



Editor: Ivan Jorgensen

Phone: 757-8051

ivan.jorgensen@sasktel.net

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Polio Regina Incorporated

3344 Baneberry Drive, Regina, Sask. S4V 2V2

Season's Greetings



My Polio Story

Zenny Burton has been a long time member of Polio Regina. She is a knowledgeable contributor to our Open Forums and newsletter and she brings an enlightened perspective to our support group by sharing her experiences. The following is Zenny Burton's Polio Story.

Zenny Burton



"Infantile Paralysis" was Dr. Sullivan's diagnosis when he made a house call to my parent's home in late May 1940. I was quite ill, running a high fever, hallucinating and complaining of leg pain.

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My Polio Story

Jeanne Hoffman has been a member of Polio Regina since the early 1990's. She has faithfully attended meetings and functions and has always been a contributor to our discussions. Jeanne celebrated her ninetieth birthday in September. She has been an inspiration to all of us and we all wish that were as agile as she is. She will be moving to Calgary in January so we at Polio Regina would like to send her off with our best wishes. The following is Jeanne Hoffman's Polio Story.

Jeanne Hoffman

I was born and raised on a farm near Paradise Hill, Saskatchewan. In the fall of 1935, when I was 14 years old, I became ill with what the doctor said was Infantile Paralysis. I was at home sick in bed with a fever for about two weeks



and missed a lot of school. The doctor said I was "gradually paralyzing". My mother took care of me. She was very meticulous in making sure the disease didn't spread. She even scalded all the dishes.

Later that fall I was taken in a heated cutter to catch the train to North Battleford to see a doctor. He said that my muscles were receding. The Polio (Infantile Paralysis) had affected my muscles on my right side from my spine down to my hand. My hand was particularly weak. I also noticed that my hearing was not that good. The treatment that I received involved

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My Polio Story - Zenny Burton - continued

Home remedies – my mother wrapped my legs in hot moist towels and massaged my legs with Rawleigh’s Camphor oil day and night for a long time. Years later I realized what my mother instinctively did to ease my pain was the treatment known as the Sister Kenny treatment for Infantile Paralysis originating in Australia.

Early in July, I remember crawling outside to where my mother was hoeing the garden, and vaguely remember learning to stand and walk again. Later that summer I was running with friends – knees knocking and feet flailing sideways. But I could run!

Two friends in one family (down the alley) were affected. Irene died (bulbar polio) and Jim had leg problems. No one else in our town was a victim.

I went to school that fall apparently cured and did not seem to have any problems. I do recollect mother giving me “what for” in my teens because she felt I wasn’t wearing heavy stockings, got frost bitten legs and the frostbite caused purplish discoloration around my ankles. Much later, I learned this purple band was due to poor circulation and pooling of blood caused by Polio. Photos from my growing years always showed me with one leg bent and the other straight. Thirty years later, Dr. Phil White, rehab doctor at Wascana Rehabilitation Hospital told me one leg was shorter than the other by three quarters of an inch. That explained the back and hip discomfort I experienced.

After High School, I earned my Registered Nurse diploma – worked in Manitoba, Alberta, and various places in Saskatchewan. I married and raised three children. I experienced a variety of strange symptoms: leg twitching, cold intolerance, fatigue, etc. but blamed a hectic, busy family life.

In 1984, my husband and I went to Lusaka, the capital city of Zambia in Africa on a four year assignment. He, Agriculture Economist, worked in the Ministry of Agriculture and Water Development. I was employed as the nurse at the Canadian High Commission (Embassy) looking after Embassy staff and Canadian expatriates health needs. Two afternoons a week (Tuesday and Thursday) my patients ranged from babies to adults with varying problems. As well I

was on call to accompany emergency medical air transfers from Lusaka to Johannesburg, South Africa. My Canadian medical officer (physician) lived in Nairobi, Kenya and visited our medical unit once or twice a year. Medical problems ranged from malaria, dysentery, infections of all sorts, and general health problems.

Life was great – I had a house servant and a yard man – both full time so physical work was minimal. Mostly, my right index finger got a work out pointing out work to be done.

Our daughter sent a couple articles about something called “Post Polio Syndrome”. I read the articles but they meant little as I was healthy and what was that all about anyway?

