikistan. Apart from Russia, no other ex-Soviet country has reported infections from the outbreak, she said.

UNICEF, the U.N. children's fund, Friday said it was starting a second round of polio vaccination in Tajikistan, aiming to reach 1.1 million children under the age of 6 and was planning additional vaccinations in Uzbekistan and Turkmenistan.

The WHO, a U.N. agency, will present its strategy for eradicating polio by 2013 at its annual ministerial meeting of 193 member states in Geneva next week.

(Source: Reuters)

Fear less, hope more; Eat less, chew more; Whine less, breathe more;

Talk less, say more; Love more, and all good things will be yours"

~ Swedish Proverb ~

JONI, JIMMIE AND "CIRCLE GAME"

~ Written by: Maggie Keller ~

A few days ago, I learned that Joni Mitchell is a polio survivor. She contracted poliomyelitis during the 1952 epidemic, when she was nine years old.
I am sure that many of you were already aware of this fact…but for me it was a revelation that left me incredulous.

You need to understand that I have been an unabashedly loyal fan of Joni Mitchell my entire adult life. I followed her career through the 1960's and '70's, listening to "that voice" which was so high, pure and sweet it could make angels weep. I knew that she had begun singing and playing musical instruments during her childhood. I was aware that she was also an extremely talented visual artist. I remembered her short-lived marriage to Chuck Mitchell.

More importantly, I was cognisant of the daughter she had chosen to give up for adoption, mere weeks after the infant's birth. This decision seemed to derive from Joni's undaunted pursuit of Lady Fortune's often illusory gift of Fame. And, yes, Joni was one of the Elect, truly one of the Gifted, who was smiled upon by the Lady. But Fortune, as Hamlet knew…"Is a strumpet," and when she bestowed her blessing on Joni, it came at great personal cost.

Equally, I was aware that her long musical career had taken many precarious twists and turns that were the result of both her strength as an artist and her bloody-minded determination to remain commercially independent. Also, I knew that the decades of chain smoking had lowered the magically high range of her vocals, and yes, that her voice was considerably lower now. But that voice has remained sure and true and the musicality of her songs has continued to evolve in a fusion of intricate subtlety.

But, in spite of knowing so much about Joni Mitchell's life, the one fact kept nagging at me. Why did I not know that she had been hospitalized in 1952 because of poliomyelitis? This was very same insidious virus that I had contracted exactly one year earlier, during the epidemic of 1951.
Furthermore, why did I care so much? Well, the answer for me was, as it was for Proust, in the remembrance of things past. The key that unlocked my understanding was to be found in a very personal set of memories; specifically, the ones about the night I met Joni Mitchell.

To begin with, we have to go back to the summer of 1966, when the decade called "the Sixties" was starting to explode. To the south of us, the war in Viet Nam was gearing up, drug usage was becoming rampant, and it seemed that revolution and change were the order of the day for all of us Baby Boomers, in North America and Europe alike. I was no different than most young people of the period. I was fascinated and intrigued by everything that was occurring, but it was the sea of changes that were happening in the music industry that affected me the most.

That summer of 1966, I was 19 years old and my life consisted of working as a waitress at St. Charles Golf and Country Club in order that I have enough money to return to my second year at university in the fall. I had been hired along with my good friend Jimmie, because the Club's comptroller was a friend of my parents. Jimmie got on because his next door neighbour happened to be the Club's Maitre d', and he knew that Jimmie needed a job. He wanted to go to university as well, but Jimmie's family had very little money. Years earlier, his Dad had had polio, which had resulted in his being unable to work to his full capacity for many years.

At that time, St. Charles was only open in the summer months. It was affiliated with the Winnipeg Winter Club and the two facilities shared the main kitchen staff, trading off during the winter and summer seasons. But, unlike the Winter Club, that hired career waiters and waitresses, St. Charles hired university students almost exclusively as its waiting staff for the May-to-September golf season.

Being employed at an exclusive, private club was quite an experience for me. We worked very hard and had long and demanding hours, but the rewards were rich in that I had the privilege of getting to know many international students, from as far away as the Caribbean and Hong Kong. We resided at the Club all summer, staying in buildings that housed separately, the male and female staff. As a result of living, eating and working together, fast friendships formed and no matter how demanding our jobs were, we always had time for fun.

One evening, towards the end of June, we decided that we needed to make some plans and go out "on the town". Remember, it was 1966, we were university students and we had very little money…let alone a car! Thankfully, one of our fellow workers, named Fred was a career waiter. During the winter he was employed at the Winter Club, but in the summer, Freddy was "lent out" to St. Charles, to provide the ballast needed to stabilize us novice waiters and waitresses. One thing that young Fred had, that we university students lacked, was a steady income and therefore…. more money. Also, Freddy had a vehicle! It was an old jalopy that he had purchased second hand…but all we saw was our ticket out for the evening away from the residences, as well as the golfers imbibing at the 19th Hole.