On our return to Canada we bought a four level split (many stairs), new employment and doing our own housekeeping and yard work. Tired – yes – but I was getting older and doing a lot of physical work so why get excited? Effects of Polio never crossed my mind, in fact, I didn’t know about this.

In the mid 1990’s things started to catch up with me. I tired easily, having leg weakness, sleep problems, occasional swallowing problems and cold sensitivity were affecting me tremendously. I saw an article about a Regina group who were Polio survivors, their symptoms and they held regular meetings. I phoned the name listed – Fred and Blenda Ramsay – but it took me two years to come to grips with the fact that the problems I was having were due to my childhood Polio. I took out a membership.

My doctor is very supportive, but admits she knows little about Polio as she was born after Salk vaccine was introduced. It took me a fair amount of time to think about assessment and diagnosis, but after finding Edmonton had such a program, I was referred to the Wild Rose clinic and in October, 2007, off I went. After a number of tests including some electrical impulse probing of affected muscles – the diagnosis was: Post Polio Syndrome.

Fatigue – both physical and mental are my constant companions. I am learning with great difficulty, to pace myself and not over do activities. A-type personality?? Cold intolerance continues, my ankles are swollen at days end and we moved to a bungalow

six years ago as stair climbing did me in. A cane is used occasionally – I must learn to use it regularly, and I no longer refuse to ask for help.

Persons in my age group all know someone who had Polio. Our younger generation must be educated about Polio, the devastating effects and the absolute need for immunization; for Polio can and will return if we are not vigilant.

Family and friends are a constant support group, as are the Post Polio support group. It is reassuring to speak with persons who have had Polio, who understand the problems we face, and always ready to share expertise, solutions and assistance. Mostly though, I appreciate their support and sense of humour as we discuss our mutual problems.

My Polio Story - Jeanne Hoffman continued

my mother massaging my muscles from my spine down my arm to my hand with camphorated oil.

In spite of these weaknesses I still worked on the farm like everyone else; I milked cows, which probably strengthened my hand, and did other chores.

I married my husband in November of 1944 and moved onto a farm in the Zehner area 12 miles North-East of Regina. We had three children, two boys and a girl. I have three grandsons, a great granddaughter and three great grandsons. My husband passed away in 1978.

After working on our farm doing heavy work like shovelling grain, before there was the convenience of a hoist on the truck, my arm got worse. My doctor sent me for physiotherapy which sometimes involved dipping my hand and arm in hot wax, wrapping them in hot towels and massaging my arm and hand.

In addition to working on our family farm, I also worked part time in the Zehner Post Office and I completed a typing course in Pilot Butte. In 1984 my son started RPH Distributors Ltd. which sells natural gas meters, regulators, risers, etc. I worked for him part time and he taught me how to do bookkeeping, invoicing and other office duties but sometimes I was left alone in the shop and had to help customers

measure pipe and pick other supplies. I worked there for 17 years.

Throughout my life the affects of Polio made me feel a bit clumsy; I couldn't do things as well as my sisters, but it really hasn't held me back. I used to crochet and I still knit and sew. I can play the piano but not as well as my sisters. My eyes water and my legs become restless and twitch at night. My biggest problem has been that my hearing has gradually gotten worse. My ear canal is so small that it is difficult to put a hearing aid in my ear. It is difficult to say whether these symptoms are a result of Post Polio Syndrome or a part of natural ageing.

I have had good success in dealing with the medical profession. I had always had some back problems and later on in life my chiropractor told me that my right side was slightly shorter than my left. He sent me for therapy which helped. My family doctor has been very good to me.

I will be moving to Calgary in January. My son and daughter-in-law are building a new house on an acreage outside of Calgary. I will be moving into their old house in Calgary. My son will be living there on weekdays while he is working so he doesn't have to commute back and forth from the acreage.

I would like to say farewell to all my friends at Polio Regina. Count your blessings and do the best with what you have!

Keep This in Mind

Drugs taken for cardiopulmonary and other problems may have important interactions with polio related symptoms.

Only you can identify yourself as a polio survivor to your doctor, dentist and pharmacist, ensure your doctor knows what drugs you are taking, and become familiar with potential side effects.

Always remember, it is no solution to take medications and continue to abuse your joints and muscles: change your lifestyle and protect your joints and muscles **first**.