Soon, we were on our way to a favourite drinking hole for university students at that time called the Fourth Dimension Coffee House. It happened to be located at the corner of Pembina Highway and University Crescent. In the early and mid-sixties, the drinking age was 21, which resulted in a proliferation of similar coffee houses, often near university campuses, across Canada and the USA.

The Fourth Dimension had a completely black interior: floors, walls, ceilings, tables, chairs and stage curtain (the stage was in the corner and was elevated about 18 inches off the floor.) Every inch of the building's inner space was black! The place was not licensed, and, as its name implied, it served a large variety of coffees; the drink of choice being, of course, Espresso. Entertainment was provided and it usually consisted of up and coming artists…mostly young musicians or poets. As university students, we regarded the "4 D", as it was known, to be the ultimate in "Cool".

Once inside and having been seated, we learned that a young and unknown folk duo by the name of "Chuck and Joni Mitchell" were playing that week. What we didn't know was that we were about to experience something sublime, and that it would become a life-long memory for Jimmie and me. Simultaneously, one musician's artistic destiny was being woven into the tapestry of time.

Chuck and Joni Mitchell came on stage, sang a couple of numbers and I turned to Jimmie and remarked, "They're good."

Now my pal Jimmie had an amazing voice. He could sing anything, be it classical, popular, folk, or rock and roll. He had perfect pitch and could remember song lyrics effortlessly, even if he only heard them once.

He grinned, and nodding his head replied," Especially her."

He was so right. By the end of the set we were all euphoric, and even though we had decided to make it an early evening, all of us ended up agreeing to stay for the last set.

At the end of the set Joni took the microphone and said that she was going to close with a new song that she had written called, "Circle Game." As the lights dimmed, Chuck stepped into the shadows leaving Joni alone on stage, lit by a solitary spotlight.

It is hard to describe precisely what occurred to us during the next 2-3 minutes, as we sat in silence, being bound to Joni by the spell she cast. She wove her magic around us and brought us into a sacred grove of sound much like those places of ecstasy that lost sailors were led to by the Singing Sirens of Ancient Lore. But, in this case, the transcendence flowing through us was transcribed, more circumspect. It was as if we were being sung to by some arcane being, one of the Gifted that abide on Earth among us mere mortals.

Whether it was our youth, or the times, or perhaps just an experience of being in the presence of great talent while in the company of trusted friends, we were, without exception, awestruck. Whatever it was, a real or imagined perfection, we knew intuitively that what had occurred was rare, yet paradoxically, clear…and oh so real. We floated out of the coffee house after she left the stage and rode home in a kind of innocent trance.

Jimmie continued to be in a blissful state all the next day. He sang the song continuously and perfectly, over and over, all the while plotting how we could convince Freddy and the others to go back and hear her one more time.

In the end, it was only Fred, Jimmie and I who returned to hear Joni Mitchell sing again. Just before the last set, Jimmie and I approached her and Jimmie asked if she would please sing the beautiful song called, "Circle Game" that we had heard her perform the previous night.

She smiled and said she would be happy to do it for him.
We waited through the set and then, near the end, Joni took the mike once more and announced that she was going to sing a request from Jimmie, who was seated in the audience. Once again, she began.

As she sang she looked at Jimmie, and she noticed that he was singing quietly along with her. She stepped off the stage and came and knelt beside him. She could hear that he knew the words and melody perfectly, and it was in that instant that Joni held the microphone up to him, and placing her head next to his, they finished the song together.

The beauty and beneficence of that wondrous night have stayed with me; a stardust memory from a time that is long past. And only now, as I gaze back through the long tunnel of the years, do I finally understand that the circularity is the connectedness that binds us, in our humanity, fragility and love.

Thank you, Joni.

And the seasons they go 'round and 'round
And the painted ponies go up and down
We're captive on the carousel of time
We can't return we can only look behind
From where we came
And go 'round and 'round and 'round
In the circle game

Aging Well with Post-Polio Syndrome

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Chronic pain is something that many people, including many individuals with post-polio syndrome, face on a day-to-day basis. In fact, from the preliminary results of our recent survey of post-polio people, we found that 373 out of 419, or 89 %, reported at least some daily pain. Of these individuals, more than half (227) rated their average pain as being equal to or greater than 5 on a scale of 1 to 10. While it is of little comfort to those experiencing PPS, you are not alone!

Although these results are preliminary, we previously completed a survey with a smaller number of participants (63) with post-polio syndrome. In this study we also found that pain was a very common issue for people experiencing PPS. Some 91 percent of the survey participants reported pain, and everyone who experienced pain also reported that they had not been pain-free during the previous month.

Another sign that pain is a major issue for people with PPS is that, in our surveys, those who reported pain said that they have experienced pain for an average of 20 years. We also asked people about where they experience pain most frequently. People responded that they most frequently felt pain in the shoulders, lower back, legs, and hips. Pain intensity was greatest in the knees, legs, wrists, lower back and head. Knowing where the most common and most severe types of pain occur is a good start to finding ways to help reduce that pain.