Message from the President and Vice-President



The year 2011 has flown by. It seems like a few months ago when Blenda and I were setting up tables in Broadway Terrace, for our annual Christmas party. Now it is time to go at it again. It is an enjoyable time for sure.

Everyone's life seems so very busy all year long and ours is no exception. We have had the honour of being at 4 weddings this past summer, with 2 of them at home in Regina, one in Penticton and one in Bismarck, N.D. That kept us hopping, plus the yardwork and garden in between

We are now preparing for our 6 or 7 week holiday in Florida, leaving near the middle of January and hopefully return near the middle of March. Our daughter, son-in-law and family will join us in February for 2 weeks. That will be a lot of fun, but it will be crazy busy, (on a holiday, yet!). We are really looking forward to that. Soon the grandchildren will not want to be going with grandparents so we shall treasure them as long as we can. NOTE: Carole will NOT be going on any rides, unless it is for toddlers!

It has been another successful year for our Polio Regina group. We are all one year older and wiser.

It will be sad to see Jeanne Hoffman leave for Calgary, but we know she has a wonderful family there to care for her. We wish her all the best on her new venture!

You are all a wonderful group to be part of. Each and every one of us plays an important part of our group. The fellowship and friendship we have with each other is so important. We both wish you all, a wonderful, peaceful Christmas with God's blessings for a healthy, prosperous 2012! See you all at the meeting in March!

Love & blessings from Wilf & Carole 

The Polio Experience

By Dr. Mavis Matheson



The following is a speech that was presented by Dr. Mavis Matheson at the Rotaract Banquet in October, 2011. She also presented it at the Open Forum at our October Polio Regina meeting.

For those of you who would like to listen to the song "Helpless" by Neil Young that Mavis played, just follow these instructions:

Google "youtube"

Enter "Neil Young Helpless" in the box and click "Search youtube.com"

A number of choices come up

Click on "The Band & Neil Young Helpless - YouTube"

It should start playing.

Introduction

Dr. Mavis Matheson had polio in 1952. She recovered and lead a busy life until the early 1990s when she developed Post-polio Syndrome. She has published several articles on Post-polio Syndrome. She is here to tell us a little bit about "The Polio Experience".

Please help me welcome Mavis Matheson.

The Polio Experience

Mr. Chairman, Ladies and Gentlemen

I am the face of polio in North America.

Tonight I'll try to help you understand the experience of Polio and post-polio syndrome and I'll say a few words about polio eradication.

Polio is a nasty disease caused by a virus. If you haven't had polio vaccine and are exposed to the polio virus you may not have any symptoms for a couple of weeks. Even then you may have only a mild, flu-like illness but if the virus gets into your nervous system, it causes pain, fever and paralysis.

What was it like to have paralytic polio? I was only 1.5 years old so I don't actually remember any details of my polio experience. Every person is different so

every polio experience was different. Some even maintained a sense of humour.

Polio survivor Michael B wrote about his first night in hospital. The nurse asked “Any pain?” He responded “No, thank you”.

Neil Young (5) had polio in the Ontario epidemic of 1951. “Helpless” the song you just heard was inspired by Neil’s childhood experience with polio. Joni Mitchell sings backup. She was 8 when she (like me) was among the 1,205 reported cases of polio in Saskatchewan in 1952 (There were 90 deaths)

Helpless (live at the Last Waltz concert, 1976 with “The Band”)

by Neil Young

Back-up vocals by Joni Mitchell

There is a town in north Ontario, (*Neil contracted polio in the 1951 epidemic in Ontario*)
With dream comfort memory to spare,
And in my mind I still need a place to go,
All my changes (*polio*) were there.

Blue, blue windows
behind the stars, (*lying in bed paralysed, windows were our only connection to the outside world*)
Yellow moon on the rise,
Big birds flying across the sky,
Throwing shadows (*fear, pain & the unknown*) on
our eyes.

Leave us (*spoken?*)
Helpless, helpless, helpless (*how it feels to be paralysed with polio*)
Baby can you hear me now?
The chains are locked and tied across the door,
(*Isolation ward*)
Baby, sing with me somehow.

Blue, blue windows behind the stars,
Yellow moon on the rise,
Big birds flying across the sky,
Throwing shadows on our eyes.

Leave us (*spoken?*)
Helpless, helpless, helpless. (*how it feels to be paralysed with polio*)
Helpless, helpless, helpless.
Helpless, helpless, helpless.
Helpless, helpless, helpless.

I wondered if the song was too long but the polio experience lasted not minutes, or hours or days but weeks, months or even years.

As you lie helpless with polio, your nerves and muscle die. By the 1950s, there were rehabilitation programs that helped polio survivors to get their function back. Because there was a stigma attached to having polio, survivors worked very hard to appear normal.

Imagine your house being invaded by mice, Mice that nibble away at the wiring destroying some wires and damaging others. You finally get rid of the mice but many areas of your home no longer have enough electrical connections. To solve the problem, you run poor quality extension cords from the outlets that still work (though they may be damaged) to areas that are “dark”. This is how with exercise and hard work polio survivors used the remaining “outlets” to their absolute maximum. Surviving nerves ended up branching out to control many times the normal number of muscle fibres.

This analogy may also help you understand why everyone who survived paralytic polio has different problems and different areas of weakness. When you run a damaged system at absolute maximum for a long time, eventually things start to break down. After working hard to get as much function as possible back, many polio survivors find their weakness is returning.

That is Post-polio syndrome. By definition, someone who had polio, regained function and was stable for 20 or 30 years gradually develops onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance). These symptoms must persist for at least a year. (Exclusion of other neuromuscular, medical, and orthopaedic problems as causes of symptoms is also required).

This is very scary to someone who experienced being “Helpless” because of polio.

There are no treatments that can stop deterioration or reverse the deficits caused by the syndrome.

You can only slow the process by not overloading the circuits.

In the early 1990’s, I began to develop weakness in my left leg, I couldn’t run a kilometre every day any

more – my leg would just quit. I pushed myself harder and over the next year I got weaker and weaker. I had to give up my medical practise because I was too tired to think clearly.

By the time I got to a doctor in Edmonton who knew about post-polio for an assessment I was exhausted and using a cane to get around. His testing revealed that not only was my leg weak but my arms were even weaker. I was too weak to be using a cane. Overusing damaged muscles is like plugging more into those extension cords. You will burn out the nerves you have left. So I started using my scooter. (It was hard to accept that I needed it but it did give me a whole new freedom).

When you buy a scooter you need to decide what you want it to look like. Should it be black to coordinate with your goth look, pink and sparkly for a Barbie look. Maybe cammo with a gun rack and dice. But this is Saskatchewan how about Rider Green with a huge S. Maybe not. Sure enough I'll be riding along and some yahoo will yell out "Hey, look at that Escargot!

Even with my scooter, I was still exhausted most of the time. It wasn't until 10 years later that I went to the Harvest Center in New Jersey and discovered I wasn't breathing properly at night. I needed to be on a ventilator. That was 2005 and it has made a huge difference. My mind has cleared up and I recover more quickly from the pain of too much activity. As long as I use my scooter to get around, use my ventilator at night and during my 1.5 hour nap every afternoon, I can get on with my life again.

So why should we work to eradicate polio?

- Self interest – Polio is only a plane ride away. If you are not vaccinated, you can carry and spread the virus for 2 weeks before showing any symptoms and 8 weeks in total. If we drop our vaccine programs, polio will spread and I hope I've told you enough about polio so you understand how devastating that could be for individuals and for our infrastructure. Remember the 1,205 cases of polio in SK in 1952. (Think of the problems created by 251 SARS cases in Canada).
- Because we can – Only people get polio. There

are no animal populations for polio to hide in, no swine polio or bird polio. We have a cheap, effective vaccine. If we vaccinate everyone it is actually possible to eradicate polio.

- It is the right thing to do.

We don't have to be helpless any more. After 25 years of hard work, Rotary and its partners have reduced polio by 99%. They are on the brink of eradicating polio, but a strong push is needed now to root it out once and for all. It is a window of opportunity of historic proportions. We, the Gates Foundation and Rotary International can eradicate Polio. Let's do it.

Helpful Hints for Winter

Squeak-proof your wipers with rubbing alcohol! Wipe the wipers with a cloth saturated with rubbing alcohol or ammonia. This one trick can make badly streaking and squeaking wipers change to near perfect silence and clarity.