Another problem with pain, and why it needs to be addressed, is that it often interferes with activities that are important to people. We also asked about this in our smaller-sample survey, and found that pain interfered most with sleep and with recreational activities, mobility and normal work activities, in that order.

Finally, we found that 70 to 95 percent of those in the smaller survey had tried a number of pain treatments – heat, acetaminophen, ice, aspirin or ibuprofen, strengthening exercises – but fewer than half of the participants with pain were using any pain treatment at the time of the survey.

The next step is to investigate ways to reduce the interference of pain in important daily activities and to test what is most effective in reducing pain for most people. It's also important to understand which coping methods are both effective and easy to use, so that people can incorporate them into their lives and continue to use them to treat their pain.

The amount of pain that people with PPS report may not surprise anyone experiencing PPS, but this is critical information to support further research about PPS pain. From such research we can determine which areas of pain are most important to target, and researchers can begin to design and test interventions to reduce the degree to which pain interferes with key activities. In future columns, we'll discuss research findings regarding different treatment options for pain management.

Research and Training Centre,
agerrtc@u.washington.edu

POLIO POST is pleased to announce the addition of a new column in our newsletter entitled:

"My Life with Polio" - (real stories about real survival)

Anyone wishing to submit their story, but are not sure of how to express it or may need help writing it, please contact Kathryn Harper at 275-0146 or scotlass@mts.net

Kathryn's Story...

Winnipeg, summer of 1952, a young mother and her two daughters (ages 9 months and 4 years) survived the long two week Atlantic voyage from Scotland. One year later, summer of 1953, splashing, squealing, giggling in the rough waters at Winnipeg Beach with her sister and cousin, the four year old was stricken with Polio, during one of the worst years of the epidemic. Her sister and cousin had no symptoms at all and never did develop Polio. Nausea and high fever surfaced. The local doctor gave her a shot of penicillin only to observe a head to toe rash soon after the injection and a body rigidity setting in. He insisted that she be taken to the Princess Elizabeth Hospital as soon as possible. He suspected Polio. His suspicions were correct.

Totally paralyzed and in an iron lung for the 3 week total quarantine, I was unable to see my parents and they were unable to see me. Being new immigrants to Canada only one year earlier, our family was stricken with this devastating situation. My mum related to me when I was in my 30's how she and dad and my baby sister came every day to the Princess Elizabeth Hospital and stood on the grass looking up at the window where they were told I was being care for – hoping, every moment that they might see my wee face at the window. That never happened and their hearts continued to break. After the three mandatory weeks of quarantine, I was released, but not recovered. Instead I had orders to return for out-patient therapy for the next 6 weeks. My dad helped me with exercises every day, even put a piece of plywood under my mattress to keep my bed firm. Then came my birthday and a new red tricycle!! Best thing that happened – my legs got stronger and my life was starting over.

I lived a normal childhood with all the other usual childhood diseases, scrapes and bumps. The scrapes and bumps were earned by trying to keep up with the other kids. I couldn't run much, was lousy at sports and got out of breath climbing even a small hill in a park, then later on in life had to take stairs very slowly, but still loving life.

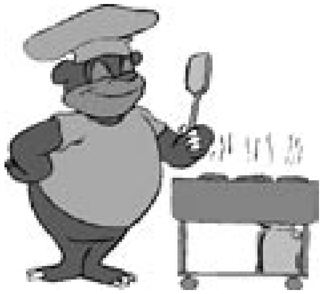
Forty years later (1990), muscle weakness, pain and fatigue began to surface to an extent that was not normal after a hard day at the office. I consulted first with my chiropractor because my arms and the front of my legs were so tired and burning. He asked me if I ever had Polio. When I said yes, he explained that his mother-in-law and his secretary had the same symptoms...and they both had Polio in the 1950's. Thus, the Post Polio Syndrome, as we now know it, was explained to me.

Over the last 20 years, I have gone from not working at all, using a cane indoors and out, to working full time, not using a cane, then as reality set in, I eventually realized I was not physically able to endure full time work. I had to adjust and cope with this new "normal". I am now working part time at a job I love. I remain healthy with my limitations, seeking therapy and assistance when needed. Life is precious. Each moment counts.

~ Kathryn Harper, Winnipeg ~

“Mark Your Calendars”

Annual Post Polio Network Barbeque



Monday June 14th, 2010

Join us at the Bourkevale Community Centre
500 Ferry Road
turn south off Portage Ave at Ferry Road towards the Assiniboine River

All the food will be catered by

Danny`s Whole Hog

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

Hope to see you there!

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

POST-POLIO NETWORK MANITOBA

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

Please note: on your address label on the newsletter envelope there is a date printed (day-month-year). This is the date your membership is due. Please remit your membership dues of $10.00 as soon as possible. Any donation greater than $10.00 will receive a tax receipt. Thank you from the board. We appreciate all of the extra funds as this offsets the cost of keeping the Post-Polio Network Manitoba functioning.

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.