Ice-proof your windows with vinegar! Frost on it's way? Just fill a spray bottle with three parts vinegar to one part water and spritz it on all your windows at night. In the morning, they'll be clear of icy mess. Vinegar contains acetic acid, which raises the melting point of water---preventing water from freezing!

Prevent car doors from freezing shut with cooking spray! Spritz cooking oil on the rubber seals around car doors and rub it in with a paper towel. The cooking spray prevents water from melting into the rubber

Fog-proof your windshield with shaving cream! Spray some shaving cream on the inside of your windshield and wipe it off with paper towels. Shaving cream has many of the same ingredients found in commercial defoggers.

De-ice your lock in seconds with hand sanitizer! Just put some hand sanitizer gel on the key and the lock and the problem is solved!

Keep your headlights clear with car wax! Just wipe ordinary car wax on your headlights. It contains special water repellents that will prevent that messy mixture from accumulating on your lights - lasts 6 weeks.

Soap Under the Sheets for RLS, Leg Cramps : The People's Pharmacy®

December 7, 2005 <http://www.peoplespharmacy.com/2005/12/07/soap-under-the/>



There is now a prescription drug (Requip) to treat RLS (restless leg syndrome). The only problem is that some people fall asleep during the day. This could be risky if they are behind the wheel. As far as we can tell, there are no side effects to putting soap under the bottom sheet.

Q. Several months ago I went to my neurologist for my yearly physical and told him about a problem I had with my legs “jumping” at night and waking me up. He gave me the technical name for it and wrote me a prescription for Mirapex. I then told him I had read in your column about putting a bar of soap in the bed, so he told me to try the soap and fill the prescription if it didn't work. I still have the unfilled prescription sitting on my bathroom vanity. When we went on a trip to Yellowstone, I took my soap along and slept fine every night we were gone.

A. This home remedy mystifies us, but we have heard from many readers like you. The risk of unwrapping a fresh bar of soap and putting it under the bottom sheet where the legs will be is almost zero. The cost is far less than a prescription. Positive responses from other readers experimenting with Ivory soap remedy:

“A while back I wrote to complain that the bar of soap under the bottom sheet quit working for my restless legs. (It was great at first.) Then I got to thinking, it worked before, so why not now? That bar of soap had been there for six months, so I replaced it. The result: no more restless legs. A few times that I had symptoms, I put my feet on the soap and the sensations went away in about two minutes.

“My husband was having severe leg cramps at night. Without telling him, I placed a soap bar under his sheets for two nights before he noticed. It worked! He's had no more cramps. We still can't believe it! “

“I have had severe leg cramps for years. When I read about putting a bar of soap in bed, I got a bar of Ivory and put it under the bottom sheet near my legs. It's been a month since I did that, and I have not had one leg cramp. In the site's informal poll: Did this remedy work? Average rating: 4.3/5 (714 votes) that's a 92% success rate!

At the Meetings

At our **September** meeting we discussed arrangements for our Christmas Party. We decided to have it at the Broadway Terrace, the same place as last year, on November 24, 2011 at 5:00 p.m.

Open Forum: Ivan Jorgensen lead the September 2011 open forum. The subject was: Our Experiences with the Medical System and Have You Been Officially Diagnosed with Post-Polio Syndrome? Ivan talked about his experiences with doctors and problems getting shoes to help his situation. Then he went around the table and asked each person about their experiences and whether they had been officially diagnosed with Post Polio Syndrome. Ivan's experiences are published in the October 2011 edition of the *Polio Regina PostBox*.

At our **October** meeting we confirmed all the arrangements for the Christmas Party.

Blenda is selling her scooter. If anyone is interested, please talk to her. Phone 543-6380.

Open Forum: Wilf Tiefenbach elaborated on the Disability Tax Credit and answered questions about filling in the form.

Dr. Mavis Matheson talked about her presentation at the Rotaract 2nd Annual Polio Plus Awareness Night Fall Dinner held on October 23rd. She then gave us that presentation which included playing the song “Helpless” by Neil Young and explained the meaning of the song. Her presentation also included the definition of Post Polio Syndrome and explained how it is diagnosed. The presentation is printed in this issue of the *Polio Regina PostBox*.

Next Meeting: After our Christmas Party, our next meeting will be held February 23, 2012 at 7:00 p.m. at our regular meeting place, Room H203 at the Wascana Rehabilitation Centre.

